



Copyright Statement

The digital copy of this thesis is protected by the Copyright Act 1994 (New Zealand). This thesis may be consulted by you, provided you comply with the provisions of the Act and the following conditions of use:

- Any use you make of these documents or images must be for research or private study purposes only, and you may not make them available to any other person.
- Authors control the copyright of their thesis. You will recognise the author's right to be identified as the author of this thesis, and due acknowledgement will be made to the author where appropriate.
- You will obtain the author's permission before publishing any material from their thesis.

To request permissions please use the Feedback form on our webpage.

<http://researchspace.auckland.ac.nz/feedback>

General copyright and disclaimer

In addition to the above conditions, authors give their consent for the digital copy of their work to be used subject to the conditions specified on the Library

[Thesis Consent Form](#)

MEDICAL DECISIONS AT THE END OF LIFE THAT HASTEN DEATH

Kay Mitchell

A thesis submitted in partial fulfilment of the
requirements for the degree of Doctor of Philosophy.
The University of Auckland, 2002.

ABSTRACT

Medical decisions at the end of life (MDELs) that have the potential to hasten death are increasingly prevalent in medical practice given (a) an aging population and (b) the increase in medical technology that allows life to be sustained beyond what it could be in the past and sometimes beyond what may be comfortable for the patient. When a decision is made to introduce life-sustaining interventions this may imply a later decision to halt these. Attitudes towards medical decisions that hasten death were explored among Greypower members, 55+ years ($N = 595$), Psychology students, 29 years and under ($N = 205$) and General Practitioners, 70 years and under ($N = 120$) in Auckland, New Zealand. Vignette scenarios were used related to withdrawing and withholding life support and nutrition and hydration, denying dialysis to a requesting patient, increasing medication to address pain at the risk of hastening death, physician supplying information, drugs, physician assisting patient to take drugs and physician giving a lethal injection to a terminally ill patient with intractable pain, on request and physician providing assisted death to a requesting tetraplegic patient. The effect of age of patient and consent on decision-making was also explored. Greypower members and Doctors had similar attitudes towards MDELs that are legal in New Zealand but over three-quarters of the Greypower members judged physician-assisted death for a terminally ill patient as justified compared to only one third of the Doctors. Psychology students were more conservative than either the Greypower members or the Doctors for all judgments related to the justifiability of MDELs. There appear to be underlying philosophical differences in the approaches to end of life decision-making by the three groups with Psychology students favouring a Sanctity of Life position and General Practitioners favouring the Status Quo. Greypower members appear to have a pragmatic approach to end of life care that does not favour one position over another.

A second study adapted the questionnaire used in Holland in 1990 by the Remmelink Commission of Inquiry exploring the incidence of MDELs among general practitioners in New Zealand ($N = 1255$). Results indicate that 63% of general practitioners had made an MDEL for the last patient who died in their practice in the previous twelve months. Practitioners could select more than one action for this patient and taking into account the probability that the end of life would be hastened, 37.2% had withheld treatment, 28.8% had withdrawn treatment and 84.9% had increased medication to relieve pain. Medication to relieve pain or other symptoms was increased in part with the intention of hastening the end of life by 24.8% of practitioners.

Actions were taken with the explicit purpose of not prolonging life or hastening the end of life and death was caused by withholding treatment 18.7%, withdrawing treatment 10.2% and prescribing, supplying or administering a drug 5.6%. In 54.8% cases, there was no discussion with the patient prior to the action taken, although in some of these cases a wish had been expressed by the patient at a previous time to have death hastened. Of the 39 cases where a drug was supplied or administered with the explicit intention of hastening death and death occurred, the drug was administered by a nurse alone in 15 cases (under physician orders, implied in the question) and the physician alone in 13 cases. In two cases the patient self-administered the drug.

In order to assess the impact of euthanasia (arguably at the extreme end of the MDEL continuum) on practitioners, a qualitative study was conducted to explore the accounts of ten Dutch doctors who had cared for dying patients, five who had performed euthanasia and five who had not. Themes were compared and contrasted to expose similarities and differences in the approaches of the two groups to patient care. Both groups endorsed palliative care as the preferred approach to the care of the dying patient. Those who had not performed euthanasia expressed their commitment to the patient in continued exploration of palliative options and a stated commitment of non-abandonment of the patient. Those who had performed euthanasia portrayed this action as the “ultimate commitment” to the patient, no other option being seen as meeting patient need. The effect on the doctor of performing euthanasia was intense. Other medical decisions at the end of life that hasten death such as terminal sedation or withdrawing nutrition and hydration were posited by the doctors who had performed euthanasia to be analogous to euthanasia, and the psychological effect on the doctor was similar. Those who had not performed euthanasia stated that these actions were not the same as euthanasia. Dissonance theory was used to explore why the two groups may portray their actions that hasten death in different ways.

ACKNOWLEDGEMENTS

Firstly, I wish to thank the participants who took part in the three studies that make up this thesis. It seems obvious to state that without them the work could not have been done, but the generous sharing of experiences that was evident in the responses to each of the studies went, in many cases, beyond what was asked of them.

Many hours of discussion about death and dying, palliative care, philosophy and methodology were patiently undertaken by colleagues, family and friends in the preparation of this thesis. In particular I wish to acknowledge my primary Supervisor, Professor Glynn Owens who created the necessarily challenging climate for inquiry that underpinned the complexity of this thesis topic. I owe him a huge debt of gratitude for encouraging me to use my own voice in this work while at the same time always presenting alternative arguments and conclusions for me to ponder. My thanks also to other colleagues at the University of Auckland who have contributed their guidance, notably my secondary Supervisor, Dr. John Duckitt who contributed much to the cross-cultural component. I acknowledge Assoc. Prof. Christopher Triggs of the Department of Statistics, Dr. Doug Elliffe and Robert McNeill of the Department of Psychology and the patience with which they assisted me with the statistical component. My thanks to Professor David Thomas, Health Research Methods Advisory Service, and Susan Waddington, Nursing Faculty for providing critical feedback on the qualitative component. In particular I thank Associate Professor John Raeburn who, in his capacity as a member of the University of Auckland Human Subjects Ethics Committee, liaised with me to satisfy that Committee that my approach to this research was ethically sound. Any short-comings in this study are mine alone and do not reflect the excellent input and advice I received from these sources.

I wish to acknowledge the assistance of people in Holland who kindly extended hospitality, shared their experiences and knowledge and introduced me to others who helped in my research. H. Gommans, Directeur Zorg (Director of Care) at Stichting Verpleeghuiszorg Voorne-Putten en Rozenburg; Prof Herb Cohen, Capelle Yssel; Dr. Sipko Huismans, Free University of Amsterdam; Dr. Zbigniew Zylicz, Hospice Rozendaal; Dr. Rein Janssens, Nijmegen University; Prof. Henk ten Have, Nijmegen University; Assoc. Prof. Theresa van Elderen, University of Leiden and Rene, Toos and Xander Lub, Hellevoetsluis.

Nicky Bebbington, Karen Knaggs and Dr. Ross Mitchell assisted with proof-reading and I owe them a debt of gratitude for meticulous work. I acknowledge my colleagues in the Department of Psychology at Tamaki, Dr. Brenda Lobb, Dr. Barry Hughes, Dr. Linda Cameron, Jeanne Reeve, Melanie Schlatter, Eric Landhuis, Sheleigh Lawler and Anne Haas and Dr Abigail Wroe, Visiting Research Fellow, and thank them warmly for their support over the last five years. My thanks also to Bill and Nari Stevenson of the Stevenson Family Trust and to my parents Craig and Nancy, for providing financial assistance to carry out research in Holland and to the University of Auckland for research funding through the Graduate Research Fund.

Finally, my thanks to my children Kate, Rachel, James and Aaron for their patience in allowing me the time and providing the support for me to complete this project in my preferred way. And to my husband Ross whose love provided me with the courage to attempt this project, and who understood and supported my reasons for doing so, thank you.

DEDICATION

*This thesis is dedicated with love to the memory of Mary Shane Goodall
August 5 – December 13, 1947*

*There is only one child in the world
and the name of the child is All Children*
Carl Sandburg

TABLE OF CONTENTS

Abstract	ii
Acknowledgements	iv
Dedication	vi
Table of Contents	vii
List of Tables	xi
List of Figures	xiii
Prologue	1
SECTION I	6
Chapter 1	6
Introduction	6
The ethics of intent in medical decisions that hasten death.....	6
Underlying principles of end of life decision-making	7
Morality in end of life decision-making.....	8
Utility and end of life decision-making.....	10
MDELs in New Zealand.....	12
<i>Constraints of health resources</i>	12
<i>Limited health care resources implicated in mercy killings</i>	13
<i>Response of society to “mercy killing” cases</i>	15
<i>The role of society in right to die reform</i>	16
Chapter 2	19
Review of literature: Medical decisions that hasten death.....	19
Withholding and withdrawing treatment.....	19
<i>The concept of death</i>	19
<i>Medical decision-making affected by legal definitions</i>	21
<i>Medical decision-making defined by quality of life</i>	23
<i>Treatment/non-treatment decision-making and futility</i>	25
<i>Nutrition and hydration</i>	27
<i>Terminal Sedation</i>	29
<i>Ventilatory life support</i>	31
Chapter 3	33
Review of literature: Planning for death	33
Advance directives	33
<i>Formalising advance care planning may not increase implementation</i>	34
<i>Advance care planning and the law</i>	34
<i>Barriers to advance care planning</i>	35
<i>Advance care planning does not address all needs</i>	36
<i>The difficulty of forecasting preferences</i>	37
<i>Reliability, durability and validity of advance care planning</i>	38
<i>Values history - the quality of a life</i>	40
<i>Proxy decision-making</i>	41
Chapter 4	46
Review of literature: International perspectives on assisted death.....	46
Physician-assisted suicide and euthanasia.....	46
The Dutch experience with assisted death.....	47
<i>The Rimmelinck Study</i>	49
<i>Research focus after the Rimmelinck Study</i>	51
The Australian experience with assisted death	54
<i>Northern Territory</i>	54
<i>Attitude of physicians to physician-assisted death</i>	55

<i>Attitude of nurses to physician-assisted death</i>	56
The American experience with physician-assisted death.....	57
<i>Attitudes of laypersons towards physician-assisted death</i>	57
<i>Attitudes of physicians to physician-assisted death</i>	58
<i>Physician-assisted death legalised in Oregon</i>	58
Physician-assisted death in New Zealand	62
<i>The Law</i>	62
<i>Parliament</i>	63
<i>Medical profession</i>	64
Comparison between Oregon, Netherlands, Northern Territory and New Zealand of prerequisites/proposed prerequisites for assisted death	66
The purpose of this thesis	4
SECTION II	68
Chapter 5	68
Study One: Perceptions on Justifiability and Legality of Medical Decisions at the End of Life that Hasten Death – Laypersons and General Practitioners in New Zealand	68
Introduction	68
Aim.....	69
Method.....	71
<i>Participants and recruitment</i>	71
<i>Measures</i>	72
Analysis	73
Cross-study results	74
Chapter 6	76
Results: 1. Philosophical principles underlying decision-making	76
Discussion	81
<i>Using Developmental theory as a theoretical framework within which to view differences in decision-making</i>	83
Caveat	87
Chapter 7	90
Results: 2. Physician-assisted suicide and euthanasia.....	90
Discussion.....	101
<i>Doctor supplying information and drugs to end life to a terminally ill patient with intractable pain</i>	101
<i>Doctor assisting a terminally ill patient with intractable pain to take drugs to end life.</i>	108
<i>Doctor administering a lethal injection to a terminally ill patient with intractable pain.</i>	111
<i>Doctor sedating a terminally ill patient with intractable pain.</i>	114
<i>"Palliative treatment" and "Hospice"</i>	115
Chapter 8	118
Results: 3. Withdrawing/withholding life-sustaining treatment.....	118
Discussion.....	123
<i>Place of care impacting on understanding of legality of actions</i>	123
<i>Effect of being unsure of legality of actions.</i>	124
<i>Impact of wording in Living Will on decision-making.</i>	125
<i>Effect of Existence of Living Will on Judging Action Justified</i>	126
<i>The potential for conflict in removing life sustaining treatment</i>	127
<i>MDELS may be more difficult when "starving" the patient is involved</i>	131
Chapter 9	134
Results: 4. Age of patient & consent in decision-making	134
Discussion.....	143

<i>Legality of withdrawing life support or nutrition and hydration</i>	143
<i>Judging withdrawing life support and withholding nutrition and hydration as justified</i>	145
<i>Consent and increasing pain medication at the risk of hastening death</i>	145
<i>Confusion on legality may be related to media reporting</i>	148
<i>Principle of Double Effect and the ethics of hastening death</i>	149
Chapter 10	152
Conclusion	152
Limitations of the study	158
SECTION III	161
Chapter 11	161
Study Two: Medical Decisions at the End of Life that Hasten Death Performed by New Zealand General Practitioners	161
Introduction	161
Aims	162
Method	162
<i>Participants and recruitment</i>	162
<i>Measures</i>	162
<i>Confidentiality and Response Rates</i>	163
Analysis	164
Results	164
<i>Occurrence of MDELs</i>	166
<i>Characteristics of physicians who had made an MDEL</i>	167
<i>Characteristics of treatment withdrawn/withheld</i>	168
<i>Affirmative answers to Question 6</i>	169
<i>Extent of life shortened when MDEL actioned</i>	169
<i>Decision-making process</i>	171
<i>Discussion with patient</i>	171
<i>No Discussion with patient</i>	173
<i>Do-Not-Resuscitate Orders</i>	177
<i>Explicit request to terminate life not carried out</i>	178
<i>Legislation</i>	179
<i>Palliative Care</i>	179
Chapter 12	181
Discussion.....	181
<i>Incidence of MDEL-actions</i>	183
<i>Access to palliative care and decision-making</i>	186
<i>Affirmative answers to Question 6</i>	189
<i>Decision-making in MDELs</i>	189
<i>Extent of shortening life</i>	190
<i>Decision-making – discussion took place</i>	191
- <i>Competency</i>	192
- <i>Discussion initiation</i>	193
- <i>Written directives</i>	194
<i>Decision-making – no discussion took place</i>	194
- <i>A request for hastened death from others</i>	195
- <i>Reasons for no discussion with the patient</i>	196
<i>Other discussants when an MDEL was actioned</i>	197
<i>Explicit request to terminate life</i>	198
<i>Do-Not-Resuscitate Orders</i>	198
<i>Legislation</i>	199
<i>Palliative Care</i>	201

<i>The special case of children</i>	202
<i>Question 6 – Was death caused by a drug prescribed, supplied or administered with the explicit purpose of hastening the end of life (or of enabling the patient to end his or her own life)?</i>	204
-Who administered the drug.....	204
-Discussion/no discussion with patient.....	205
-Physician interpretation of questions implicated in responses	206
Summary and Conclusion	208
Limitations of the study	211
SECTION IV	213
Chapter 13	213
Study 3: The Dutch Experience – Physicians’ Caring for the Dying Patient	213
Introduction & Methodology.....	213
Aim.....	215
Procedure.....	215
Interview Process	216
Analysis	217
Reflexive Account	219
Chapter 14	222
Results:	222
Category 1: Palliative Care.....	223
Chapter 15	244
Category 2: Euthanasia-Palliative Care: Continuum vs Dichotomy.....	244
Category 3: Autonomy	250
Chapter 16	262
Category 4: Euthanasia.....	262
Chapter 17	285
Discussion.....	285
<i>Palliative Care</i>	285
<i>Treatment withdrawal, terminal crises and euthanasia</i>	287
<i>A multi-disciplinary approach to care</i>	288
<i>The development of palliative care as a discipline in Holland.</i>	289
<i>Terminal sedation and euthanasia</i>	291
<i>Autonomy</i>	292
<i>The euthanasia request</i>	294
<i>Protocols and Processes of Euthanasia</i>	296
<i>Effect on doctor of performing euthanasia</i>	297
<i>Using dissonance theory as a theoretical framework within which to examine one approach that may be taken to resolve any psychological discomfort related to death hastening actions.</i>	300
Conclusion and Implications	308
Shortcomings of the study	310
SECTION V	313
Chapter 18	313
"The Pause"	313
References	318
Appendices	318
Appendix A: Culture: Relativity, context & socialisation	
Appendix B: Vignette Questionnaire used in Study One	
Appendix C: Values history form	
Appendix D: Questionnaire used in Study Two, Rummelink replication	
Appendix E: Participant Information Sheet and Consent Form for Study Three	

LIST OF TABLES

Table 4.1: Main conditions under which elective death may be given in Oregon and the Netherlands, formerly given in the Northern Territory* and proposed for New Zealand...	67
Table 5.1: Table showing demographic breakdown of age, gender, ethnicity and strength of religious beliefs of Young and Older Laypersons and Doctors.	75
Table 6.1: Table showing two vignettes compared to investigate possible philosophical differences in how Young and Older Laypersons and Doctors approach decision-making.	76
Table 6.2: Table showing summary statistics for Laypersons and Doctors on judgments of justifiability and legality of assisted death on request for a tetraplegic patient and denying dialysis to a requesting patient.	78
Table 7.1: Table showing four vignettes compared to investigate level of tolerance by Young and Older Laypersons and Doctors for physician-assisted death.	91
Table 7.2: Table showing questions related to the function of palliative care and hospice.	92
Table 7.3: Table showing summary statistics for Young and Older Laypersons and Doctors on level of tolerance and judgments on legality for physician-assisted death and terminal sedation ..	94
Table 7.4: Table showing judgments of Young and Older Laypersons and Doctors on the meaning of the terms "palliative care" and "hospice"	101
Table 8.1: Table showing three vignettes compared to investigate effect of a Living Will on the decision-making of Young and Older Laypersons and Doctors on justifiability and legality of actions.	119
Table 8.2: Table showing summary statistics for Young and Older Laypersons and Doctors on judgments on justifiability and legality of actions with and without a living will.	121
Table 8.3: Excerpts from media reporting on the Hugh Finn case showing the polarity of opinion from several sections of society on the withdrawal of nutrition and hydration in this case.	128
Table 9.1: Table showing vignettes compared to investigate effect of age of patient on the decision-making of Laypersons and Doctors on justifiability and legality of withholding nutrition and hydration.	135
Table 9.2: Table showing vignettes compared to investigate effect of age of patient and consent on decision-making of Laypersons and Doctors on justifiability and legality of actions.	136
Table 9.3: Table showing summary statistics for Young and Older Laypersons and Doctors on judgments on justifiability and legality of end of life actions as a function of consent and age of patient	138
Table 9.4: Table showing effect of ethnicity of Young Layperson respondent on judging it justified to increase pain relief for a child or adult knowing that death could be hastened.	142
Table 10.1: Table showing difference in judgments of Young and Older Laypersons and Doctors on judgments on justifiability of medical decision	153
Table 11.1: Table showing reasons given for not participating in study by general practitioners who returned blank survey.	165
Table 11.2: Table showing demographic breakdown of general practitioners participating in study.	165
Table 11.3: Table showing medical decision at the end of life (MDEL) performed by general practitioner on the last death attended in the previous 12 months	167
Table 11.4: Table showing demographic details of doctors who answered affirmatively to Question 6.	170
Table 11.5: Table showing estimation of shortening life, based on the last-mentioned MDEL taken in the last death attended in the previous 12 months.	170

Table 11.6: Table showing discussion status with the patient about the last-mentioned MDEL.	172
Table 11.7: Table showing characteristics of discussion with patient about the last-mentioned MDEL.	173
Table 11.8: Table showing decision-making after no discussion with patient about the last-mentioned MDEL.	174
Table 11.9: Table showing reason given for no discussion with patient about the last-mentioned MDEL.	176
Table 11.10: Table showing representative statements of reasons given in “Other” option for not discussing possible hastening of death from act or omission with patient	176
Table 11.11: Table showing discussion with others when there was no discussion with the patient and no known wish expressed by the patient.	177
Table 11.12: Table showing Do Not Resuscitate (DNR) order for patients for whom an MDEL was made and those for whom death was unexpected but the doctor had previous contact with patient.	178
Table 11.13: Table showing request to terminate life that was not carried out.	178
Table 11.14: Table showing perceived impact of present legislation in New Zealand on MDEL actioned	179
Table 11.15: Table showing access to palliative care and use of palliative care or pain control services by all respondents (<i>n</i> = 1255).	180
Table 12.1: Table showing comparison between Dutch and New Zealand general practitioners of last mentioned MDEL (withdrawing/withholding combined for analysis).	185
Table 12.2: Table showing reasons given for non-discussion when Question 6 was answered affirmatively (<i>n</i> = 17).	196
Table 12.3: Table showing details of cases answered affirmatively in Question 6.	205
Table 13.1: Table showing position, age and religious affiliation of ten Dutch doctors interviewed.	216
Table 14.1: Table showing categories and themes represented in discursive accounts of Dutch doctors who have performed euthanasia and Dutch doctors who have not.	222
Table 14.2: Table showing issues arising around characteristics of palliative care for Dutch doctors who have performed euthanasia and Dutch doctors who have not.	224
Table 14.3: Table showing issues arising around palliative care, treatment withdrawal and terminal crises for Dutch doctors who have performed euthanasia and Dutch doctors who have not.	232
Table 14.4: Table showing issues arising around team approach to palliative care for Dutch doctors who have performed euthanasia and Dutch doctors who have not.	237
Table 14.5: Table showing issues arising around delivery of palliative care to the consumer for Dutch doctors who have performed euthanasia and Dutch doctors who have not.	240
Table 15.1: Table showing issues arising around palliative care that hastens death for Dutch doctors who have performed euthanasia and Dutch doctors who have not.	244
Table 15.2: Table showing issues arising around autonomy in end of life decision-making for Dutch doctors who have performed euthanasia and Dutch doctors who have not.	252
Table 16.1: Table showing issues arising around the request for euthanasia for Dutch doctors who have performed euthanasia and Dutch doctors who have not	263
Table 16.2: Table showing issues arising around protocols and processes associated with delivering euthanasia for Dutch doctors.	270
Table 16.3: Issues arising on effect of performing euthanasia for Dutch doctors who have done so and potential effect for Dutch doctors who have not.	275

LIST OF FIGURES

Figure 1: Drawing by woman dying of cancer	3
Figure 6.1: "Yes" responses of three groups on justifiability of granting tetraplegic patient request for assisted death and denying requests for dialysis to elderly patient.....	80
Figure 6.2: Combinations of principles employed by Laypersons and Doctors when comparing the justifiability of assisted death of a requesting tetraplegic patient or denying dialysis to a patient who has requested it.....	80
Figure 6.3: Suggested location of underlying philosophical principles used in decision-making according to Kohlberg's theory of moral development.....	85
Figure 7.1: Judgments of Young & Older Laypersons and Doctors on the legality of doctor supplying information, drugs, assisting patient to take drugs, administering a lethal injection & terminal sedation of a terminally ill patient with intractable pain, on request..	93
Figure 7.2: Judgments on justifiability by Young and Older Laypersons and Doctors of supplying information or drugs, assisting to take drugs, giving a lethal injection or terminally sedating a dying patient on request.....	94
Figure 7.3: Relationships between Doctors' religiosity and judgments on justifiability of supplying information or drugs, assisting patient to take drugs or giving a lethal injection to a terminally ill patient with intractable pain, on request.....	96
Figure 7.4: Comparisons between European-Pakeha /Other Ethnicities Combined Young Layperson and Age Comparison 18-35/70-80 year old Laypersons on judgments on justifiability of hastening death action.....	98
Figure 7.5: Figure showing decision tree approach of physician responding to a request for assisted death.	106
Figure 8.1: Judgments on the legality of withdrawing life support and withdrawing or withholding nutrition and hydration from a permanently comatose patient with and without a Living Will.	120
Figure 8.2: Judgments of justification by Young and Older Laypersons and Doctors of withdrawing life support and withdrawing and withholding nutrition and hydration with no Living Will from a comatose patient with no hope of recovery	122
Figure 9.1: Comparisons for Laypersons and Doctors between judging it justified to withdraw life support, withhold nutrition & hydration and increase pain relief with or without consent at the risk of hastening death for an adult or child.....	139
Figure 9.2: Responses of Young Laypersons on judging legality of withdrawing life support, withholding nutrition and hydration and increasing medication at the risk of hastening death for an adult and baby	140
Figure 9.3: Responses of Older Laypersons on judging the legality of withdrawing life support, withholding nutrition and hydration and increasing medication at the risk of hastening death for an adult and a baby.	140
Figure 9.4: Responses of Doctors on judging the legality of withdrawing life support, withholding nutrition and hydration and increasing medication at the risk of hastening death for an adult and baby.	141
Figure 9.5: Effect of ethnicity of Young Layperson on judgments of legality of increasing pain relief for a child or adult knowing that death could be hastened, with consent.....	143
Figure 10.1: Judgments by Young and Older Laypersons and Doctors on justification of medical decisions that hasten death.....	154

Figure 10.2: Judgments by Young and Older Laypersons and Doctors on legality of medical decisions that hasten death.	154
Figure 11.1: Frequencies of treatment withdrawn or withheld by general practitioners making a MDELHD	168

PROLOGUE

Early in the 1990s, a patient who had suffered irreversible brain damage secondary to hypoxia was referred to hospice. He was in his early fifties and had suffered a heart attack one night. His wife, and two daughters provided resuscitation while waiting for the ambulance. Unfortunately a scan revealed wide spread irreversible brain damage and he was not expected to live. Although breathing independently, he was deeply comatose and given the extent and irreversibility of his injury it was decided not to commence tube feeding but to allow him to die. He was provided with a side-room in one of the wards and his wife and daughters stayed with him. An intravenous line provided minimal fluids to maintain patient comfort and death was expected within days. After several weeks with the family providing small amounts of food orally, death had not occurred and tube feeding was commenced at the insistence of his family. The patient was discharged home with a naso-gastric tube in situ with a referral to hospice for terminal care.

There appeared to be nothing unremarkable about this English immigrant family. The two daughters were at University and their mother had elected to stay at home to care for the family, the patient having been fit and a good provider until his heart attack. In the weeks after he returned home, he continued in a semi-comatose state. He was rousable and appeared awake for most of the day but did not engage in purposeful activity and was unresponsive to instruction. His condition resembled the persistent vegetative state originally noted by Jennet & Plum, (1972). His oral intake was minimal and because of the risk of choking and the time it took to feed him, sustenance was delivered via the feeding tube. He would often appear restless and pull the tube out. The family learned to re-insert the tube.

After several weeks, a rigorous rehabilitation exercise programme was commenced at the wife's insistence involving "patterning", under the supervision of an overseas expert in this procedure. The underlying thesis to this method of rehabilitation was the re-training or patterning of areas of the brain that were undamaged, to perform the functions the damaged areas would normally undertake. The lounge was given over to the equipment necessary for these exercises. Using the assistance of a team of volunteers, there were two sessions per day during which individual teams of four or five would exercise the patient's limbs. While his daughters were often there they had their University studies to contend with. His wife was present for and assisted with,

almost all sessions. The schedule of volunteers included more than 50 people from the area who were involved in the rehabilitation effort.

Home care was provided for 30 hours a week but the patient's total dependent state necessitated a huge physical commitment from the family, particularly his wife. The rehabilitation programme continued for more than a year with little evidence, if any, of an improvement in the patient's physical or cognitive function.

Eighteen months passed and the wife felt unwell and was diagnosed with bowel cancer. After surgery, the doctors informed her that they could offer her no other treatment and she instigated a rigorous dietary regime for herself supplemented with complementary therapies such as colour therapy and others. Initially she appeared to do well but after a few months her condition deteriorated. During this period her husband's exercise regime was cut down and finally stopped. The two daughters began caring for both parents at home as their mother's condition worsened. Eventually their father was placed in a private hospital.

The wife had already implemented diet and meditation in her quest for a cure but was interested in drawing as therapy, having heard about this from a participant in an Ian Gawler workshop¹. She drew a picnic scene with two little people drawn in the centre of the picture. She explained that the two little people were herself and her husband. She had drawn a picture of a picnic that the two of them had shared when they were courting. At the bottom left-hand corner was a brightly patterned scene with grass, flowers and a carefully drawn picnic setting. The bottom right-hand corner had a fence running across it with a car behind it. The number-plate corresponded to the first car her husband had ever owned. In the top right-hand corner she had drawn a sun, yellow wispy clouds and blue sky. In the top left-hand corner she had continued the sky but a hay-rick piled high with hay bales stood waiting in the distance, outlined against the sky (see Figure 1, p. 3).

When asked to explain the picture, the wife talked of the picnic day and how happy they both had been. The details, including the number-plate on the car, suggest the memory was very vivid. She began to cry and indicated that she wanted she and her husband to stay together.

¹ Ian Gawler is an Australian who used diet and meditation to overcome osteosarcoma and subsequently established the Ian Gawler Foundation and published books (Gawler, 1984; Gawler, 1987) advising others how to survive cancer.

Figure 1: Drawing by woman dying of cancer

When the older daughter was asked what she understood her mother meant by this, she too cried and indicated that she understood that her mother knew she was dying and wanted her husband to die with her. Several days later the wife died. After discussions with doctors, nurses and the family, the husband attended her funeral in a wheelchair with the naso-gastric tube withdrawn. He died ten days later of a chest infection, having managed only minimal oral intake in the meantime.

This story clearly demonstrates the complexity of end of life decision-making, which does not occur in a vacuum but is influenced by the context within which it occurs. A strong sanctity of life position may argue that the husband's death at this time was wrong. Clearly he was not imminently dying and may have lived for years with appropriate [sic] management. Others may question that the family were not well served by the hospital agreeing to put the feeding tube down in the first place, given that the CT scan showed no possible hope of recovery. With adequate counseling at the time the family may have recognised this. No-one who was involved in the decision-making believed that withdrawing the tube was anything but the correct decision. The effects of the action and the consequence are remembered many years later – underpinning the seriousness of such decision-making – and have influenced the subject of this thesis.

THE PURPOSE OF THIS THESIS

The purpose of this thesis is threefold. Firstly, to explore the attitudes of both laypersons and physicians in New Zealand related to individual decisions at the end of life - what is considered justified and judgments on legality. Secondly, to explore the occurrence and character of end of life decision-making that hastens death in New Zealand. Thirdly, to explore the professional context of end of life decision-making – how a physician both affects the dying situation and is affected by the dying situation.

It is important to clarify the terms used in this thesis. Medical decisions at the end of life, (MDELs) refer to medical treatment or non-treatment decisions made by a physician attending a patient who is dying. In this context treatment including nutrition and hydration may be withdrawn or withheld. Such treatment could also include life support, dialysis, blood transfusions, medications including antibiotics, or any treatment that has as its purpose the prolongation of the life of the patient. Within this context also, medication may be increased to provide comfort to the patient, and this may occur at the risk of hastening the death of the patient, the principle of double effect.

“Euthanasia” (EU) refers to the administration of a lethal drug to the patient by a doctor with the explicit intention of causing death. “Physician-assisted suicide” (PAS) refers to the prescribing or supplying of a lethal drug with the explicit intention of causing death, the patient self-administering the drug. Physician-assisted death refers to a physician *intentionally* hastening the death of the patient, unless otherwise stated.

The terms "the Netherlands" and "Holland" will be used interchangeably throughout the thesis but both refer to the whole of the country normally referred to as Holland, the home of the Dutch people.

Thesis structure

Because of the complex nature of the topic and the need to draw on a wide range of disciplines, methodologies and data, the structure of the thesis deviates somewhat from more conventional studies.

The thesis comprises five sections.

Section One combines a general introduction with a literature review and consists of four chapters briefly summarising the role of ethics, morality and utility in end of life decision-making. Chapter 4 gives a brief overview of the present situation in New Zealand related to this topic.

Section Two comprises the first quantitative study. The attitudes of Laypersons and Doctors to end of life decisions that may hasten death are presented over six chapters.

Section Three comprises the second quantitative study. This study examines the decision-making around a recent death reported by General Practitioners in New Zealand and comprises two chapters.

Section Four comprises the third study, a qualitative project reporting the experiences of five Dutch doctors who have performed euthanasia and compares this with the reports from five Dutch doctors who have not found this action necessary in their practice. There are five chapters in this section.

Section Five is a short section summarising the project.

SECTION I

CHAPTER 1

INTRODUCTION

THE ETHICS OF INTENT IN MEDICAL DECISIONS THAT HASTEN DEATH

Under New Zealand law, there is no provision for either euthanasia or physician-assisted suicide and they both remain illegal and outside the domain of accepted medical practice. Other medical behaviours that shorten life that do not have the intention of hastening death are considered to be ethical and legal in New Zealand as they are generally wherever western medicine is practiced². The important distinction is that the intent of the physician is to relieve the patient's suffering. If death occurs sooner as a consequence of the action (or inaction), provided it was never the primary intention, it is regarded as part of ethical medical practice (Gillett, 1991).

The question of medical decisions at the end of life (MDELs) is becoming increasingly complex and it is questioned whether withdrawing or withholding treatments, a widely accepted practice, is ethically different from actively taking measures to end life. In 1993, Baby Rianne was born in a Dutch hospital with multiple handicaps and life-sustaining treatment was withheld. When she was four days old, at the request of her parents, the doctor gave her a lethal injection while she lay in her mother's arms. The doctor was charged with murder but acquitted. The euthanasia of children remains a difficult area in Holland mainly due to problems with adherence with protocols laid down by the Royal Dutch Medical Association (RDMA) under which euthanasia must be performed i.e. voluntary, informed decision. In the case of Baby Rianne, the prosecution

² It should be noted that there may be cultural variations. For example, until very recently turning off life support was considered murder in Hong Kong (Wan, 1999). In New Zealand withdrawing life support when appropriate is considered normal medical practice.

appealed but the acquittal was upheld on a defense of *force majeure*³, which was an accepted defense in euthanasia cases in Holland⁴. The doctor maintained that giving the injection was "not the killing decision (the) killing decision was to withhold treatment". There was no moral difference only an emotional difference between killing and withholding futile medical treatment, therefore there should not be a legal difference (Griffiths, Bood & Weyers, 1998, p. 83; Klotzko, 1997).

In 1992 Dr Cox, a British physician, administered an injection of potassium chloride to Mrs Boyes who was terminally ill and suffering intractable pain. Her condition was appalling, with septicemia (blood poisoning), abscesses and ulcers, heart and lung problems, gangrene, multiple pathological fractures (fractures that occur spontaneously as a consequence of the underlying pathology) and intractable pain. Dr Cox was subsequently charged with attempted murder, reduced from murder because the body had been cremated and cause of death could not categorically be confirmed (Brahams, 1992). A thoughtful commentary on this case states that "the law draws a rigid distinction between 'acts' and 'omissions to act'. It is, however, not clear that this necessarily reflects a fundamental *moral* difference, in all circumstances." (Ferguson, 1997, p. 370) (emphasis in original). It seems that the Courts may have on one level acknowledged this by suspending Dr Cox's 12 months prison sentence. However even this was regarded as being too harsh a sentence in some quarters (Brahams, 1992).

UNDERLYING PRINCIPLES OF END OF LIFE DECISION-MAKING

There are several underlying principles that are invoked whenever the issue of hastening the death of patients is discussed. The main opposing arguments are based on the principles of Sanctity of Life and Personal Autonomy. Often invoked are the principles of Utilitarianism (which embraces resource conservation but also quality of life judgments (Singer, Martin, & Kelner, 1999)) and the Status Quo which, in New Zealand, supports the ethics and laws that prohibit the intentional taking of innocent life.

The Sanctity of Life principle and indeed much of New Zealand law (New Zealand Crimes Act, 1961) is based on Judeo Christian teachings prohibiting the intentional taking of innocent life. This ethic rests on the assumption that all human life is sacred. Those who subscribe to this principle believe it is never permissible intentionally to kill a patient, to abort a foetus,

³ Force majeure refers to a force which it is reasonable not to resist – in this situation, the extreme suffering of the patient, and the request for assistance to die provides a defence for euthanasia (Griffiths, Bood, & Weyers, 1998).

⁴ Superseded by the recent legalisation of euthanasia in Holland although could conceivably be invoked when "legal" euthanasia occurs that does not strictly meet the guidelines.

intentionally to let a patient die, or to use quality of life as a basis for medical decisions on the (non)treatment of a patient. A prohibition on the taking of innocent life is also enshrined in the Hippocratic Oath (Hippocratic Oath, [online]). Conversely, medical practice tolerates decision-making that will hasten the death of the patient, when this is deemed to be the best action for the patient.

Utilitarian decision-making is based on the premise that decisions should maximise the possible beneficial outcomes of any decision and the benefit to the individual should not be at the expense of the benefit to the many. John Stuart Mill's Harm Principle states that any harm done by exercising one's freedom to maximise personal benefit when making a decision, must be weighed against the potential harm to others when that freedom is exercised (Mill, 1910). It is claimed that such decision-making is closely linked to quality of life decisions in health care, where the benefit/cost ratio of continued treatment and the prolongation of life must be weighed (Singer, 1996). Such decision-making may not always be according to the wishes of the patient.

The principle of personal autonomy is strongly supported in individualistic cultures that advocate self-determination (Triandis, Brislin, & Hui, 1988). Research supports the view that New Zealand is an individualistic culture (Hofstede, 1991). Personal autonomy in this context has the underlying premise that the person under consideration has the opportunity to exercise their own discretion in making decisions that pertain to his or her own death whether that may be to hasten death or to have all possible treatments to sustain life (see Appendix A: Culture, Relativity, Context & Socialisation).

The Status Quo principle is derived from decision-making that is in accordance with current principles that sustain, in this case, the legal and ethical norms of medical decision-making in New Zealand as proscribed in the law and the Hippocratic Oath. Both specifically prohibit the intentional taking of innocent human life (New Zealand Crimes Act, 1961). However the Oath does prohibit abortion and New Zealand society now legally tolerates this practice which suggests a willingness to change the "rules" in accordance with public demand. This is a classic Act Utilitarian perspective.

MORALITY IN END OF LIFE DECISION-MAKING

Rachels presents the "minimum conception" of morality - given, he says, that if one goes further than the seemingly simplistic Socratean view, you risk offending someone.

"(M)orality is, at the very least, the effort to guide one's conduct by reason - that is, to do what there are the best reasons for doing - while giving equal weight to the interests of each individual who will be affected by one's conduct" (Rachels, 1993, p. 13).

Using the case of Baby Jane Doe⁵ Rachels illustrates the ideal process of reasoning when making moral judgments in end of life care. The underlying moral assumption was to do the best for this baby. In order to understand the health care issues and prognosis, an "expert" was required to supply information, an expert source being pivotal to successful reasoning. Rachels points out that the same method of reasoning, i.e. "what is best for baby", is used by both sides. The outcome of the reasoning depends on the **facts** that inform the reasoning process, irrespective of the accompanying feelings that cannot be relied on to inform reasoning. Such feelings may be irrational, prejudiced, selfish or a product of cultural conditioning (Rachels, 1993) (see also Owens, 1999 which encompasses an argument for seemingly "ethical" decisions as more appropriately "falling within the domains of either empirical science and/or personal aesthetics" (p. 88). This author argues for an "open position" that resists "attempting to bolster our personal aesthetics with a spurious overtone of morality" (p 99).)

Rachels suggests that if we want to discover the truth,

"...we must try to let our feelings be guided as much as possible by the reasons, or arguments, that can be given for the opposing views. Morality is, first and foremost, a matter of consulting reason: the morally right thing to do, in any circumstance, is determined by what there are the best reasons for doing." (Rachels, 1993, p. 10).

"Moral thinking and moral conduct are a matter of weighing reasons and being guided by them" (Rachels, 1993, p. 43).

Thus, the presentation of the "facts" becomes pivotal in deciding if it is morally justified to allow euthanasia.

According to Rachels, there are stages in moral reasoning.

- (i) get the facts straight
- (ii) recognise the role of personal prejudice in interpreting facts
- (iii) define the moral principles that relate to the issue i.e. Sanctity of Life, Personal Autonomy
- (iv) test each moral principle
 - is it sound?
 - is it being applied appropriately?
 - if not, reject it
- (v) make judgment.

⁵ Baby Jane Doe was born in 1983 in New York State with several serious problems requiring surgery. Parents listened to experts and decided against surgery. Right to Life advocates petitioned the courts to allow Baby Jane Doe to have surgery against the parents' wishes. This was granted in the New York Supreme Court but the decision was overturned in a higher court. Finally, the federal government investigated the case on the basis of possible discrimination against a handicapped person (See also Singer, 1996).

Such reasoning requires a "conscientious moral agent" exemplified by impartiality in relation to those affected, impartiality beyond personal convictions, the scrupulous application of guidelines, rules and principles, critical assessment of the facts, and a commitment to action (Rachels, 1993, p. 13).

UTILITY AND END OF LIFE DECISION-MAKING

While behaviourism (Skinner, 1974) may explain why we may want a hastened death (to avoid aversive stimuli such as pain, suffering, dependency etc), moral reasoning relies on facts that support having or not having an assisted death and these include the wider concerns of society. John Stuart Mill argues that each person has sovereignty over their own body and mind (Mill, 1910, p. 78). Mill and later utilitarian commentators also argue persuasively against the utility of allowing suffering in sentient beings. However, following the reasoning of these same commentators, the suffering an individual endures and requests release from is a necessary, but not sufficient reason to condone euthanasia in a society. Arguments by Peter Singer, an ardent utilitarian advocate of animal rights, allows for those instances where the collective good may outweigh the harm being done by experimenting on animals (Singer, 1990). But this argument which puts the happiness of the collective before the happiness of the singular may not necessarily be seen as just.

Some would argue that rights cannot be discounted, there are "limits on how an individual may be treated, regardless of the good purposes that might be accomplished" (Rachels, 1993, p. 108). Utilitarianism is concerned with the consequences of actions. Therefore, we are morally obliged to infringe on the rights of any person or group to behave as they wish when their actions threaten the wellbeing of another who cannot offer sufficient defence for self-protection. Mill's Harm Principle embodies the necessary clarification of this point.

That the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right. These are good reasons for remonstrating with him, or reasoning with him, or persuading him, or entreating him, but not for compelling him, or visiting him with any evil in case he do otherwise. *To justify that, the conduct from which it is desired to deter him must be calculated to produce evil to some one else.* (Mill, 1910, p. 78). (emphasis added)

The establishment of Rule Utilitarianism, a modification of the classic theory, shifted the emphasis from considering the utilitarian merits of each act independently to establishing "general rules of conduct" that produce the greatest good (Rachels, 1993, p. 112). Individual acts would

then be considered and interpreted in the light of these rules, or laws that each society must establish for itself.

Many factors work together to produce the customs of a society. The society's values are only one of them. Other matters such as the religious and factual beliefs held by its members and the physical circumstances in which they must live are also important. We cannot conclude, then, merely because customs differ, that there is a disagreement about *values* (emphasis in original). The difference in customs may be attributable to some other aspect of social life. Thus there may be less disagreement about values than there appears to be (Rachels, 1993, p. 23).

A society could not sustain itself in any coherent way if everyone was in fear for his or her life. Thus, arguably there is a universal prohibition on activities defined as “murder” (although what constitutes “murder” in any given society may differ). Smaller communities may form in self-defence, but inherent within the new community would be a prohibition on “murder”. While individual cultures may disagree on what is regarded as a legitimate exception to this rule, the prohibition in general, is still agreed upon (Rachels, 1993). Nations may variously judge it justified killing during war or as punishment for capital crime (punitive euthanasia) and the Netherlands and others have extended the exception to the rule of killing to include euthanasia under certain conditions. The Dutch do not see moral rules as absolute (as for example in Kantian⁶ ethics with its categorical imperative) but have used the defence of "*overmacht*" (unlawful action taken when a conflict of duties occurs) (Griffiths et al., 1998, p. 62).

For ten years the Dutch have publicly tolerated killing practices that are illegal, as a way of testing new "rules of conduct" around the practice of mercy killing. In Holland euthanasia has recently been legalised (Gordijn & Janssens, 2001; Dutch policy on voluntary euthanasia, 2000; Upper House of the States General, 2001) after being legally tolerated under a practice the Dutch call “gedogen”, a “try before you buy” approach to proposed social change. This allows society to iron out any problems that a proposed course of action such as legalising euthanasia may incur. When the practice is accommodated successfully in society, steps are made to formalise the arrangement under law (Griffiths et al., 1998; Leenaars & Conolly, 2001).

By questioning the established codes of conduct around the intentional killing of some persons who request it, the Dutch have questioned the validity of their present laws relevant to the taking of innocent life *in all cases*. Using a classical Act-Utilitarian approach, they have questioned whether allowing euthanasia will cause greater harm to society than denying the individual the right to it, and decided it will not.

Act-Utilitarianism is ... a radical doctrine which implies that many of our ordinary moral feelings may be mistaken. ... it challenges us to rethink matters that we have heretofore taken for granted (Rachels, 1993, p. 114).

⁶ Certain moral duties are inalienably right, one cannot in good conscience deny them.

Finding their "codes of conduct" wanting from a classic Utilitarian perspective (best outcome for most number), the Dutch are revising these as they pertain to euthanasia and physician-assisted suicide. The recent law change in Holland legalising euthanasia is a classic Act-Utilitarian approach resulting from a change in the fundamental *belief* related to the practice of the taking of innocent life in certain cases. This is now ratified in law and therefore cannot legally be regarded as "murder". (One could argue that the "moral" distinction is unchanged).

The sections of the New Zealand Crimes Act 1961 which concern the medical profession were enacted so long ago that it has been questioned whether they are now wholly relevant to modern medical dilemmas (Auckland Area Health Board v Attorney-General, 1992; Tobin, 1993). Questioning and testing the moral commonsense of such laws will at the very least expose their enduring utility. If they are found wanting, applying Utilitarian ethics with its avoidance of "incorporating into moral theory prejudices, feelings, and 'intuitions' that have no rational basis" (Rachels, 1993, p. 115), may afford a new way of examining dying. Precedent has been set in New Zealand for reviewing present end of life care practices using a Utilitarian approach. A Utilitarian perspective has been applied to recent legal judgments based on "best outcome for patient", as a justification for withdrawing or withholding treatment from patients, with or without their agreement (Auckland Healthcare Services Ltd v L & L, 1998; Shortland v Northland Health Ltd, 1997; Auckland Area Health Board v Attorney-General, 1992) (discussed elsewhere).

MDELS IN NEW ZEALAND.

There are several reasons why it is important to examine MDELS in New Zealand at this time, some of which go beyond the usual right-to-die issues. Medical technology has developed to the point where death or at least the timing of death is increasingly becoming an option. Patients and families are more frequently being offered options at the end of life (EOL) - to take up treatments or forgo them, to increase pain relief at the risk of shortening life, to withhold or withdraw nutrition and hydration, to stay on life support or switch it off. For the layperson, this may be the first time they have been exposed to any of these options and the process that accompanies such decision-making, the factors that contribute to the decisions and the effects of those decisions on those involved, need to be examined.

Constraints of Health Resources.

Some patients and families may increasingly be faced with a lack of options. The case of Rau Williams, who requested dialysis but was refused on the grounds of poor prognosis from other complicating medical conditions and age, confronts us with the spectre of health care rationing. At the time, the Prime Minister of New Zealand, responded to a query on television about the

denial of bone marrow transplants to leukemia sufferers over the age of 55 by stating that such decisions on the distribution of health resources was entirely the domain of the medical profession (Cross-fire Election Special, 1999). The suggestion here that age and/or infirmity may render a person less likely to be eligible for the treatment options increasingly becoming available is of concern from the quality of life point of view as well as for the human rights implications. This is particularly so when one considers that loss of independence and loss of dignity were the reasons most cited for seeking a hastened death in Oregon's first year of legalised physician-assisted suicide (Chin, Hedberg, Higginson, & Fleming, 1999). On the one hand there are more sophisticated treatments becoming available, and on the other hand these resources are being made available to sections of the population only (Hamel et al., 1999).

Research has shown that physicians who practice resource-conserving medicine are significantly more likely than their resource-intensive counterparts to provide a lethal prescription at the request of a terminally ill patient (Sulmasy, Linas, Gold, & Schulman, 1998). Resource-conserving doctors tend to be community based and general practitioners (Hanson, Earp, Garrett, Menon, & Danis, 1999) and it may be significant that in the Netherlands general practitioners are the physicians most likely to practice euthanasia (van der Maas et al., 1996). Considering this, it is not difficult to understand why those who are marginalised in society are less likely to vote for euthanasia or physician-assisted suicide (Bernabei et al., 1998; Finlay, 1985; Hooper, Vaughan, Tennant, & Perz, 1996; MacDonald, 1998a; Madorsky, 1997; Singh, 1979). Those who have limited access to private health care funding because of age, a priori health problems or poverty may rightly perceive themselves to be marginalised when it comes to the provision of health care.

Limited health care resources implicated in mercy killings.

The constraints on New Zealand's health care resources and/or the allocation of those resources have been directly implicated in at least three so-called mercy killings recently⁷. Although these cases did not involve the medical profession, the response to the cases provides an interesting commentary on mercy killing and how the general public in New Zealand perceives this. In July, 1997 Janine Albury-Thomson strangled her 15 year old autistic daughter, Casey, and was given a three year sentence for manslaughter (later reduced to 18 months) after entering a plea of diminished responsibility. A review of the 21 letters that were written to Television One when

⁷ There have been other cases of mercy killing in New Zealand that have been dealt with leniently by the Courts. In 1991 Warren Ruscoe helped his best friend to die after an accident left him tetraplegic and was sentenced to 1 year supervision on appeal after a 9 month sentence for aiding suicide (see R v Ruscoe, 1992). In 1988 Peter Novis shot his terminally ill father, was convicted of manslaughter and sentenced to 12 months supervision (R v Novis, 1988). In 1990 Roger Stead was sentenced to 3 ½ years for killing his mother on request (R v Stead, 1991). The maximum term in New Zealand for assisting suicide is 14 years (New Zealand Crimes Act, 1961).

they featured this case on "60 Minutes" (For Casey's Sake, 1998) revealed that none condemned Albury-Thomson. The general consensus was that justice would have been better served if she had been released back into the community to mother her two younger children. Only one letter raised the issue of what constituted justice for Casey, although this respondent also appreciated that there may have been mitigating circumstances.

Another case was that of John Karnon and his wife, both in their eighties. John Karnon had cared for his invalid wife for years with apparently little support. Driven by constant and unrelieved pain, she begged him to help her die. After a failed murder/suicide bid which left one dead and one hospitalized, Mr. Karnon was subsequently charged with murder. He received a suspended sentence and one year's community service. The press and the public were overwhelmingly sympathetic to John Karnon and his plight (Hendery, 1999; Wall, 1999a; Wall, 1999b).

A further case was that of Nancy Helm, a 70 year-old woman in the South Island of New Zealand who arranged a successful [sic] murder/suicide for herself and her adult handicapped son. She apparently had become increasingly concerned about how he would be cared for when she became incapable of doing so (Family not supported in Down's case, 1998). A later media report suggested that staff at the care facility involved with this family disputed claims that the family did not receive the assistance they needed (Hospital promises changes, 1998). However Mrs. Helm had stated prior to the murder/suicide that she was concerned with staffing changes and that there were difficulties between her son and one of his flatmates (Family not supported in Down's case, 1998).

These three recent cases highlight the importance of liaison between families and care agencies and close monitoring of those families who have expressed frustration or, if they do not express frustration, are objectively deemed to be under extreme pressure. For example, increasing age of parents or partners of the dependent and disabled, other young children in the family, socio-economic constraints are indicators of risk. One report on the Karnon killing suggested that there will be more mercy killings in the future in New Zealand as the population ages and "sickness and old age" take their toll (Masters, 1999). This is supported by reports from elsewhere that investigate the increase in mercy killings that have older sick women as their targets and their husbands as the agents (Canetto & Hollenshead, 2000).

The above cases clearly focussed society on the problem of "re-victimising" the victims of socially constructed inequalities. It was clear from the media, television and commentary in the

public domain that society felt Albury-Thomson and Karnon had been punished enough and that the system was implicated in the killings by not providing the support these families needed. A Catholic spokeswoman would not condemn the light sentence Karnon received despite the church's opposition to euthanasia (Masters, 1999).

Response of society to "mercy killing" cases.

Following the Albury-Thomson case, there was a call for a change in the laws for murder to codify a "diminished responsibility" plea where there is evidence of mental disorder falling short of "legal insanity". This would allow for a court to avoid the New Zealand mandatory sentence (for murder) of 15 years imprisonment, (MacLennan, 1998). At the same time, a bill calling for "degrees of murder" was introduced into parliament which would make some forms of killing more/less reprehensible under the law and allow for flexibility in sentencing for third-degree murder (Neeson, 1998). However a Parliamentary Select Committee advocated caution in adopting such an approach recommending deeper exploration of the anticipated ramifications of such a law (Caution on degrees of murder, 1999 p A14).

When considering degrees of murder the focus tends to be on first degree murder and the call for harsher sentences for very serious crimes. This has been particularly evident in the wake of a series of brutal murders in New Zealand involving home invasions. However cognizance should also be taken of third degree murder for killing that is considered to be less reprehensible under the law, and which could result in non-custodial sentencing. If this type of charge becomes an option under law in New Zealand society, it is necessary to seriously consider the possible ramifications for some sections of the community who are not receiving the necessary support to maintain a reasonable and acceptable quality of life.

If some forms of killing are regarded as the "unfortunate" results of social injustice and inequality (as with the above three cases) and the law treats such cases with leniency, mercy killing (voluntary or non-voluntary) could be seen by some as a viable option. Even if society does not go this far, there could be a negative psychological effect on those who are at risk when they consider that killings without the request/consent of the victim, have occurred in the past and been treated leniently by the Courts. Moreover, in such cases, the perpetrators have received the sympathy of the public at large.

A similar case to the Albury-Thomson case occurred in Canada. Robert Latimer killed his daughter with carbon monoxide in the front of the family vehicle after she was faced with continued painful and inconclusive surgery to correct the effects of severe cerebral palsy. She

could not talk, feed herself or walk and was suffering. The case was treated leniently by the courts (two year sentence) and the disabled community made it clear that they felt "endangered" by such decisions (Nichols, 1997). The effects of this on society, and the psychological effect on those involved need to be considered particularly in the light of the published literature that highlights the concerns of the marginalised and disabled (see Madorsky, 1997).

Subsequently the Latimer sentence was repealed and replaced with a 10 year sentence, which many considered to be excessive (Roberts, 1998). Appeals on Latimer's behalf continue to this day (Wake, 2001). One juror in the appeal case which resulted in an increase on the original sentence summed up the general feeling of the public (71% in one poll) who judged Latimer had been treated harshly (Mahoney, 2001). The juror indicated that he would not have voted to convict if he had known Latimer would get a ten year sentence.

"They should look at it and make a new law and give him some leeway. I don't think he should be in there", Mr. Keyko said from his home in North Battleford. It's not doing him any good and it's not doing us any good (Laghi, 2001).

In New Zealand lobbyist for the National Assembly for People with Disabilities, Susan Hickey is committed to fighting moves to legalise euthanasia, believing the disabled are at risk by such moves (Yandall, 1999) (see Batavia, 2000; Batavia, 1997 and Gill, 2000 for a discussion of the issues for disabled). However a recent case in New Zealand concerned a patient suffering the results of tetraplegia who successfully begged for the right to be allowed to die after the withdrawal of life support (Death of patient who begged to die, 2000) (to be further discussed). Such cases challenge the assumption that the disabled may prefer not to have the option of voluntary euthanasia available to them.

The role of society in right to die reform

The role of government in the euthanasia debate needs to be considered. In the Netherlands, the increasingly formalised protocols for euthanasia have paralleled the fortunes of some of the more liberal parties in Government. In the 1998 elections the reformist D66, a small but key partner in a three-way coalition, fought the election on a pro-euthanasia ticket. "Labour Prime Minister, Wim Kok (had) said the issue could play a role in talks to form a new coalition" (van der Leij, 1998). New Zealand is now governed increasingly by coalitions. It is clear that if a minor coalition party made euthanasia a key issue it could conceivably become the focus of "trading" with one of the larger parties with support for wider issues being promised in return for favourable consideration of right to die issues.

Commenting on how euthanasia got onto the agenda for public debate in Holland (and subsequently for the Dutch Government to commission an investigation into the incidence of hastened death decisions in Holland⁸), Griffiths et al. conclude that two kinds of change occurred in Dutch society. The first was a cultural change, "characterized by the words secularization, individualization and democratization" and the second was a change in medical technology which "greatly increased the doctor's ability to postpone death" (Griffiths et al., 1998, p. 49). This ability was considered not always to be in the best interests of the patient.

The issue of patient autonomy in determining the manner and time of death became a focus of public concern (Griffiths et al., 1998; van der Maas, Pijnenborg, & van Delden, 1995). The Dutch responded to these changes in their society by encouraging public debate, encouraging methodologically sound research and ultimately putting in place a system that would encourage transparency of practice in EOL care decision-making and ongoing assessment of those practices (Griffiths et al., 1998). Dutch proponents of euthanasia are quick to caution against other countries adopting their euthanasia practices (van Delden, Pijnenborg, & van der Maas, 1993). Citing the unique character of Dutch society and the rooting of its euthanasia policy in "culture, politics and the provision of health care", the international community is warned that Dutch policies are "not an export article" (Shapiro, 1997, p. 24).

One of the difficulties in tracing the process by which the Dutch system evolved is that of language. Few outside of the Dutch themselves speak their language and the day to day press reports, television coverage and anecdotes that typify a society are not readily available for study by those who do not speak the language. It is therefore difficult to understand the parallel debates and expressed concerns that must have been operating at the time from all quarters (and no doubt still do). We must rely on Dutch commentators to supply this information and excellent overviews are available (see Kimsma & Leeuwen, 1993) for a useful history of the euthanasia movement in Holland and (Griffiths et al., 1998, pp. 43-86, 157-195) for commentary on the debate since 1945 including legal developments through case law). These authors conclude, after discussing the role of the Government, the medical fraternity and the Church in formalising Dutch euthanasia policies that the leading principle has become the principle of autonomy or self-determination, the leading principle in moral and legal decisions in Holland since the 1960s.

⁸ Known as the Remmelink investigation into MDELs in Holland in 1990/1991 this was the most comprehensive research into physician-assisted death undertaken in any country and subsequently led to the formalisation of protocols under which physician-assisted death could be invoked without legal repercussions for those involved (van der Maas, 1992).

It has been argued that it is inappropriate to try to establish guidelines or policies on physician assistance in dying without a strong research base to determine how those practices are manifested (Morrison & Meier, 1994) and this was certainly the motivation for the original Remmelink research. An examination of the society in which the euthanasia debate is embedded would seem to be a crucial factor in determining the desirability of accommodating the practice. The health care system and practices, the legal system, social support and the values of society at large will all impact on the feasibility of such practices (see Appendix A, Culture, Relativity, Context and Socialisation).

CHAPTER 2

REVIEW OF LITERATURE

MEDICAL DECISIONS THAT HASTEN DEATH

Many medical decisions that hasten death at the end of life may be part of medical practice that is committed to delivering compassionate care to the individual. A decision may be made to withdraw or withhold treatment including nutrition and hydration, dialysis, life support or chemotherapy including antibiotics, knowing that death may be hastened as a consequence. A decision may also be made to increase morphine or another narcotic to address symptoms, knowing that death may be hastened as a consequence. Such actions are legitimated under the principle of double effect first proposed by Thomas Aquinas in the 13th century and refined since by Catholic moral theologians. When an unwanted event occurred (death) as a consequence of actions to achieve a desired effect (freedom from pain), the good outweighed the bad effect (Becker & Becker, 1992).

WITHHOLDING AND WITHDRAWING TREATMENT

The increasingly interventionist approach of modern medicine to medical problems that in the past resulted in death can create anomalies of treatment. Once a medical decision is made to intervene to stave off death by engaging in life-sustaining measures, a decision often needs to be made further down the track to discontinue such treatment - to "let die". How far we intervene in the "letting die" action is increasingly cause for concern. Wherever there is confusion in New Zealand about the legality of an action that could potentially hasten death, recourse is available through the courts to determine its status.

The concept of death

In the past, our concept of death has relied on the cessation of circulation - the heart stopped beating, and the person stopped breathing. With the invention of the respirator in the 1950s which allowed for the mechanical ventilation of patients, another definition of death was required, one that relied less on circulation than on perfusion. From the early 1980s, it has been widely recognised by nations that practice western medicine that the death of one organ, the brain, is to

be used as a measure of the death of a person, a notable exception until very recently being Japan (Singer, 1996).

When death can be said to have occurred is a chosen point and has changed over time. The point we now recognise as that at which death has occurred may change again in the future and it is up to the medical profession to make that distinction (Auckland Area Health Board v Attorney-General, 1992,). In other words, the *diagnosis* of death is medical although the point is made that the *definition* of death is legal (Williams, 1983 p 281). The death of the brain has been chosen as the “point” of death but as we know more about the brain it may no longer be tenable to point to brain death as an indicator of “death”. Relying on cortical death may see the patient still breathing independently but never regaining (or expected to regain) consciousness. Similarly relying on brain stem death, the person will never wake up nor breath independently but recent developments in science indicate that even a “dead” brain continues to stimulate the hormone activity necessary to maintain life through a negative feedback system (Singer, 1996).

As medical technology increases, the diagnosis of death may continue to be dependent on such advances. If so, the “definition” of death may need to be employed as the benchmark by which we make our decisions on whether or not to start or continue life-sustaining treatment. In fact, this is already being done. Decisions are being made not to treat or not to feed “non-viable” infants. Similarly, in a landmark decision in New Zealand, life support was discontinued for a patient with an irreversible neurological disease, *despite* medical evidence that there was still some brain activity (Auckland Area Health Board v Attorney-General, 1992,). Intensivists at Auckland Hospital in 1992 sought a Court order to allow them to turn off the life-support on Mr L who suffered from Guillain-Barré syndrome. The patient was not "brain dead" as that term is normally understood. Rather, there was no communication between an impaired brain and the rest of his body. His condition was described by Justice Thomas as "...'living dead' as much as if he were brain stem dead" (Auckland Area Health Board v Attorney-General, 1992, p. 646).

In making the order, Justice Thomas acknowledged that the judgment could be used as "guidelines" for future practice (although should not create a precedent). He stated that it would "ultimately be for the medical profession, *sensitive to the values of the community* (emphasis added) and alert to the requirements of the law" to make the decision about whether the "definition of death" should be revised (Auckland Area Health Board v Attorney-General, 1992, p. 646) (see Skegg, 1994, for a critical summary of this case in the light of previous rulings in New Zealand and elsewhere, including Airedale NHS Trust v Bland, 1993).

Elsewhere a redefinition of “brain death” is considered unnecessary and we are invited to focus on “those capacities that an individual has lost, rather than those capacities the individual retains” (Fisher, 1999, p. 474). Individuals who no longer have a *meaningful* life although retaining some biological function are not well served by interventions that prolong their existence. Life reduced to vitalism alone may have little value for the person to whom the life belongs and calls into question the whole meaning of sanctity of life when considering withdrawing or withholding life-sustaining measures (Dworkin, 1993; Fisher, 1999).

Medical decision-making affected by legal definitions

With the advances in medical technology and medicine, life and death can become a continuum, with a decision having to be made at some point to perform an act of commission or omission to achieve the end of the life. The application of a definitive demarcation point between living and dying can be difficult and it is suggested that in seeking to find this, we are engaging in a "verbal activity" (Auckland Area Health Board v Attorney-General, 1992, p. 645). Such verbal activity is necessary for enquiry and to further knowledge in the area but may restrict the complicated nuances of some dying scenarios by using categorical labels and absolute terms. Justice Thomas seems to recognise the restrictive nature of language when he suggests we need to "look behind the words and to ask what is the essence of the doctors' established approach" in medical decisions at the end of life (Auckland Area Health Board v Attorney-General, 1992s, p. 645).

Doctors in New Zealand sought legal advice before turning off life support on Mr. L, having been warned that nursing staff who did not agree with the action would involve the police. This is reminiscent of the case of Tony Bland in the United Kingdom. Tony Bland was an 18 year old young man who suffered cerebral anoxia secondary to a crush injury at the Hillsborough disaster on 15th April, 1989. He was subsequently diagnosed as suffering from persistent vegetative state (PVS). On the 4th February 1993, the Law Lords upheld the decision of lower courts that it was legal for the doctors to withdraw artificial feeding (Airedale NHS Trust v Bland, 1993) and he died on 3rd March 1993. The severe physical deterioration reported in the post mortem findings indicated that the decision to not prolong life by continued feeding was the most humane one (and it could be argued that a more humane decision would have been to discontinue feeding earlier to circumvent such extreme physical deterioration). He weighed 36 kgs, suffered severe flexion contractures of the arms, right wrist and fingers as well as flexion and adduction of the left thigh and bilateral plantar flexion of both feet. Examination of internal organs showed bronchopneumonia, pyelitis, cystitis and a periprostatic fistula with loculated pus. Extensive erosion of brain tissue indicated he would never have recovered consciousness (Jarmulowicz, 1995).

Doctors who cared for Tony Bland sought legal advice before discontinuing tube feeding and the House of Lords ruled that food and fluids did not constitute “medical treatment” and could therefore be withdrawn as artificial feeding was delaying death (Airedale NHS Trust v Bland, 1993). Subsequently the British Medical Association (BMA) published guidelines under which treatment, including feeding, could be withdrawn or withheld from patients (British Medical Association, 1999c). In summary these stated that

The primary goal of medical treatment is to benefit the patient by restoring or maintaining the patient's health as far as possible, maximising benefit and minimising harm. (Section 1.1)

If treatment fails, or ceases, to give a net benefit to the patient (or if the patient has competently refused the treatment), the primary goal of medical treatment cannot be realised and the justification for providing the treatment is removed. (Section 1.1)

Unless some other justification can be demonstrated, treatment that does not provide net benefit to the patient may, ethically and legally, be withheld or withdrawn and the goal of medicine should shift to the palliation of symptoms. (Section 1.1)

Prolonging a patient's life usually, but not always, provides a health benefit to that patient. It is not an appropriate goal of medicine to prolong life at all costs, with no regard to its quality or the burdens of treatment (Section 1.2)

Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions. (Section 6.1)

Treatment should never be withheld, when there is a possibility that it will benefit the patient, simply because withholding is considered to be easier than withdrawing treatment (Section 6.2) (British Medical Association, 1999c).

Physicians may find themselves treating patients according to what is perceived to be legally correct when they consider the treatment inhumane. A New Mexican paediatrician is reported to have spent an “agonizing hour” trying to resuscitate a non-viable infant against his judgment that this was the best decision, just because he feared legal censure if he did not do so (Singer, 1996, p. 109).

Figures from Britain suggest that there are between 1000 and 1500 people in a persistent vegetative state (PVS)⁹ (Singer, 1996, p. 59). Figures for New Zealand are not available although a report from 1996 indicated that there were “only about one or two cases of persistent vegetative state a year in New Zealand” (Coma guides reassessed, 1996). However the guidelines from the BMA suggested that patients in a persistent vegetative state “or in a state of very low awareness closely resembling PVS, currently require legal review” (British Medical Association, 1999b) (Section 21.1). Justice Thomas’ ruling on Mr L suggests that New Zealand is already

⁹ Profoundly brain-damaged people who may appear to be awake (eyes open) and responsive but who respond on a reflex level with no evidence of cognitive functioning (Jennett & Plum, 1972).

prepared to withdraw treatment from patients who may not absolutely meet the present criteria for PVS or brain death (Auckland Area Health Board v Attorney-General, 1992).

Justice Thomas' ruling has been criticised on the basis that the decision should have privileged the autonomy of the patient as the Cruzan¹⁰ decision had by citing values implicit in the patient's previous statements or the wishes of the proxy decision-maker who was aware of patient values (both Mrs L and Mr L's brother wanted treatment discontinued). Rather the ruling privileged the role of the doctor by using "best medical practice" as the basis of the ruling (Tobin, 1993).

Skegg argues that Justice Thomas' ruling is useful in providing the medical profession with protection in such cases.

"Fortunately, given the main emphasis of Thomas J's judgment in Re L, there is a good prospect that New Zealand health professionals will be able to deal with these difficult issues without being 'inhibited by considerations pertinent to their own self-interest in avoiding criminal sanctions' " (Skegg, 1994, p. 238).

However it is perhaps an indication of the difficulty experienced by those who seek to give guidance in such matters that both Justice Thomas in the case of Mr L and the Law Lords in the case of Tony Bland stated that their judgments should not constitute a precedent for future related actions (Airedale NHS Trust v Bland, 1993; Dyer, 1993; Auckland Area Health Board v Attorney-General, 1992). Latterly, the requirement in the United Kingdom for physicians to seek permission from the Courts before withdrawing food and fluids has been criticised and a call made for such a requirement to be changed (Jennett, 1999).

Medical decision-making defined by quality of life

Singer argues that the Bland decision was a quality of life decision, given that Tony Bland could have continued on for years with artificial hydration and nutrition. By making the decision as they did, Singer argues that British courts used the quality of the life involved as the basis for deciding whether that life should continue.

"There can be no doubt that, with the decision in the Bland case, British law abandoned the idea that life itself is a benefit to the person living it, irrespective of its quality. If Lord Goff thought life itself was always of value, he would not have been able to say that treatment that prolongs human life can be futile, and the other judges would not have been able to maintain that the care given to Anthony Bland was not benefiting him. The conclusion we can draw is that British law now holds that for life to be a benefit to the person living it, that person must, at a minimum, have some capacity for awareness or conscious experience" (Singer, 1996, pp. 67-68).

¹⁰ Nancy Cruzan suffered permanent brain injury after an automobile accident in 1983 in the United States. She was in a persistent vegetative state for seven years until death. Her parents sought permission from the Courts to remove her feeding tube, were refused, appealed and the appeal upheld in the Supreme Court. Cruzan finally died in 1990 (Cruzan v. Director Missouri Department of Health, 1990)

In making his ruling in the case of Mr L, Justice Thomas referred to *Airedale vs Bland*, and used emotive language to express his views that the life of Mr L was not worth living *despite* continued brain function. Justice Thomas described Mr L as the “living dead” (*Auckland Area Health Board v Attorney-General*, 1992). While acknowledging that Mr L still had some cognitive functioning he stated that Mr L was “denervated and unable to interact in any way with his environment”, such views being reported in the popular press (*A matter of death and the living dead*, 1992).

When the terms ‘medically beneficial’ or ‘futile’ are used in the context of medical decisions to limit treatment, they are employed to “disguise the fact that a quality of life judgment is being made” (Singer, 1996, p. 112). Singer cites three cases that occurred in Britain between 1981 and 1990 where Courts of Appeal judged it acceptable not to sustain the lives of severely disabled infants on the basis of quality of life. A further case in Melbourne in 1989 involved Baby M who was born with spina bifida. The parents agreed to conservative management of their baby, which involved the administration of paracetamol and phenobarbitone, and feeding on demand. This was by no means the only choice that could have been offered to them. Elsewhere babies with spina bifida were operated on to close the opening at the base of the spine, and ongoing treatment maximised their potential. Baby M died after 12 days and an inquest revealed that she had been receiving sub-optimal feeding to maintain life, the phenobarbitone suppressing the “demand” necessary to elicit feeding (Singer, 1996).

Phenobarbitone is a drug of choice when doctors are considering terminal sedation¹¹ (Quill & Byock, 2000). The preferred drug for pain relief is morphine and it is recognised that opioids are not effective in inducing/maintaining sedation (Quill & Byock, 2000). There seems to be only one reason why phenobarbitone would be employed in the case of Baby M rather than morphine to keep her comfortable, and that is to induce sedation (as it is used for in terminal sedation) which would result in reduced demand for feeding. The treatment given to Baby M was found by the coroner to be the best medical decision. Further, the coroner found “that the infant died ‘from natural causes’, although ‘in the presence of phenobarbitone and morphine at toxic levels’”. The decision was met with approval by medical fraternity, the Roman Catholic Archbishop of Melbourne and the general public (Singer, 1996, p. 127) indicating societal tolerance for a medical decision taken explicitly to hasten the death of the baby.

¹¹ Terminal sedation is used when a terminally ill patient has intractable unbearable suffering and is sedated until death. Food and fluids are withheld.

Bland had his tube feeding discontinued for the purpose of achieving his death and this was acknowledged by the Lords in their ruling.

“The majority of the judges in the House of Lords referred to the administrator’s intention in very direct terms. Lord Browne-Wilkinson noted that ‘the whole purpose of stopping artificial feeding is to bring about the death of Anthony Bland’ (Airedale NHS Trust v Bland, 1993, p. 383). Lord Mustill was equally explicit: ‘the proposed conduct has the aim for ... humane reasons of terminating the life of Anthony Bland by withholding from him the basic necessities of life’ (Airedale NHS Trust v Bland, 1993, p. 388).

Lord Lowry also accepted that “the intention to bring about the patient’s death is there” (Airedale NHS Trust v Bland, 1993, p. 379). The judges could have said that they were discontinuing extraordinary or disproportionate (to patient benefit) medical treatment and that death was an unfortunate side effect, thereby fudging the fact that they were causing Bland to die. Singer argues that they did not do so because feeding could only be judged to be extraordinary treatment if the life being maintained had already been judged to be not worth maintaining (Singer, 1996, p. 73).

Keown criticised the Bland decision on the basis that this was inconsistent with the sanctity of life principle (Keown, 1993). Medical decision-making based on a sanctity of life principle may need to be revisited in the light of medical technology which can maintain a life reduced to vitalism only. Singer argues that medical decisions should rather now be based on utility - whether or not sustaining life will benefit or harm the patient (Singer, 1996, Chapter 4) and in the light of the above pivotal judgments it appears that this is increasingly being done. The precedent has been set for quality of life judgments informing decisions on whether a patient should live or die.

Treatment/non-treatment decision-making and futility

In the Bland judgment, the Law Lords decreed that withdrawing a feeding tube or withdrawing life support may involve a positive act, but it should not be classified as euthanasia. The acts were considered part of an overall decision to omit to feed or ventilate the patient. Therefore, they are acts of omission, not commission. However, the judges who subscribed to this view, admitted that it seemed irrational to allow Tony Bland to die over a period of days from lack of food, but not to allow him to die by lethal injection. They cited the law as the reason for upholding such a seeming irrationality and suggested the need for fresh legislation (Airedale NHS Trust v Bland, 1993).

Singer questions whether doctors can really believe that there is a huge difference between the two actions, citing that the way doctors are trained makes it easier for them to accept removing a feeding tube but not giving a lethal injection. However, “both are equally certain ways of

bringing about the death of the patient” (Singer, 1996, p. 221). Rachels concurs, arguing persuasively for moral equivalence between “active” (doing something to kill the patient) and so-called “passive” (letting die without intervention) euthanasia because both have similar motives of reducing suffering and similar outcomes of patient death (Rachels, 1975).

Some doctors agree that the “fine ethical distinctions” between acts of omission and commission may be fallacious (Billings & Block, 1996). The controls put in place wherever assisted death is legalised make it more likely to be safer than other MDELs that are not subject to such guidelines (Brock, 2000). Others strongly maintain that the intent of the physician is crucial in classifying actions taken (or not taken) as either acceptable medical practice or medical practice outside the law (Churchill & King, 1997; Gillett, 1991; Gillon, 1999; Kelly, 1999; Padmanabhan, 1999). The question of whether treatment decisions in accordance with either of these two traditions is moral or ethical as they are presently interpreted, is open to argument (Paris, 1986; Singer, 1996).

It is argued that continued treatment for a patient who receives no benefit “as a whole”, regardless of the localised beneficial effect to one part of the body, is futile (Schneiderman, Jecker, & Jonsen, 1990, p. 949). However the concept of futile therapy is questioned as a discrete entity – rather it is judged to be part of a continuum of low efficacy therapies that may have some value. Estimates “of treatment successes are clouded by disagreements of language, statistical uncertainty, and social prejudices” (Lantos et al., 1989, p. 83). Further, differences in values (including symbolic) placed on outcomes may cause disagreement between physician and patient on treatment decision-making (Lantos et al., 1989; Perry, Rivlin, & Goldstone, 1999).

The provision of life support for patients with *Pneumocystis carinii* pneumonia secondary to advanced AIDS has resulted in positive physiological outcomes (Friedman, Franklin, Rackow, & Weil, 1989; Peruzzi, Skoutelis, Shapiro, et al., 1991). While the majority of AIDS patients in another study accepted a rationale of medical futility when treatment decisions were proposed in a hypothetical scenario, a significant minority (12%) of these patients rejected the medical futility rationale (Curtis, Donald, Caldwell, & Collier, 2000). An association between rejection of the futility rationale and a desire for aggressive therapies prompted these authors to encourage physicians to explore patient attitudes towards treatment preferences to improve communication between physician, patient and family in end of life decision-making (Curtis et al., 2000). Anything that will improve communication at the end of life is judged beneficial given the potential for misunderstandings and conflict (Ashby & Stoffell, 1991; Churchill & Danis, 2001; Goold, Williams, & Arnold, 2000; Quill, 2000).

The division of “futility” into quantitative (physiologic) and qualitative (whole person) benefit (Schneiderman et al., 1990) is extended elsewhere to provide realms of responsibility in decision-making between physician and patient/family, based on expected outcome (Jecker & Pearlman, 1992). Successfully returning a patient to a former physiological state may meet practitioner judgments of best treatment but if that physiological state does not incorporate a return to the former “personhood” of the patient, the patient may question the efficacy of the action proposed. These authors argue that judgments on futility based on both these perspectives will more successfully reflect the decision stakeholders (Jecker & Pearlman, 1992).

The difficulty of defining when a treatment should be enacted, withdrawn or withheld is acknowledged, given the subjective and often value-laden judgments inherent in such decision-making. Clinical decision-making is often based on the subjective appraisal of the physicians involved (Christakis & Asch, 1993; Cohen et al., 2000; Goh & Mok, 2000; Hamel et al., 1999; Waddell, Clarnette, Smith, Oldham, & Kellehear, 1996). Until reliable and valid objective criteria for futility are developed, it is argued that decision-making should be based on medical ethics that embrace beneficence and non-maleficence as per the Hippocratic Oath (Goh & Mok, 2000). However elsewhere it is argued that the complexity of the “medico-socio-legal-philosophical-ethical issue” of medical futility should be left to the courts and legislature to resolve (Smith, 1995, p. 14).

Nutrition and hydration

Several pivotal cases related to medical decision-making at the end of life have involved the question of discontinuing nutrition and hydration (N&H) (Cruzan v. Director Missouri Department of Health, 1990; Airedale NHS Trust v Bland, 1993; In re Karen Quinlan, 1976; Palmer, 1998). However not all cases where N&H are withdrawn reach the Courts (Gregory, 2000a; Kmietowicz, 1997) and the action appears to be taken relatively often (Dyer, 1999). It is argued that the action is only justified if the patient is terminally ill and continued provision would delay death and increase suffering (Twycross, 1999; Paul, 1999).

Unlike other forms of treatment which may be withheld but the patient may still survive, the only outcome of withholding nutrition and hydration is the death of the patient. For this reason critics of the practice are ethically opposed (Paris, 1986). However when a patient is terminally ill, the provision of artificial feeding¹² may be a burden to the patient and provide little benefit. Patients in end-stage disease may be unable to utilize the nourishment provided (Gillick, 2000). In such

¹² Delivery of nutrients via a nasogastric, gastrostomy or enterostomy tube

situations the burden of providing tube feeding with its attendant management problems may outweigh any benefit to the patient in terms of prolonging life.

The issue is also raised that this invasive method of feeding patients may be taken in an effort to avoid the time-consuming (and therefore expensive) effort of orally feeding patients. The spectre is then raised that the ability of the patient to utilize the food is not monitored and feeding may continue for longer than is either ethical or appropriate (Brodeur, 1991).

The question of whether death by dehydration is painful has been addressed (Billings, 1985; Zerwekh, 1983). Evidence suggests that withholding fluids in end stage disease does not affect patient comfort (Dunlop, Ellershaw, Baines, Sykes, & Saunders, 1995; Zerwekh, 1983) and may even enhance it with patients requiring less panning, experiencing less gastrointestinal upset and less pulmonary congestion (Andrews & Levine, 1989; Zerwekh, 1983). Patients have also been clinically observed to be mildly euphoric (Dolan, 1983; Zerwekh, 1983). This euphoria has been attributed to an alteration in body chemistry producing increased endorphin levels and dynorphin accompanied by an analgesic effect produced by ketosis (Printz, 1992). These effects appear to be associated with *total* starvation. Once a decision is made to withdraw or withhold nutrition and hydration, any measures to maintain comfort should not include anything that could block ketone production and produce discomfort by rekindling hunger in the patient (Sullivan, 1993). A ketone-blocking effect has been noted with the provision of IV 5% dextrose solution (Aoki, Muller, Brennan, & Cahill, 1975). Alternatively, electrolyte levels in patients undergoing terminal sedation may remain normal with one author noting this phenomenon in half the patients studied in such a group (Oliver, 1984).

Anorexia and loss of appetite is associated with the terminal stage. Patients admitted to a terminal care facility were monitored and despite an intake insufficient to sustain basal nutritional requirements, 63% ($n = 32$) experienced no hunger and 34% had hunger initially but subsequently lost all appetite. Significantly, all patients were conscious and capable of expressing their needs to caregivers, a prerequisite for inclusion in the study (McCann, Hall, & Groth-Juncker, 1994).

An account of the Indian *muktibhavans* (houses of salvation) that care for dying pilgrims indicates that those who are still eating and drinking of their own volition are not judged to be close enough to death to stay in the muktibhavan. Seventy-four of 81 families confirmed that the person they had bought to the muktibhavan to die had ceased oral intake for up to several weeks beforehand. The concept of stopping food and fluids being implicated in accelerating dying for the terminally

ill is postulated as a western concept, “cultural” and “arbitrary” and as such “amenable to being rethought” (Justice, 1995, p.42).

The provision of food and drink is strongly attached to the emotional bonds we share (Brodeur, 1991; Winkler, 1987). However hospice nurses who had observed deaths in which dehydration was implicated had significantly more positive attitudes towards dehydration than those who had not had such experiences (Andrews & Levine, 1989).

Any discomfort experienced by dehydration are subjectively reported to be alleviated by comfort measures such as small sips of water or mouth cares which will not rehydrate the patient but will keep the membranes moist and prevent breakdown of the epithelial tissue (Zerwekh, 1983; Twycross & Lichter, 1998; McCann, Hall & Groth-Juncker, 1994; Billings, 1985).

Arguably, inherent in any decision to withdraw or withhold treatment must be a commitment to the adequate provision of palliative care sufficient to obtain a “good death” for the patient (Cohen et al., 2000).

Terminal Sedation

The most controversial of palliative alternatives in the care of the dying patient is that of terminal sedation – where a patient is sedated until death during which time nutrition and hydration are withheld. When the intent of the action is to address intractable suffering this is judged to be a “useful adjunct in the palliative armamentarium” (Rousseau, 1996 p 1786) and may successfully address the needs of patients and families at this time (Cherny & Portenoy, 1994; Fainsinger, 1998; Kenny & Frager, 1996; Quill, Lo, & Brock, 1997b; Rousseau, 1996; Twycross & Lichter, 1998). It is argued that reversible factors contributing to the situation should be addressed prior to implementation to ensure that terminal sedation is the most appropriate action to be taken (Fainsinger, 1998). It is claimed that thorough assessment has been instrumental in a reduction of cases requiring palliative sedation (Fainsinger, Tapper, & Bruera, 1993; Pereira, Hanson, & Bruera, 1997). It is suggested that physicians should differentiate between “difficult” symptoms and “refractory” symptoms and an algorithm is proposed to assist in a systematic assessment, preferably involving a multi-disciplinary team (Cherny & Portenoy, 1994). Such suggested approaches and cautions appear to give emphasis to the seriousness of sedating a patient close to death.

The term “slow euthanasia” was employed to describe the hanging of a morphine drip or providing sedation (such as barbiturate) until the death of the patient (Billings & Block, 1996). These authors questioned why physicians will instigate this course of action knowing that it will

lead to the drawn out but inevitable death of the patient, but will not consider a faster death for the patient via a euthanatic. They suggest that having the patient die slowly over a period of time may provide the physician with a buffer against feelings of guilt and fear of legal consequences. “Slow euthanasia puts an acceptable face on an otherwise forbidden practice” (Billings & Block, 1996, p. 27).

This article produced a strong reaction. The authors were accused of conflating the actions of doctors who increase morphine in response to suffering knowing that death will be hastened (palliative care sanctioned under the principle of double effect) with doctors who increase morphine in response to suffering in order to hasten death (Dickens, 1996; Mount, 1996; Portney, 1996; Regnard, 1999). The former were acting according to ethical guidelines that prohibit the intentional taking of innocent life but allow for a consequence of hastened death while the latter clearly intend the death of the patient (Dickens, 1996). It is argued that intention of action (even when actions may be identical in all other respects) are what differentiates between palliative care and euthanasia (Gillett, 1991).

Concern was expressed also that the actions described by Billings and Block (Billings & Block, 1996) were represented by “catchy new slogans” such as ‘slow euthanasia’ and ‘double-effect euthanasia’ that misrepresented the compassionate and ethical use of morphine and sedation in the care of the suffering dying patient (Mount, 1996). Further research supported the wide spread use of sedating agents in the care of dying patients by palliative care experts in response to intractable suffering. Seventy-seven percent ($n = 61$) reported having used sedation in the previous 12 months, often with more than one patient. When considering the context of the action taken, these authors concluded that the actions known as “terminal sedation” could more correctly be defined as “sedation for intractable distress in the dying” (Chater, Viola, Paterson, & Jarvis, 1998) however “palliative sedation” may be a more parsimonious term (Rousseau, 2000).

Arguably, “terminal sedation” is not a discrete entity but exists on a continuum. Patients may be offered sedation with other therapy to relieve anxiety or fear, they may be sedated but rousable or they may be rendered unconscious and unrousable. When debating the ethics and efficacy of such actions it is necessary to be clear about how the term is being used (Hardy, 2000).

Terminal sedation has been posited as an acceptable legal and ethical alternative to physician-assisted suicide or euthanasia (Bernat, Gert, & Mogielnicki, 1993; Quill, Lee, & Nunn, 2000). Physicians who have difficulty assisting a patient to die by dehydration may arguably be obliged to offer palliation for distressing symptoms experienced as a consequence, similar to them being

expected to relieve distressing symptoms resulting from the withdrawal of any life-sustaining treatment (such as dialysis) or the refusal of life-sustaining treatment (such as antibiotics).

“Just as a physician must continue to provide palliative care for a competent patient who refuses to have surgery and is dying of sepsis from a gangrenous extremity, palliation remains a physician’s obligation for a patient who chooses to die by terminal dehydration. Patients who voluntarily choose this option after being informed about their alternatives should be assured that they will not be abandoned and that every effort will be made to promote comfort until death arrives” (Miller & Meier, 1998, pp. 561-562).

Elsewhere (Orentlicher, 1997) it is argued that sedating patients to address intractable suffering and then withdrawing nutrition and hydration as is the custom, is euthanasia. While arguing that sedation may be an appropriate response to suffering, withdrawing hydration does not address the suffering, it aims to kill the patient and therefore constitutes euthanasia.

Ventilatory life support

The case of Mr L (discussed above) involved the withdrawal of ventilatory support from a patient who was not “brain dead” and who had not requested withdrawal. It was acknowledged that he had indicated at a previous time that he would not want to live in such a condition (Auckland Area Health Board v Attorney-General, 1992). More recently a highly publicised case in New Zealand related to the withdrawal of ventilatory support from a requesting tetraplegic patient, knowing that death would ensue. In November, 2000, Brian Park died in New Zealand following a public plea to be allowed to die after an accident that left him tetraplegic and ventilator-dependent (NZPA, 2000). Brian Park had initially requested assistance to die by having ventilatory support withdrawn immediately after the accident. Following counseling from the attendant team at Burwood Hospital in Christchurch, Park entered into a contract with the team that he would complete a rehabilitation programme at the Unit and his wish to die would be reassessed three months after discharge into the community. Initially it was reported that Park’s wish to die had abated but three months after discharge home he requested the discontinuation of life support and died peacefully with his family six days later (Death of patient who begged to die, 2000)

The above cases parallels a similar case reported in the USA. A 17 year-old male suffered paralysis after a diving accident and was rehabilitated back into the community, enrolled at a community college and received full professional and family support. He found his life intolerable and requested for his ventilator to be disconnected. After assessments as to competency a court order confirmed that his wishes should be honoured. He died 25 months post-injury after the ventilator was withdrawn (Maynard & Muth, 1987).

Both of these cases involved cessation of life support on request after a period of time between accident and event. Although a request for death may be common in critical care for patients who are traumatised and severely injured, we are cautioned against precipitous action that may cause the “premature death of a person who could have lived a happy and productive life” (Patterson, Miller-Perrin, McCormick, & Hudson, 1993, p. 506). In fact these authors argue that the physical, psychological and emotional trauma immediately post-injury would render questionable the competency of any request for assistance to die at this time.

The difficulty of determining when life support may be discontinued has been addressed and variability in judgments has been noted between countries, but also between institutions within countries (Winter & Cohen, 1999). Although the law and medical ethics in decision-making may give guidance, the complex nature of much decision-making translates into a requirement for decisions in the clinical setting. Team members “consult and negotiate with one another in trying to establish a course of action” (Seymour, 2000, p. 1246). Seymour uses Lupton’s characterisation of “subjectivity” as dynamic and “often fraught with ambivalence, irrationality and conflict” (Lupton, 1997 (as cited in Seymour, 2000)).

The need for effective communication in health care has long been recognised in psychology (Ley & Spelman, 1967). A requirement for increased education on communication in end of life care has been recognised in medicine (Charlton, 1993). Decision-making at the end of life can create conflict between physician and family (Goold et al., 2000), physician and patient (Churchill & Danis, 2001; Gregory, 1997), within families (Kumar, 2000) and within the health care team (Kent & Owens, 1995). Identifying and addressing potential barriers to effective communication between patients, families and physicians could assist in end of life care planning. When patient, family and physicians utilise different principles or values in end of life decision-making, there is a potential for conflict. One way of circumventing some of this conflict is by utilising advance care planning.

CHAPTER 3

PLANNING FOR DEATH

ADVANCE DIRECTIVES

Advance directive (AD), or living will (both terms used interchangeably here (Singer, 1994b)) refers to the written preferences for treatment or non-treatment that a person expresses when they are well, to be invoked at a future time when illness, accident or dementia affects the ability to express those preferences. Such a directive can include the appointment of a person to act as proxy decision-maker in the event of incapacity. The proxy will have durable power of attorney over health care decisions and should be someone who is trusted to make decisions as the person would themselves if they could (Emanuel & Emanuel, 1998).

The perceived need for a living will was originally advanced 30 years ago (Kutner, 1969). Advances in medical technology raised concerns that treatment may continue beyond what would be in the best interests of the patient and an increase in the implementation of ADs has been attributed to fear of patients of over-treatment by doctors at the end of life (Robertson, 1995). Support for such a view has been strengthened by the results of the influential SUPPORT study of 9,105 seriously ill patients in the United States. Preferred options of non-treatment were not documented in patient notes, physicians were unaware of patient preferences, and nearly half of the patients who died during the study received mechanical ventilation prior to death (SUPPORT Principal Investigators, 1995).

Several high profile and influential (on the right to die debate) court cases have ensued when physicians have wanted to continue treatment but family have wanted life-sustaining measures such as artificial ventilation or feeding withdrawn from patients (Gostin, 1997). In New Zealand over-treatment at the end of life may not be such a concern. In the last decade the New Zealand courts have been consulted when the medical profession has wanted to discontinue treatment but patient (Shortland v Northland Health Ltd, 1997), family (Auckland Healthcare Services Ltd v L & L, 1998) or other concerned parties (Auckland Area Health Board v Attorney General, 1993) have wanted treatment continued.

Formalising advance care planning may not increase implementation

The increasingly high profile issue of controlling one's death through the use of an AD has been dealt with in conceptually different ways depending on the culture. It is suggested that in America with the emphasis on self-determination, approaches to ADs can be overly legalistic (Solomon, 2000). In the United States one formalised approach to advance care planning has been taken with the passing of the Patient Self-Determination Act (PSDA) in 1991. As a condition of receiving Medicare or Medicaid reimbursement in the United States, all hospitals, nursing homes and hospices must advise patients on admission of their right to execute an AD and their right to accept or refuse treatment (La Puma, Orentlicher, & Moss, 1991). Despite the enactment of the PSDA the majority of patients in the United States have not completed an AD (Aitken Jr, 1999; Hughes & Singer, 1992; Johnston, Pfeifer, & McNutt, 1995).

In six randomly chosen nursing homes, AD documentation in nursing home medical records increased by 30% after the introduction of the PSDA. However, the majority of residents who had completed a directive, had done so prior to admission. This suggests that the main effect of the PSDA had been to formalise nursing home documentation procedures on existing ADs rather than increase the completion of ADs per se (Bradley, Wetle, & Horwitz, 1998).

Advance care planning and the law

“One especially salient purpose of advance directives is to avoid recourse to the courts to resolve difficulties associated with decision-making for incapacitated patients such as those in a persistent vegetative state” (Editorial, 1992, p. 1321).

The requirement for guidance in such decision-making that would preclude the courts becoming involved was also alluded to by Justice Thomas in his judgment in the *Mr L* case (*Auckland Area Health Board v Attorney-General*, 1992). However, this presupposes firstly, that the advance directive has some standing in law, and secondly, that physicians are aware of that legal standing.

In all of the United States and in three Australian states and two territories, such a declaration has statutory basis. New South Wales, Tasmania and Western Australia are similar to New Zealand and the United Kingdom - although no statutory basis exists for an AD, they may still be valid under common (judge made) law (Biegler, Stewart, Savulescu, & Sken, 2000). This means that an advance directive is as binding on doctors as a contemporaneous decision but it is only binding if certain conditions are met such as legal conditions. However, even then the directive could be disregarded. Docker uses the analogy of speeding in a speed restricted zone - the limit may be disregarded but the infraction does not always involve a penalty (Docker, 1998).

Doctors seem to be confused over the legal standing of advance directives. Of 214 general practitioners in the UK, only 49% were aware that advance directives carry legal force (as in doctors are bound to follow them as if they were a contemporaneous decision of a competent adult) (Bowker, Stewart, Hayes, & Gill, 1998). Other research indicates that despite the guidance of the British Medical Association and other publications, NHS trusts in Britain remain ambivalent about implementing policies for advance directives leading to calls for national guidelines to be established (Diggory & Judd, 2000).

Notwithstanding arguments that warn of the dangers of legalising the AD (Treloar, 1999; Ryan, 1996) (to be discussed later), when medical decisions are difficult and prognosticating uncertain, physicians may find a legally binding directive helpful in decision-making (Biegler et al., 2000; Waddell, Clarnette, Smith, & Oldham, 1997). It is argued (Hughes & Singer, 1992) that an AD may also be helpful by providing protection for physicians from liability if they follow the directive and are later challenged.

In New Zealand, a durable power of attorney is covered by law in the Protection of Personal and Property Rights Act, 1988, s 98. A durable power of attorney is presented in two parts. The first covers property, and the second covers welfare. It is the second part, less frequently addressed by lawyers with their clients that involves the appointment of a health care proxy to make end of life care decisions on the part of a person who has become incapacitated (pers com Chris Wilson, Solicitor, Herne Bay Law). However there are limits to the extent of the proxy's power. Standard medical treatment which has the intention of saving the patient's life, or preventing serious harm may not be refused by a proxy under New Zealand law. Similarly, if a proxy makes a decision on behalf of the patient to limit care, even if this has been discussed in detail at a former time with the patient, others are at liberty to challenge this (Tobin, 1993).

Barriers to advance care planning

There is consistent evidence from the literature that both healthy and unhealthy people are in favour of considering advance death care planning, and would appreciate the opportunity to discuss this with their doctors (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; Gamble, McDonald, & Lichstein, 1991; Haas et al., 1993; Sam & Singer, 1993). Barriers to such discussions have been identified. Among patient barriers to such discussions were attributed: believing the doctor should initiate the discussion, believing the doctor should make the decisions, considering such discussion relevant to sick and old only or not considering the topic personally relevant (Emanuel et al., 1991; Sam & Singer, 1993). A further patient barrier related to literacy, with persons in Canada preferring to discuss directives but not write them, identifying inability to

write as a barrier (Sam & Singer, 1993). Longer patient/practitioner relationships were related to increased likelihood of advance care planning (Wenger et al., 2001) and when such discussions occur, patients react positively and find them helpful (Emanuel et al., 1991; Gamble et al., 1991; Tulsky, Fischer, Rose, & Arnold, 1998).

Conversely, physicians may prefer not to initiate a discussion with their patients. Physician identified barriers include perceived emotional instability of the patient or too few previous visits (Tulsky et al., 1998), physician discomfort, perceived time constraints (Morrison, Morrison, & Glickman, 1994), a belief that patients share the doctors' values and preferences and therefore discussion is not necessary (Hofmann et al., 1997) and different racial profile of doctor and patient (Haas et al., 1993; Wenger et al., 2001). As noted, difficulties with language have been identified as a barrier to patients completing an advance directive (Sam & Singer, 1993). This might imply that immigrant citizens or those who have English as a second language in New Zealand may require particular efforts to ensure they are not disadvantaged in discussions on end of life care options.

People were more likely to want to discuss treatment preferences and appoint a proxy if they were familiar with or had experience of, intensive care or CPR (Sam & Singer, 1993). Taking into account the apparently limited impact of the PSDA, if it is considered that the completion of an advance directive has merit, initiatives to increase their use may need to be encouraged within the doctor/patient relationship through public and professional education programs, rather than through statutory intervention (Hughes & Singer, 1992; Sam & Singer, 1993; Tulsky et al., 1998).

Advance care planning does not address all needs

Other commentators emphasise cultural differences in approaches to end of life care (Martin, Emanuel, & Singer, 2000; Neuberger, 1998) which may see practitioners adopting a paternalistic role withholding the truth of negative diagnoses from the patient (Kashiwagi, 1991; Martin et al., 2000). Such an approach would rule out the use of an AD because the frank discussion necessary to complete such a directive would not be possible. Moreover, the underlying philosophical principle of advance directives is personal autonomy (Singer, 1994a). This principle is neither sought nor recommended in many collectivist cultures.

It is clear that behind each diverse approach to end of life planning is the desire to alleviate the suffering of the patient and to act in their best interests (Martin et al., 2000). In noting the diversity of approaches expressed by practitioners, Solomon encapsulates the spirit of care that motivates them all while acknowledging the difficulties that can accompany such care.

“What all these commentators share is a commitment to individualising decisions. Not through prior ADs about a hypothetical time, but in the moment - a moment that is inevitably conflicted, uncertain, fraught with ambivalence. One that requires acts of human kindness, more than treatment directives.” (Solomon, 2000).

Solomon touches on one of the problems that lie with ADs, and which has led to several commentators cautioning against the legalisation of ADs (Ryan, 1996; Treloar, 1999). Arguing that an AD might be invoked in a situation the patient had not envisaged, Treloar points out that an AD that precludes active treatment for a patient suffering dementia might prohibit treating a urinary tract infection with antibiotics. Such a complaint is not life threatening but will cause misery for the patient if left untreated. Further, he argues that healthy patients cannot envisage how they may react in future times when they become incapacitated. It could be dangerous to assume a patient, particularly a patient whose “personality, concerns, beliefs and ... understanding” is altered by dementia, still feels the same as they did when the directive was written (Treloar, 1999, p. 1060).

Dementia has been shown to be the most feared of disabilities in old age among respondents in both the United Kingdom and the United States. In London, 90% of medical inpatients ($N = 76$) requested no active treatment in advanced dementia (Schiff, Rajkumar, & Bulpitt, 2000) and 95% of respondents in a Minnesota study on cognitively normal adults over 65 years requested CPR, artificial ventilation or artificial nutrition and hydration be discontinued in advanced dementia (Gjerdingen, Neff, Wang, & Chaloner, 1999).

The difficulty of forecasting preferences

It is argued (Ryan, 1996) that healthy individuals may employ defence mechanisms such as denial to avoid fully engaging with the possibility that they may suffer a terminal illness in the future. As a consequence of not acknowledging that they could suffer such an illness preference for medical interventions in such an event is often under-estimated. Ryan cites anecdotal and empirical evidence that suggest that individuals who have experienced serious illness are more likely to want more intervention (Ryan, 1996). As we age, we are increasingly confronted with the possibility that illness could be our reality at some time in the future. One way of coping with this possibility could be by comforting ourselves with the idea that the worst of such an illness could be avoided by choosing an elective death before things become unbearable. If a terminal illness develops, this coping strategy would no longer work and we may be “faced with balancing real dying with the possibility of real suffering” (Ryan, 1996, p. 96). In such an event, Ryan argues that most of us will struggle on, perhaps using denial to maintain a hope that a cure will be found. In any event, by employing psychological coping mechanisms when young, older

or terminally ill, we can confound the concept of correctly predicting our future health care preferences for the purposes of an advance directive. However Ryan does not reject the concept of ADs out of hand. Following his argument, those who are already critically ill may be in a better position to make a directive which can be respected, a view with which others concur (Goold et al., 2000; Martin et al., 2000).

Similarly, those who have irreversible conditions where the ability to convey preferences is permanently lost (as in persistent vegetative state) would have no chance in the future to change their decision. In this case an AD would be helpful in assisting proxies to make decisions on behalf of the patient (Ryan, 1996). Elsewhere it is acknowledged that requests for hastened death should be discounted from patients who are suffering extreme pain as the request is made under compulsion. In such a case an AD completed at a previous time and which covers this contingency could be considered (Flew, 1999). It could be argued that those who are critically ill may also be acting under compulsion when they complete a directive limiting treatment. Fear of what may be coming may create a desire for the dying to be over faster. Patients may want personal financial resources to be conserved for others rather than used on treatment or hospitalisation. Similarly, patients may fear becoming a burden on loved ones by lingering. However only 19% of Ontario physicians ($n = 637$) agreed that patients frequently change their minds about life-sustaining treatment after becoming terminally ill (Hughes & Singer, 1992). For most people, treatment preferences appear to be grounded in a consistent belief system (Patrick et al., 1997).

Reliability, durability and validity of advance care planning

The problematic issue with ADs therefore rests mainly with concern over how durable and therefore valid, such a directive is (Emanuel, 1994b). It seems crucial to the whole concept of ADs that the directive accurately addresses the situation being experienced at the time the directive is activated. How best to create such a directive has been addressed by targeting two main areas. Firstly, assessment of the competency of the patient to complete a directive, particularly if there is some cognitive impairment such as dementia. Secondly, the directive must reflect the true wishes of the person under consideration.

Validity of directive

Competency is not a global state but recognised as a state specific to decisions or situations reliant on the ability of the person to comprehend, maintain a stable position, appreciate consequences and manipulate information (Applebaum & Grisso, 1988). Because someone has a cognitive impairment, this does not necessarily exclude them from being able to complete a valid AD

(American Geriatrics Society Ethics Committee, 1996). To assist cognitively impaired subjects with understanding, a patient-centred approach of assessing patient competency to complete an AD has been developed by using a test-retest (10-14 day interval) vignette scoring system in the presence of an interviewer. Interviews were taped and two independent psychiatrically qualified raters scored the subject for competency using the Silberfeld competence assessment score from the recorded interviews. Test-retest, intratest and interrater reliability were high and correlations with the independent competency assessment score established a valid cut-off point for competency. The authors claim that the test can be applied in the clinical setting and is particularly useful as it takes into account the importance of imagining future situations (Fazel, Hope, & Jacoby, 1999).

The use of advance directives in cases of extreme dementia has been criticised on the philosophical basis of personhood.

“It is argued that the personhood of patients is radically altered by the onset of incompetency. Therefore it is inappropriate to direct a now-incompetent person’s health care on the basis of the treatment preferences that that person expressed when he or she was competent ... the interests of the person have been radically altered by the loss of competence” (Singer, 1994a, p. 111).

Although this argument may be philosophically compelling, advanced dementia may be the most feared condition of degenerative aging and one in which people seem to be most likely to want treatment withdrawn or withheld (Gjerdingen et al., 1999; Schiff et al., 2000). This is therefore one condition for which people *would* desire to have advance care planning. Bioethicists who argue from personhood that directives should not be invoked in severe dementia could be out of kilter with the preferred choice of the populace. Elsewhere we are warned that ethical guidelines proposed by bioethicists and which underpin difficult medical decisions at the end of life may not correctly reflect physician judgment on best medical care. Rather it is suggested that bioethics should have regard to what practitioners say and do when formulating any advances in that field (Dickenson, 2000; Editorial, 1997). The development of interdisciplinary, multidisciplinary and transdisciplinary research is endorsed as a means of developing “valid” ethics research (Singer, Pellegrino, & Siegler, 2001).

Reliability of directive

Secondly, the AD must be reliable, it must correctly reflect at some future time the preferences of the person making the directive. Instructions that are specific to certain scenarios would more accurately reflect patient wishes. Research suggests that HIV positive patients prefer a disease-specific advance directive (Singer, Thiel, Salit, Flanagan, & Naylor, 1997). The advantages of such an approach allows those with pre-existing conditions that will probably cause death at some

time to be very specific about their wishes. The disadvantage of such an approach is that such specificity does not allow for random health compromise that could increase suffering if not addressed (Singer, 1994b).

“Dr Glick of Israel tells the story of a young Bedouin patient with a completely reversible pneumonia, but because he had an advance directive asking not to be intubated, he was allowed to die. Dr Glick asks us to consider: Is this really what the patient would have wanted?” (Solomon, 2000)

When a person has lived with a chronic life-threatening disease for some time, they may regard the measures taken to maintain health status as a normal part of living, and not necessarily a treatment to be discontinued. Attempting to elicit patient preferences for withdrawal from dialysis from 400 haemodialysis patients, one study found that although mechanical ventilation, CPR and artificial nutrition and hydration were addressed, withdrawal from dialysis was “rarely discussed” in advance care planning by dialysis patients. These authors suggest that because such patients integrate dialysis into their daily routine, discontinuation is less likely to be considered. The disease-specific AD would be helpful in focusing discussions on dialysis and assisting practitioner/patient communication on end of life care choices (Holley et al., 1999).

The New Zealand courts have recently dealt with two cases where dialysis patients were refused continuation of treatment on grounds of futility. The patients involved vigorously and publicly challenged this view, one successfully (Carroll, 1997) and the other unsuccessfully (Lewis, 1999).

For healthy people, directives may specifically address certain scenarios using vignettes to convey possible compromised states that can accompany old age. The person notes preferences for treatment or non-treatment in a given situation, including resuscitation, mechanical ventilation, surgery, dialysis, blood transfusions, artificial nutrition and hydration, antibiotics and pain medication (Emanuel, 1991). However, even such a reasonably generic approach that still specifies treatments/non-treatments can cause problems with interpretation if they do not accurately cover the situation in which the directive is activated. Given the complexity of modern intensive care situations and technology, it is suggested that a values history is more useful than an advance directive.

Values history - the quality of a life

Values histories focus on the declarant’s values rather than specific instructions, forming a basis from which decisions on medical treatment can be made. This allows for flexibility that crosses situations but decision-making is made within the context of expressed values and goals (Docker, 2000; Doukas & McCullough, 1989; Gibson, 1990). Doukas & McCullough challenged the emphasis that the literature places on the relative importance of the value principles of autonomy

and beneficence in medical decision-making. Their findings indicate that family burden considerations (beneficence) are more influential in advance care planning for respondents than issues relevant to patient ability to communicate or physician compliance with patient wishes (autonomy). These authors also found that respondents preferred quality of life over longevity, discussions on what constituted quality of life for the patient providing a good basis for advance directive communication (Doukas & McCullough, 1989).

Schneiderman et al. also advocate *patient* quality of life judgments as a measure for advance care planning suggesting that these are useful to guide physicians in their choice of treatment. “Physicians, through their training and experience, are best able to understand which treatments (or lack of treatments) best meet their patients’ wishes” (Schneiderman, Pearlman, Kaplan, Anderson, & Rosenberg, 1992b, p. 2120).

It is suggested that a values history could be used as a stand-alone directive, or in conjunction with a more standard advance directive (Docker, 2000). Emanuel goes further to suggest that ideally

“... a patient’s advance directive will combine three kinds of statement: broad values, goals and specific examples. Only when seen together and interpreted as a whole can a person’s wishes be adequately conveyed” (Emanuel, 1991, p. 1222).

Discussions on patient judgments on quality of life appear important in light of research that suggests that patient and practitioner views on patient quality of life can be disparate. An American study on 258 elderly outpatients and 105 of their primary physicians, found that physicians significantly underestimated patients’ quality of life on all levels of a multi-dimensional quality of life measure compared to patients’ subjective evaluations. Judgments on perceived quality of life were significantly associated with physicians’ attitudes towards life-sustaining treatment for the patients (Uhlmann & Pearlman, 1991).

Proxy decision-making

Doctors may prefer to follow their own judgments on best care, and ignore advance directives. Over half of the doctors who had used a directive in a clinical setting reported that they had not always acted in accordance with it. Reasons given related to problems with the directive itself, family disagreement, non-terminal illness and perceived likelihood the patient would change the directive if aware of present circumstances (Hughes & Singer, 1992). Similarly, a prospective randomised clinical trial of 204 hospitalized patients (100 of whom died during the study) showed that the presence of an advance directive had no effect on reduction in treatment or costs in end of life care (Schneiderman, Kronick, Kaplan, Anderson, & Langer, 1992a). However the authors

stress this result should be viewed with caution given that the majority of patients could communicate their wishes prior to death and caregivers were therefore not reliant on the directive.

Other studies support the concept of doctors acting in accordance with their own agenda with physicians' personal values and attitudes influencing treatment decision-making (Doukas & Gorenflo, 1999; Orentlicher, 1992; Rebagliato et al., 2000; Schneiderman, Kaplan, Pearlman, & Teetzel, 1993; Waddell et al., 1996). Personal preference of physician has also been demonstrated to influence decisions on treatment withdrawal. Physicians were "twice as likely to prefer to withdraw blood products or haemodialysis compared to antibiotics, and about half as likely to withdraw tube feeding, mechanical ventilation and intravenous fluids" (Asch & Christakis, 1996, p. 106). Other studies indicate that physicians' judgments on what treatment or non-treatment patients may prefer can be poor (Bedell & Delbanco, 1984; Uhlmann, Pearlman, & Cain, 1988).

Further research from the United States indicated that a majority of physicians considered that suicide can be rational in certain circumstances and 31% ($n = 114$) considered physician-assisted suicide should be legal in certain circumstances. The authors caution that the opportunity physicians have to influence public and legal opinion related to physician-assisted death make it "vital" that the "determinants of physicians' attitudes to self-determined death" be studied (Duberstein et al., 1995, p. 395).

Physicians may also find their preferred way of treating a patient at variance with the advance directive and/or the proxy decision-maker, usually a family member (Gamble et al., 1991; Schiff et al., 2000). Goold et al. address the potential conflict between physicians and family members in end of life decision-making identifying that the family may be unprepared for the decision-making process, in denial of events and suffering grief or guilt. Outlining the potential effect these psychological states can have on communication between physician and family, these authors suggest helpful ways of facilitating communication. Families have different expectations of usually unfamiliar events, often (mis)informed by multiple sources including friends, internet or television. They need to be both informed of the present situation and future prognosis in terms they can understand, and be advised of the best options of care for their loved one (Goold et al., 2000).

Poor survival prediction by physicians has long been acknowledged as a problem (see Christakis & Lamont, 2000; Parkes, 1972), not the least because over-estimating life-expectancy may delay the commencement of appropriate palliative care (Parkes, 2000; Smith, 2000). Physician/family

communication may be affected as the doctor tries to compensate for prognostic uncertainty at a time the family is relying on the doctor to be open and honest. Lack of time, high patient loads and a medical climate that does not encourage lengthy discussions with the family will all negatively impact on the opportunity to facilitate the decision-making process at this stressful time (Goold et al., 2000).

Relatives are frequently the proxy decision-makers when treatment withdrawal is proposed for incompetent patients but may not always be in agreement with physician recommendations (Smedira et al., 1990). Family proxy decision-making on behalf of relatives may not always reflect the preferred choice of the person being considered (Alpert & Emanuel, 1998; Ditto et al., 2001; Koenig, Wildman-Hanlon, & Schmader, 1996; Ouslander, Tymchuk, & Rahbar, 1989; Uhlmann et al., 1988). The potential stress of proxy decision-making is acknowledged. Of 17 people living with their spouse, five did *not* choose the spouse as the proxy when completing an advance directive. The reasons given included that “it was not fair to expect them to make these types of decisions; they would be too emotional to be rational and they would not make the decision the participant would have wanted.” (Schiff et al., 2000, p. 1640).

It is suggested that the decision-making capacity of family may be impaired by depression and anxiety. Family members ($n = 920$) of 637 patients in 43 intensive care units in France were assessed for depression and anxiety. The prevalence of symptoms of anxiety and depression in family members was 69.1% and 35.4%, respectively. Symptoms of anxiety or depression were present in 72.7% of family members and 84% of spouses. The authors concluded that the psychological effects of events on family members need to be considered when they are being asked to make decisions on behalf of their loved ones (Pochard et al., 2001).

Given the potential for misunderstandings and misrepresentations of advance care preferences (Silveira, Di Piero, Gerrity, & Feudtner, 2000) any intervention that increases the understanding of proxies of what was in the mind of the patient when the AD was formalised, is crucial. To this end, commentators advocate ongoing discussions between interested parties to keep all concerned abreast of the current thinking and situation of the patient (Aitken Jr, 1999; Emanuel & Emanuel, 1998; Gamble et al., 1991; Patrick et al., 1997; Singer, 1994a). Given previously noted preferences of patients to have the doctor initiate discussions on advance care planning, any measures to increase physician motivation and compliance to do so would be helpful. Computer-generated reminders have been found to increase physician initiated discussions on advance care planning six-fold (Dexter et al., 1998). Advance care planning is not a document, “but a complex process involving many parties over time” (Emanuel & Emanuel, 1998, p. S23).

The view that advance directives increase the accuracy of proxy decision-making was challenged by the results of a randomized controlled trial tested for the efficacy of advance care planning in assisting proxy decision-makers to accurately predict patient preference for (non)treatment. Assigning outpatients aged 65 and over and their self-designated surrogate decision-makers to one of five experimental conditions where judgments between patient and surrogate were compared, none of the interventions was found to improve the accuracy of surrogate decision-making. The authors concluded that their results challenged current thinking that ADs are a means whereby the accuracy of proxy decision-making can be improved. However surrogates based decisions on one type of AD only, values based or scenario based (Ditto et al., 2001). Decision-making based on *both* vehicles may have proved more accurate.

It is suggested (Martin et al., 2000) that the premise of AD planning in today’s socio-medico-ethical environment be extended to embrace the patient’s *preparation* for death, a social process. Such preparation is influenced by personal relationships and allows all to “determine settings for care and limits of life-sustaining treatments which may inappropriately lengthen dying, and facilitates reflective discussion of values, goals, and preferences with loved ones in a non-crises environment” (Martin et al., 2000, p. 1673). Encouraging open communication around dying and any outstanding interpersonal issues may be an opportunity to strengthen personal relationships. However as part of a “social process” such communication may also have the potential to disrupt relationships and some form of mediation may be appropriate.

Martin et al. provided a comprehensive list of options available to the person contemplating death preparation and argue that the choice of format for any advance directive should reflect patient-centred and culturally appropriate norms as a way of more accurately accessing patient wishes. These could include

- | | |
|-------------------------------|---|
| Instruction | Living will – describes type of care preferred or not preferred |
| Proxy directive | Durable power of attorney for health care – indicates proxy decision-maker |
| Detailed directive | A work-sheet that leads through a process facilitating thought about preferences and goals – can be formalised |
| Non-detailed directive | Blank provision for person to detail preferences (reservations as to interpretability and application expressed by authors). |
| Values history | Statements on values with which person agrees/disagrees and a series of statements regarding care which person can select/reject. |

Or

Answering questions in narrative form about health care values (recommended by authors as helpful for proxies when situation may be ambiguous as to patient preference).

Generic

Widely applicable to many potential situations.

Disease-specific

More specifically reflective of situations that will likely occur in relation to a priori conditions.

Obviously a combination of approaches will provide a more comprehensive indication of end of life care preferences for those who must interpret patient wishes (Emanuel & Emanuel, 1998; Martin et al., 2000).

Advance care planning is a process that takes place over time and reviewing and updating plans as age and patient condition change would assist in maintaining the integrity of any decision-making.

CHAPTER 4

INTERNATIONAL PERSPECTIVES ON ASSISTED DEATH

PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA

Although only recently legalized, euthanasia had been permitted in Holland under protocols established in 1993. A minor change to the Law on the Disposal of Corpses allowed for a doctor to report a death as "not natural" but there was no prosecution provided the "requirements of careful practice" had been followed (Griffiths et al., 1998, p. 80). Euthanasia in practice had been occurring in Holland for many years beforehand.

Other countries have looked closely at formalising assisted death in their culture. Australia became the first country in the world to legalize physician-assisted death in 1995 when Rights of the Terminally Ill Act 1995 was passed in The Northern Territory (Rights of the Terminally Ill Act, 1995). Although this law was repealed a few months later, four people available themselves of the opportunity (Kissane, Street, & Nitschke, 1998). More recently (1997), Oregon legalized physician-assisted suicide and in the three years since its inception, around 70 people have made use of the law (Oregon Health Division, 2001a; Oregon Health Division, 2001b). Belgium has recently debated euthanasia along the same lines as Holland and this is expected to become law in the near future (Reuters, 2001). Recent research in Flanders, the region of Belgium where 60% of the population lives indicates that 1.3% of deaths in 1998 could be attributed to euthanasia or physician-assisted suicide (Deliens et al., 2000). Moreover, this study found that administering lethal drugs *without* the request of the patient occurred in a similar number of cases as Australia (Kuhse, Singer, Baume, Clark, & Rickard, 1997) and significantly higher than in the Netherlands (Deliens et al., 2000).

End of life (EOL) practices that hasten death in Holland may include either euthanasia or physician-assisted suicide. Others consider there is a legal and/or ethical difference between these two facets of assisted death (Deigh, 1998). Most notably, the Oregon Death with Dignity Act allows for doctors to prescribe drugs in sufficient quantity to allow a suitable patient (screened as per stated protocols) to commit suicide at a time chosen. However, doctors are not

permitted to actively involve themselves with the patient taking the drugs, or to give an injection to assist the patient to die in the event of a failed attempt at suicide (Oregon Death with Dignity Act, 1997). Such actions would be regarded as euthanasia, which is illegal in Oregon. However, making a distinction between euthanasia and physician-assisted suicide for practical purposes can lead to anomalous and tragic consequences.

Graphic accounts of the protracted deaths of young men who chose suicide at the end of their fight with AIDS make horrific reading. Two young men took large doses of morphine in failed bids to die. One lapsed into a coma and took three days to die with his friends constantly injecting him with morphine at the doctor's advice. Another awakened in extreme distress, believing he must be in hell. His friends calmed him and he then took morphine and seconal to achieve death within 20 minutes. A third vomited his cocktail of morphine, tranquilizers and alcohol and had to start again. His friend, concerned at the time it was taking him to die and fearful of having to go through the whole process a third time, smothered him with a pillow (Ogden, 1994). The suffering of the people involved in this process can hardly be imagined, but the determination to die is self-evident. Accounts from Holland also give some insight into the difficulties that can be experienced for those who seek an elective death. Invariably problems were greater in instances of physician-assisted suicide rather than euthanasia (Groenewoud et al., 2000).

In Holland, euthanasia and physician-assisted suicide as well as other medical behaviors that shorten life are considered together for "philosophical analysis, empirical description and effective regulation" (Griffiths et al., 1998, p. 18). Given the above account, one could argue that they are considered together on compassionate grounds also if palliative care has not been successful in meeting patient need.

THE DUTCH EXPERIENCE WITH ASSISTED DEATH

Few cases of euthanasia are prosecuted in the Netherlands and those prosecuted under Article 293 or 294 of the Penal Code can be defended under a defence of "necessity". Article 40 of the Dutch Penal Code allows for a defence of *force majeure* where the overwhelming distress of the patient in this situation necessitated an illegal response by the doctor to relieve the distress (Griffiths et al., 1998). Such a defence may now be even less necessary with the recent legalisation of euthanasia in Holland (Dutch policy on voluntary euthanasia, 2000).

The first case of euthanasia involving a suffering and terminally ill person to come before the courts in Holland was in March of 1952 when a doctor was found guilty of killing on request after

giving his brother lethal drugs. The doctor was not jailed. It is probably reflective of the pragmatic tolerance the Dutch display towards contentious moral issues and personal autonomy (Gordijn, 2001) that the Court decided to adopt a restrained approach. Subsequent to this, Holland had adopted a similar permissive stance towards other issues of autonomy related to the sex industry and drug taking. Griffiths et al. write that it is significant the case did not cause a public uproar and even the RDMA did not comment on the case although it was noted in a Dutch medical journal (Griffiths et al., 1998, p. 44). Such restraint would soon change.

From the mid-1960s euthanasia was publicly debated in the Netherlands although euthanasia continued to be practised seemingly unchallenged. One Dutch doctor published details of four cases of euthanasia in which he was involved at this time. There was no reaction from the public or, significantly, from the judiciary (Spreeuwenberg, 1999). Debate in Holland continues to this day as the Dutch constantly revisit the protocols under which euthanasia occurs, challenge these in the public domain and the courts and redefine the process (Griffiths et al., 1998, pp. 43-88).

An example of how “euthanasia in practice” has helped to redefine the practice of euthanasia in Holland is given by the Chabot case. In 1994 Dr Chabot helped a patient to commit suicide. She was not terminally ill, but suffered unbearably with depression that had proven intractable¹³. The Courts agreed that the patient’s suffering was extreme and intractable and that Dr Chabot had a defence under necessity. However he was found guilty under Article 294 because he had not consulted with another physician. There was no Court imposed punishment but a medical tribunal disciplined the doctor. Subsequently the government revised the guidelines to reflect that a request for euthanasia from a psychiatric patient required an examination by two other doctors, one a psychiatrist. The patient no longer had to be in a terminal phase of a somatic illness (Griffiths et al., 1998).

Although debate centres more on sustaining the practice, not condemning it, it does have its critics in Holland (ten Have & Welie, 1996; Zyllicz & Janssens, 1998). Other Dutch defend their stance on assisted death by the principles of "respect for human dignity, accountability, and scrupulousness" (Dillmann, 1996, p 100). Such principles would cause no quarrel with doctors elsewhere, however their application to the practice of euthanasia and assisted suicide may. The Royal Dutch Medical Association has received international condemnation for supporting

¹³ Mrs. B was 50 years old with a 20 year history of depression. She had suffered an abusive relationship and seen one son commit suicide and one son die of cancer. She no longer wished to continue living and had expressed a wish to die on many occasions (Griffiths et al., 1998).

euthanasia and physician-assisted suicide in Holland¹⁴ (Bostrom, 1989; Fenigsen, 1997; Hendin, 1995; Hendin, 1996; Hendin, Rutenfrans, & Zylicz, 1997; Keown, 1995; Keown & Jochemsen, 1999). Bert Keizer, Dutch physician, was interviewed by a BBC Radio 4 religious programme about his professional practice, which included allowing for euthanasia (Keizer, 1997a). Part of this interview is worth reporting, as an illustration of how illogical this doctor perceives such criticism to be.

Interviewer "Just when, if you could date such an event, would you say that you left religion behind you?"

Keizer "Well, Trevor, as it happens, I know precisely when this occurred: it was seven minutes after my first erection. No sooner did my libido rear its tiny little head, than God dashed from the premises. Striking, ain't it?"

Interviewer "I'm sorry, but I can't leave that in. No, really, it's impossible. This is a religious programme, you know."

Keizer "I know. But the preposterous suggestion that in Holland patients are being killed by their doctors (can) stay in." (Keizer, 1997b)

Ignoring the assumption that those who practice euthanasia are divorced from religion, Keizer instead goes on to point out that doctors face requests for euthanasia with "fear and trembling", and in fact, prefer to do anything other than agree to the request (Keizer, 1997b). Others agree (Narratives from the Netherlands, 1996; Onwuteaka-Philipsen, van der Wal, J Kostense, & van der Maas, 1999; Sheldon, 1996). The emotional impact on the doctor of hastening death has been recorded. The negative impact was greatest for euthanasia (75%, $n = 159$) and assisted suicide (58%, $n = 34$) but a significant number reported feelings of "discomfort" after life ending without an explicit request (34%) and death after the alleviation of other symptoms (18%). However, the weighted average over types of actions indicated that overall 52% of physicians had residual feelings of "comfort" and 42% had residual feelings of "discomfort" (Haverkate, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2001).

The Rummelink Study

In 1990-1991, a Government appointed committee in Holland, the Rummelink Commission, carried out an investigation into medical decisions at the end of life that hasten death (MDELHD). This ground breaking work¹⁵ (hereinafter referred to as "the Dutch study" or "the Rummelink study") was possible because doctors were guaranteed immunity from prosecution in return for honest reporting of practices, even when this involved the intentional killing of patients as in euthanasia or physician-assisted suicide. The research was conducted in response to a brief that precluded concentration on euthanasia and physician-assisted suicide *outside* of the context of

¹⁴ See (Dillmann, 1996) for an account of the role of the RDMA in implementing and sustaining a voluntary euthanasia policy in the Netherlands.

¹⁵ There were three studies performed – detailed interviews with 405 physicians (stratified sampling as to discipline), a death certificate study (retrospective analysis of 7000 certificates) and a prospective study collecting information on 2250 deaths. This is discussed more fully in Section Three.

other medical decisions at the end of life that hasten death. Thus euthanasia was placed on a continuum of care that included withdrawing and withholding treatments or increasing medication to address symptoms at the risk of hastening death (van der Maas, van Delden, & Pijnenborg, 1992).

The published results of the commission of inquiry confirmed that “serious” decisions concerning the end of life were made in 38% of all deaths, and 1.8% of deaths involved painless killing at the request of the patient (Pijnenborg, van Delden, Kardaun, Glerum, & van der Maas, 1994; Pijnenborg et al., 1995; van der Maas et al., 1992; van der Maas, van Delden, Pijnenborg, & Looman, 1991). A life-terminating act without the explicit request of the patient was reported as occurring in two of the studies 0.8% (death certificate study) and 1.6% (prospective study). The authors estimated this to be approximately 270 cases in the period under investigation (Pijnenborg, van der Maas, van Delden, & Looman, 1993). It was acknowledged that these could have been interpreted as being the result of a physician killing a person who was defenceless. Alternatively, and the authors indicated that this was more probably the case, this could have been interpreted as “a response to the injustice that a patient unable to make an explicit request has to suffer to the end even when his or her doctor ... and perhaps the relatives ... feel confident that the patient’s wishes would have been for life to be ended” (Pijnenborg et al., 1993, p. 1198). Support for this were reports from respondents that half the patients had indicated at a previous time that they would prefer euthanasia if suffering was unbearable. Almost all patients were close to death and suffering, many could not verbally respond and death was hastened by hours or a few days only. Consultation invariably occurred with others (van der Maas et al., 1992).

Concern has been expressed about the incidence of life-terminating acts without request and it is postulated that this is “evidence” of the slide down a slippery slope towards increased incidence of non-voluntary euthanasia (Hendin et al., 1997; Keown, 1995). However respondents had indicated that the public debate in Holland about euthanasia had made open discussion about death between doctor and patient, easier. The incidence of life-terminating acts without request is expected to decrease over time as society becomes more open about death planning and filling advance directives (Pijnenborg et al., 1993).

These authors concluded that their results indicated a need to have medical decisions made at the end of life scrutinized in more depth in “research, teaching and public debate” (van der Maas et al., 1991, p. 669). Subsequently a set of guidelines was established by the Royal Dutch Medical

Association¹⁶ (RDMA) sanctioned by the Government, to formalise and control the practice (Dillmann, 1996; Griffiths et al., 1998).

Research focus after the Rummelink study

In 1995 a follow-up study was done in Holland, using similar methodology to the original Rummelink study. These authors predicted an increase in euthanasia and other MDELs that hastened death given the aging population and increased opportunity for medical intervention to prolong life. Similarly they predicted a decrease in MDELs without an explicit request with an increasing emphasis on patient autonomy. Both predictions were confirmed in the study. The incidence of euthanasia increased to 2.4% (from 1.8%, (van der Maas et al., 1992)). This could partly be attributed to increased reporting of euthanasia which increased from 486 in 1990 to 1466 in 1995 following the introduction of standardised reporting procedures and protocols (van der Maas et al., 1996). Similarly, the proportion of cases where opioids were increased with possible life-shortening effects remained constant between the studies while the proportion in which treatment was withheld or withdrawn increased slightly. The authors concluded that there was little evidence that the acceptance of euthanasia in Holland had led to an increase (van der Maas et al., 1996).

Consultation

Research was now possible on the procedural and clinical difficulties faced by physicians. Guidelines included a consultation with another physician and one study found 42% of physicians questioned ($n = 405$) had acted as a consultant for euthanasia. There was a continuing reciprocal relationship noted between physicians with an invitation to consult occurring from the same physician and 41% of consultants having asked the attendant physician to consult at some stage. This familiarity was considered a potential threat to the independence of the consultation (a requirement under the guidelines) which could indicate a requirement for independent “consultants” trained specifically for this purpose. The importance of the consultation was highlighted by 28 physicians in this study reporting that they had advised against performing euthanasia. Asked to describe up to three such cases, 48 cases were reported on where the consultant did not agree the request met procedural requirements (approximately half of these related to insufficient palliative care) (Onwuteaka-Philipsen et al., 1999). The point is made that unless training for “consultation” included a good grounding in palliative care options, it would fall short of the specificity of the guidelines (Hendin, 1999).

¹⁶ The Royal Dutch Medical Association is a professional medical organisation with 25,000 members constituting 60% of working physicians.

General practitioners agreed that the consultative process was important in the euthanasia decision-making with 81% ($n = 305$) agreeing that this should occur in all cases of physician-assisted death. However only 60% agreed that physicians should be trained to be consultants and only 54% agreed that training should include palliative care. Those more likely to think training in consultation and palliative care were necessary were GPs who had been working for 10 years or more in general practice, and GPs who had never been consultants. With regards to concerns expressed above about lack of independence in consultation, 75% agreed that a consultant and physician coming from the same locale did not pose a threat to consultant's independence. The authors concluded that GPs understood and took seriously the role of consultation in euthanasia decision-making but emphasised a greater requirement for palliative care training, particularly given the ongoing new developments in this discipline (Onwuteaka-Philipsen, Kriegsman, van der Wal, Dillmann, & van Eijk, 1999).

It is perhaps significant in the light of professional opinion that palliative care is not well done in Holland (Matthews, 1998) that guidelines in hospitals and nursing homes are more likely to cover a written policy on euthanasia than on the alleviation of pain and symptoms (Haverkate, van der Wal, van der Maas, Onwuteaka-Philipsen, & Kostense, 1998). Palliative care that addresses difficult symptoms is a discipline that requires specific training and may benefit from guidance in order to remain within ethical guidelines. It has been questioned whether some palliative care practices that involve sedation and starvation are in fact different from euthanasia (Billings & Block, 1996; Quill, Dresser, & Brock, 1997a).

Difficulties delivering euthanasia

Data taken from two studies in Holland (van der Maas et al., 1991; van der Maas et al., 1996) indicated that there were clinical problems with the delivery of euthanasia (EU) and physician-assisted suicide (PAS). The biggest problem related to problems with completion including not achieving coma (4.2% with EU; 12.3% with PAS). Also included were difficulty finding a vein for IV administration, myoclonus, nausea or vomiting, difficulty administering oral drug. In 21 cases where PAS was planned, the patient received EU. In 12 cases the reason given was problems with completion – the death took too long (9 cases), the patient did not become comatose (1) or the patient awoke from a coma (2) (Groenewoud et al., 2000). It is argued that such difficulties strengthen the necessity for the guideline which states the physician must be present for the euthanasia event, or if the patient does not want this, nearby to intervene if necessary (Groenewoud et al., 2000; Nuland, 2000). This is a positive aspect related to procedure that is straightforward under Dutch guidelines compared with the guidelines for Oregon (to be discussed later).

A procedural aspect of the guidelines relates to the pharmacists' responsibilities in supplying the euthanatic, and a clinical aspect is the administration of the euthanatic by the doctor in a way that maintains the comfort of the patient (Onwuteaka-Philipsen, Muller, & van der Wal, 1997b). In a descriptive study of the attitudes of GPs and pharmacists in North Holland to standardized packaging of the euthanatic and delivery set, all pharmacists ($n = 27$) and 88% of GPs ($n = 77$) agreed that standardisation was possible in the administration of euthanasia. Moreover a very high majority from both groups agreed that standardisation was important and the choice of one intravenous and one oral package was sufficient (Onwuteaka-Philipsen et al., 1997b). These results suggest that standardisation of the euthanatic may help to alleviate clinical problems with the performance of euthanasia.

Reporting procedures

Guidelines put in place after the Remmelink Report was published encouraged transparency of practice and an increase in the number of cases of euthanasia reported was noted. From 1981 to 1985 only 71 cases were reported. In 1991, reporting almost doubled from the previous year to 866 cases and by 1995 this had increased to 1466, or approximately 41% of suspected cases (van der Wal et al., 1996). These authors conclude that the implementation of a notification procedure does promote adherence to the "requirements for careful practice" (van der Wal et al., 1996, p. 1710).

The recent legalisation of euthanasia in Holland has followed a decade where euthanasia practices have been reported, prosecuted and researched in Holland. The guidelines implemented by judiciary in conjunction with the RDMA and supported in law by a small change to the Burial Act (Griffiths et al., 1998) left doctors obliged to report themselves as having committed a felony because euthanasia was neither legal nor decriminalised. The move was criticised as legally wrong by lawyers, given that a person is not expected or obliged to give incriminating evidence against him or herself (Sheldon, 1993). The recent change to legalisation of euthanasia in Holland was in part necessary to address this anomaly. Legalisation did not appreciably alter the conditions under which euthanasia could be given.

Vulnerability of certain populations

There was a relationship noticed between the type of disease experienced and the likelihood of euthanasia occurring. In the 9 years until 1993, 0.82% of deaths in North Holland were attributed to euthanasia. Broken down into diseases, euthanasia occurred as a percentage of total deaths from each disease 13.41% (AIDS), 5.35% (multiple sclerosis), 4.08% (amyotrophic lateral

sclerosis) and 2.26% (cancer) (van der Wal & Onwuteaka-Philipsen, 1996). This suggests an a priori vulnerability to the practice of euthanasia based on diagnosis.

Transparency of practice in Holland related to physician-assisted death has allowed critical public analysis and research related to non-voluntary euthanasia and/or the vulnerability of certain members of society in euthanasia decision-making (Berghmans, 1999; Brownstein, 1997; Cusveller & Joshemsen, 1996; Jochemsen, 1998; Kissane & Kelly, 2000; Muller, van der Wal, van Eijk, & Ribbe, 1995; Onwuteaka-Philipsen, Muller, & van der Wal, 1997a; Spanjer, 1995; Sullivan, Ormel, Kempen, & Tymstra, 1998; van Thiel, van Deldon, de Haan, & Huibers, 1997).

The large body of methodologically rigorous research on assisted death that is available from the Dutch has underpinned much of the international commentary on assisted death from the medical profession. Philosophers and ethicists have debated the issue for years, but empirical research conducted in the clinical setting has been thin on the ground until the last decade. By making their empirical research available to the international community the Dutch have encouraged others to examine medical practices related to assisted death and question end of life care practices that may not best meet patient need.

THE AUSTRALIAN EXPERIENCE WITH ASSISTED DEATH

Northern Territory

In 1995, Australia became the first jurisdiction in the world to legalize euthanasia with the passing of the Rights of the Terminally Ill Act (ROTI) (Rights of the Terminally Ill Act 1995, 1995). The Act came into effect on July 1, 1996 (Rights of the Terminally Ill Regulations 1996, 1996) after a period where challenges and legal amendments were met. Four patients availed themselves of the opportunity for an elective death in The Northern Territory (Kissane et al., 1998).

Under Australian law the Federal Government may over-rule the laws of territories but not that of states. A private members bill was introduced to the Commonwealth Parliament and this was successful in over-ruling the Northern Territory legislation. The Euthanasia Laws Bill 1996 that repealed the ROTI Act came into effect in March 1997. The ROTI act had been law for less than a year (Kissane et al., 1998; Quirk, 1998).

All four patients who sought elective death under the ROTI Act were attended by Dr Philip Nitschke (Kissane et al., 1998). Dr Nitschke has continued to lobby strongly for the legalisation of euthanasia in an Australian state. He has set up euthanasia advice clinics in Melbourne,

Sydney, Tasmania and given lectures on how to commit suicide in New Zealand. (Barbeliuk, 2000; Devereaux, 2001). Dr Nitschke has been careful not to contravene the laws prohibiting assistance to commit suicide maintaining that he does not “advise counsel or assist” a person to commit suicide but does offer advice on “peaceful escape” that other physicians felt constrained from doing (Barbeliuk, 2000, p. 05).

Attitude of physicians to physician-assisted death

Predating the Rimmelinck investigation, a descriptive study investigated the practices and attitudes of physicians in Victoria, Australia (Kuhse & Singer, 1988). The questionnaire had pre-screening questions to identify doctors who had treated terminally ill patients and therefore were eligible for questions on end of life care. This methodology is similar to the Death Certificate Study (Rimmelinck) and questions related to decision-making in the study are also reflective of that research. Where the enquiry differs it is largely that doctors in this study were asked about actual medical practice *and* attitudes (Kuhse & Singer, 1988). In the Rimmelinck work doctors were asked about actual medical practice only (van der Maas et al., 1991). Kuhse and Singer found that 40% of respondents ($n = 869$) had received requests for assistance to die, and 12% of these had taken active steps to bring about death. Of those who had assisted death ($n = 107$), 80% had assisted death “two or three times” or “more frequently” (Kuhse & Singer, 1988). This seems to be evidence of a willingness to perform euthanasia particularly given that 40% ($n = 869$) stated they would be willing to perform euthanasia if it was legal (and considered necessary, presumably). However not all actions explicitly to hasten death would necessarily be described as euthanasia as that term is normally understood. Withdrawing and withholding treatments can have the same effect as administering a lethal drug in procuring the death of the patient. So can increasing morphine to address pain. In this research it was unclear what constituted the “active steps” taken to obtain the death (Kuhse & Singer, 1988).

In 1996, these researchers conducted research into actual medical practice related to hastening death practices using the questionnaire from the Rimmelinck death certificate study. Using statistical adjustment results were extrapolated to percentage of Australia deaths. Results indicated that 1.8% of Australian deaths were attributed to euthanasia or physician-assisted suicide (Kuhse et al., 1997). Moreover, 30% of all Australian deaths followed a medical decision explicitly taken intentionally to end the life of the patient. In only 4% of cases this followed an explicit request of the patient. The authors concluded that the present law in Australia prohibiting euthanasia and physician-assisted suicide had not prevented some doctors from such practices. Further, actions to hasten the death of the patient that do not fall under the definition of euthanasia or physician-assisted suicide were taken without the request of the patient (Kuhse et al., 1997).

Other research from Australia indicated that 57% ($n = 1271$) of practitioners in New South Wales and the Australian Capital Territory agreed that a change in law to allow euthanasia was desirable (Baume, 1998; Baume & O'Malley, 1994). Moreover, in response to a request for physician-assisted death, 5.8% of surgeons in Australia ($n = 683$) report that they had provided the means to the patient to commit suicide or had provided a lethal injection (Douglas et al., 2001).

Attitude of nurses to physician-assisted death

Nurses are also involved in hastening death decisions and practices. Research of nurses in Victoria reported 55% ($n = 921$) had been asked by a patient to hasten death (either through passive or active means) and 78% ($n = 943$) agreed that a change in law to accommodate active euthanasia was desirable (Kuhse & Singer, 1993). Younger nurses were more likely than older nurses to judge a change in law desirable, more likely to judge it “proper” to assist doctors to end a patient’s life (in some cases) and more likely to be involved in providing active voluntary euthanasia if it were legal (Kuhse & Singer, 1993). Comments by respondents indicated concerns by nurses of over-treatment by doctors, a preference for patient autonomy in decision-making related to assisted death, and an acknowledgment of the ambiguity involved in increasing morphine “to unofficially hasten death and officially to remove pain” (Kuhse & Singer, 1993, p. 319). A particularly interesting finding of this research is that the authors report that sometimes “doctors’ instructions are sufficiently ambiguous to leave scope for nurses to make their own decisions about how they should respond to a patient’s request for death to be hastened” (Kuhse & Singer, 1993, p. 320).

Similar results were found in research on nurses in South Australia with 47% ($n = 278$) confirming they had received requests from patients to hasten death by withdrawing treatment and 30% had received requests for active euthanasia. Active steps were taken to bring about the death of the patient by 19% (52 nurses) and in nearly half these cases there was no request from the patient. Fifteen of these nurses had acted on doctors’ orders and four had acted as a result of a team decision. Of the 52 nurses who had taken active steps to bring about the death of a patient, 7 did not think it was right to have done so and did not think such actions could ever be condoned. The study also found that the action being illegal was not necessarily an indicator that the action was considered “wrong” and the authors concluded that “what many regard as reasonable or proper medical practice is in conflict with the law” (Stevens & Hassan, 1994, p. 546).

The above research indicates that nurses could potentially have a major role in death-hastening practices in Australia.

THE AMERICAN EXPERIENCE WITH PHYSICIAN-ASSISTED DEATH

Research from the United States indicates that physician-assisted suicide and euthanasia are being practised by the medical profession and there appears to be a tacit acceptance of “guidelines” that govern the practice (Emanuel, Daniels, Fairclough, & Clarridge, 1998) although it is illegal in all states except Oregon. Unrelieved pain has been identified as a reason given by physicians for assisting patients to die (Emanuel et al., 1998) and has been implicated in the desire for euthanasia as an option by patients with painful metastatic cancer (Sullivan, Rapp, Fitzgibbon, & Chapman, 1997). Oregon is well served with hospice programmes and the point is made that no patient would ever have to choose physician-assisted death because of a lack of hospice care (Jackson, 2000).

Attitudes of laypersons towards physician-assisted death

Positive attitudes of laypersons (patients and general public) towards physician-assisted death were associated with patient experiencing pain or fear of pain in general public (Emanuel, Fairclough, & Emanuel, 2000; Sullivan et al., 1997; Wilson et al., 2000; Worthen & Yeatts, 2000), patient experiencing depression (Chochinov, Wilson, Enns, & Lander, 1998; Emanuel, Fairclough, Daniels, & Clarridge, 1996), belief in autonomy (Singh, 1979; Wilson et al., 2000), higher education of respondent (Caddell & Newton, 1995; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; Ostheimer, 1980). In HIV and AIDS patients “disintegration”, a loss of self and loss of ability to initiate and maintain a supportive social structure were related to a desire for assisted death (Lavery, Boyle, Dickens, Maclean, & Singer, 2001).

Negative attitudes among laypersons (patients and general public) were associated with minority race of respondent (Emanuel, 2000; Singh, 1979), increased age of respondent (Bachman et al., 1996; Emanuel, 2000; Ostheimer, 1980; Seidlitz, Duberstein, Cox, & Conwell, 1995), strength of respondents’ religious belief (Bachman et al., 1996; Caddell & Newton, 1995; Finlay, 1985; Ganzini et al., 1998; Singh, 1979) and respondent belief that suffering has meaning (Worthen & Yeatts, 2000).

In Oregon and Washington 56% ($n = 140$) of patients with amyotrophic lateral sclerosis said they would consider suicide and 78% of these said they would request medication for this purpose. However this may relate to a need to feel a sense of control over events given that only one patient indicated the medication would be taken immediately. Thirtysix others would keep the medication for “future use”. Those who scored higher for hopelessness were significantly more likely to say they would consider suicide (Ganzini et al., 1998). Hopelessness correlates with suicide ideation among terminally ill patients with cancer (Chochinov et al., 1998) and it is

therefore questioned whether terminally ill patients who express interest in suicide are different from well patients who express suicide ideation (Chochinov, 1999).

Attitudes of physicians to physician-assisted death

A significant number of doctors in America would practice physician-assisted death if this were legal (Bachman et al., 1996; Cohen, Fihn, Boyko, Jonsen, & Wood, 1994; Meier et al., 1998) and have practiced physician-assisted death despite it not being legal (Emanuel et al., 1998; Emanuel et al., 1996; Emanuel et al., 2000; Meier et al., 1998; Slome, Mitchell, Charlebois, Benevedes, & Abrams, 1997). Physicians do not necessarily hold that physician-assisted death should be legalised. Given the choice, the majority ($n = 973$) in one study indicated that they would prefer no legal ruling, physician-assisted death should be neither legal nor illegal (Whitney et al., 2001).

An analysis of several studies concerning the willingness of physicians to comply with requests for assisted suicide and euthanasia indicated that legalisation may lead to more participation than before-the-fact surveys indicate (Wilson & Chochinov, 1996). However elsewhere medical students from Oregon indicated they were significantly less likely to express willingness to participate in physician-assisted suicide than controls from other states (Mangus, Dipiero, & Hawkins, 1999) which suggests that when faced with the actuality of legality attitudes may change.

Physician-assisted death legalised in Oregon

Oregon legalised physician-assisted suicide with the passing of the Oregon Death with Dignity Act, through statewide votes in 1994 and again in 1997 after legal challenges had prevented the application of the Act (also known as Measure 16) (Oregon Health Division, 1997). The Act allowed for the prescribing and supplying of lethal drugs to end life, but did not allow the physician to administer the drugs. In other words, euthanasia is still illegal. In the first three years of operation, 70 patients have availed themselves of the opportunity of committing suicide using the Act (Oregon Public Health Services, 2000).

Oregon has a similar population size to New Zealand (approximately 3.5 million) and is similarly equipped with hospices and palliative care practitioners. Fifteen persons availed themselves of the option of physician-assisted suicide in the first year this was available – October 1997 to October 1998 (Chin et al., 1999). It could be assumed that this number may include some people who had been waiting for the opportunity to legally obtain drugs to hasten death. If we use these numbers as a guide to what one could expect in a population of 15.5 million, the approximate population of Holland, it would equate to 66 persons. In fact, research shows that there are approx. 2,700 cases of euthanasia reported a year in the Netherlands with 41% of

euthanasia deaths actually reported in 1995 (van der Wal et al., 1996). Whether this indicates under-use in Oregon or over-use in Holland is another matter, but it has been argued that the disparate numbers may be related to the high use of licit morphine in Oregon and the provision of wide-spread palliative care services. Holland has only 7 hospices and palliative care may not be developed or disseminated widely (Mitchell & Owens, 2000).

One Dutch palliative care specialist testified to the British House of Lords that deficiencies in palliative care in Holland could partly be attributed to the lack of palliative facilities. The availability of euthanasia as an alternative to palliative care may undermine a commitment to finding a palliative solution (Matthews, 1998). Elsewhere it has been suggested that a lack of palliative care expertise may have been implicated in Holland and the Northern Territory developing legal structures to accommodate the practice of euthanasia as a way of addressing the suffering of patients (Buchanan, 1995). Intractable suffering can be a very real problem for patient and practitioner alike (Mount & Hamilton, 1994).

Who uses physician-assisted death?

The growing body of research from Oregon on physician-assisted death indicates that pain is not the reason people are seeking this option. Rather loss of dignity and independence are cited as reasons for seeking death (Chin et al., 1999; Ganzini et al., 2000; Oregon Health Division, 2000; Oregon Health Division, 2001a; Oregon Health Division, 2001b; Oregon Public Health Services, 2000; Sullivan, Hedberg, & Fleming, 2000). This has led to a call for physicians to address the problems of disability, loss of autonomy (Fins & Bancroft, 1999) and depression (Edwards & Conner, 1999) as a way of preventing the perceived patient requirement for assisted death. However research from data of the second year of Oregon's Death with Dignity Act suggests that requests for assistance to commit suicide are also motivated by patient determination to control the death event (Sullivan et al., 2000). A highly publicized assisted suicide event indicated that the patient involved chose this option rather than have her family witness her physical and mental deterioration from breast cancer with brain metastases. She was reported as saying, "I like the control" (Smith, 2001).

In 1999, 33 patients received lethal medications and 27 died after ingestion (median age 71 years). Pathologies involved were cancer ($n = 17$), amyotrophic lateral sclerosis ($n = 4$) and chronic obstructive pulmonary disease ($n = 4$). All had health insurance (necessary for hospice admission in Oregon) and 21 were hospice patients. Those who used physician-assisted suicide were comparable to those who died in the wider population for age, race and residence however a

higher level of education was associated with this option ($p < .001$). Reasons for seeking assisted death in 1999 were consistent with those reported in 1998 (Sullivan et al., 2000).

A postal survey of the experiences of physicians with the Death With Dignity Act (65% response rate, $n = 2649$) indicated that approximately 1 in 6 requests for drugs were granted and 1 in 10 requests actually resulted in suicide (Ganzini et al., 2000). Patients ($n = 221$) gave as their reasons for requesting assistance to die, loss of independence (57%), poor quality of life (55%), readiness to die (54%) and desire to control the circumstances of death (53%). However also implicated were perception of a financial burden to others (11%) and lack of social support (6%). As with results from Holland (van der Maas et al., 1992), a significant number of requests were rescinded after palliative interventions by the doctor compared to those who had no intervention ($p = < .001$). However it is interesting that 81% of those who completed suicide were enrolled in a hospice programme. Whether this indicates that palliative interventions were ineffective or that they were effective but not sufficient for the person to change their mind is unclear.

Characteristics of the patients who committed suicide were similar to characteristics of terminal patients in the wider population for incidence of depression, or vulnerability on a minority basis (race, gender, poverty) and health care coverage (Ganzini et al., 2000). These authors conclude that minority and vulnerable populations do not appear to have been adversely affected by the adoption of the Death with Dignity Act.

Opposition to physician-assisted death

Since the inception of the Oregon Death With Dignity Act, there have been ongoing initiatives at a Federal level to repeal the Act (see O'Keefe & Hogan, 1999 for an account of how opponents continue to endeavour to manipulate Oregon's decision by employing federal law to overthrow state law). This is reminiscent of what happened in Australia and despite Oregon voters twice having voted the Act in, it may yet be repealed. The federal Drug Enforcement Authority (DEA) may be utilized to prohibit the availability of strong narcotics necessary for assisted suicide. This would leave physicians with no way of prescribing the necessary drugs to obtain elective death. Moves to repeal the Act are criticised firstly on the basis of federal interference with State law and secondly for interfering with the preferred management by physicians of their patients (Orentlicher & Caplan, 2000: The assisted-suicide ban, 1999; Undoing Oregon's Law, 2001).

The continued challenge to the Act may have left some doctors concerned about the legality of assisting a patient to die. Concern was expressed by physicians in Oregon that writing the prescription may violate federal DEA law (82%, $n = 1841$) (Ganzini et al., 2001) and seven physicians expressed concern that retroactive sanctions would be enforced by the DEA (Ganzini

et al., 2000). Concern about reputation was also expressed by those who were willing to write a prescription with 58% ($n = 1841$) of physicians at least “a little” concerned about being labelled a “Kevorkian” (Ganzini et al., 2001).

The difficulty for some patients of finding two doctors (required under the Act) to agree to PAS may be too much for patients who are debilitated and near death and has been implicated as a possible reason for low numbers in Oregon using the option (Barnett, 1999; Chin et al., 1999). This may be related to physician preference not to be involved in the practice. In Holland the Dutch Voluntary Euthanasia Society reported members had difficulty in obtaining euthanasia despite the practice being officially sanctioned. Doctors either refused to discuss it, agreed to help and then retracted, were unavailable when the patient’s condition deteriorated and the locum would not honour agreements with the original doctor or standard euthanasia declarations were ignored by hospitals and nursing homes (Sheldon, 1996).

Opposition affects delivery of care to dying patients

One tragic consequence of the continued challenge to the law is that doctors have become increasingly nervous about aggressively treating pain under the principle of double effect, fearful that this would be misinterpreted as euthanasia. In 1999 the Oregon medical board became the first board in the USA to discipline a doctor for *undertreating* pain. The Joint Commission on Accreditation of Healthcare Organisations now requires all hospitals to be accredited in pain assessment and treatment to qualify for Medicare and Medicaid payments (Barnett, 2001). Proponents of palliative care suggests there has been a “cultural shift” with health care providers now developing palliative care initiatives to meet patient need (Barnett, 2001).

A self-administered postal questionnaire to Oregon physicians eligible to prescribe under the Act (66% response rate, $n = 2641$) indicated that since the inception of the Act 76% of physicians had increased their palliative care knowledge and 79% had increased confidence in their ability to control pain. Further, 69% reported they had sought to increase recognition of psychiatric disorders. Referrals to hospice had increased for 30% and 33% perceived that the availability of hospice had increased since before the Act. Just over half the physicians responding supported the Death with Dignity Act and around one third opposed it (Ganzini et al., 2001)¹⁷.

¹⁷ Results from these two studies (Ganzini et al., 2000; Ganzini et al., 2001) are based on the same survey. Details of the methodology are available in the first article published. There is no explanation given in the second article for the slight differences in response rate and n .

Criticism of the research which indicates there are few problems with the Act are made on the basis that palliative care offered to patients is not investigated and critiqued, and that the financial situation and emotional states of patients is not adequately assessed. These authors link their concerns with the Oregon Health Department's monitoring with flaws in the law.

“The flaws in OHDs monitoring come in part from the problems and flaws in the Oregon law. Intolerable and unrelievable suffering – a requirement for assisted suicide in the Netherlands – is not a requirement of the Oregon law; the diagnosis of a terminal illness is sufficient. The presumption and stipulation in the Oregon law that a diagnosis of terminal illness is sufficient for assisted suicide does not encourage physicians to inquire into the source of the medical, psychological, social and existential concerns that usually underlie such a request, an inquiry that leads patients and physicians to have the kind of discussion that often leads to relief for patients and makes assisted suicide seem unnecessary. Nor are physicians asked or required by the Oregon law to make such an inquiry” (Foley & Hendin, 1999, p. 41).

Similar concerns had been expressed previously (Emanuel & Daniels, 1996) (see Goodwin, 1997 for an opposing viewpoint). Elsewhere many of the difficulties attached to the process by which the law is implemented, monitored and possibly refined are attributed to a “maturation process” (Woolfrey & Campbell, 1998, p. 15). The professional and personal relationships of those involved in physician-assisted dying in Oregon can be expected to undergo a change as people alter their approach to the care of the dying in radical ways (Kade, 2000; Kirk, 1998; Woolfrey & Campbell, 1998).

PHYSICIAN-ASSISTED DEATH IN NEW ZEALAND

The Law

The legal distinction between “killing” and “letting die” is to be found in Part VIII of the New Zealand Crimes Act 1961 and associated case law (Key, 1989). There is an absolute prohibition on euthanasia and assisted suicide. “s63 provides

“No-one has a right to consent to the infliction of death upon himself; and if any such person is killed the fact that he gave any such consent shall not affect the criminal responsibility of any person who is party to the killing” (New Zealand Crimes Act, 1961).

Key further interprets that under s174, “merely asking to be killed may be criminally culpable” (Key, 1989, p. 226).

Withdrawing or withholding life-sustaining measures could be interpreted as contravening New Zealand laws related to the duty to provide the necessities of life under Section 151 of the New

Zealand Crimes Act 1961. However such cases have been heard and judged using wide latitude of interpretation by the courts in New Zealand when the actions are deemed to be best medical practice (Auckland Area Health Board v Attorney General, 1993; Auckland Healthcare Services Ltd v L & L, 1998) (both a priori judgments when physicians had sought permission to remove life-sustaining treatment). This mirrors similar judgments in the United Kingdom (Airedale NHS Trust v Bland, 1993) and in the United States (In re Karen Quinlan, 1976).

The difficulties of interpreting and applying laws developed for New Zealand society at a time when modern medical ethical dilemmas would not have been envisaged are evident in the judgment by Justice Thomas in the Mr L case (Auckland Area Health Board v Attorney General, 1993) and were widely reported in the media (A matter of death and the living dead, 1992). These have been the subject of thoughtful comment elsewhere (Ahdar, 1996; Downey, 1995; Key, 1989; Oddie, 1998; Skegg, 1994; Tobin, 1993).

Following the ruling by Justice Thomas, a call was made for empirical data to be collected to justify an examination of how medical decision-making stood in relation to the opinions of wide society on decision-making at the end of life, including assisted death.

“Informed debate means that quantitative empirical data are needed more than philosophical or legal ingenuity. A survey amongst care givers and patients needs to be carried out. On the basis of these data policy can be debated and made, and legislation can result” (Henneveld, 1994, p. 158).

It is perhaps a commentary on the difficulty of collecting such sensitive data that this has not thus far been done.

Parliament

A 1999 survey asking if New Zealand politicians would support legislation to legalise voluntary euthanasia had a very low response rate of 12.5%. Of those who answered, 63% replied that they would support such legislation (Dominion, 1999). However the response bias, that those who would support the issue were more likely to reply is probably responsible for this high "Yes" rate, given the lack of support in parliament for the Death with Dignity Bill in 1995.

The Death with Dignity Bill proposed that a terminally ill patient over 18 years of age, suffering intractable pain should have the right to request and receive assistance to die from a doctor (NZPD 549, 1995). It was introduced by Michael Laws who stated he was motivated to do so in part by the plight of his friend, fellow parliamentarian Cam Champion who was dying of cancer and requesting the option of voluntary euthanasia (Speden, 1995)

Opponents of the Bill argued that it contravened the sanctity of life, euthanasia was unnecessary with palliative care, suffering was part of life, it would jeopardise doctor/patient relationships and could place some at risk in the community (NZPD 549, 1995). When Laws lobbied to have the Death with Dignity Bill introduced he made a last emotional statement before voting commenced.

“Finally, if we do not address this issue tonight, I have to say that it will come back to haunt us. Whether it is as a citizen’s initiated referendum in 12 months or as another private member’s Bill in the next Parliament, which could be less than 12 months away, this is the moral and ethical issue of our time. I hope we have the insight, the intelligence, the will, and ultimately, the courage to let the people of this country share their wisdom with us. We cannot walk away from their grief. We cannot walk away from their suffering, and we cannot walk away from their truth” (NZPD 549, 1995, p. 8725).

The House was divided on the question that the Death with Dignity Bill be introduced with 29 for and 61 against such a move and the motion was defeated (NZPD 549, 1995). The voting was a conscience issue and may not have reflected the opinions of members' constituents given that past polls in New Zealand indicate over 70% in favour of voluntary euthanasia for terminally ill and suffering people (Roy Morgan Poll, 1992; Heylen Poll, 1982). Some members stressed that their vote was based on their personal views and conscience (Hons. Anderton, Cullen and Kelly) even if this meant disregarding the expressed wishes of the electorate they represented (Hon. Carter) (NZPD 549, 1995). That the stand represented by such “conscience voting” could lead to their losing in the next election was considered a risk that had to be taken (Hons. Carter and Cullen) (NZPD 549, 1995).

The issue of legislation for voluntary euthanasia may need a bottom-up ground swell from the public as it may be too sensitive an issue for most politicians to champion actively. However it may be significant that Chris Carter, Member for Te Atatu has stated he intends to introduce legislation to legalise and regulate euthanasia in New Zealand (pers com Hon Chris Carter, 17 April, 2001).

Medical profession

A position paper on euthanasia on behalf of the New Zealand Medical Association was published in 1996 and the authors concluded by expressing “deep misgivings about any legislative moves to legalise euthanasia” (Gillett, Bloore, & Ngata, 1996, p. 44). This document looks at the wide social context within which decision-making occurs and acknowledges the diversity and complexity of opinion internationally and nationally regarding assisted death. These authors make the point that the strongest advocacy for assisted death occurs wherever (a) there is a commitment to “active and aggressive intervention to prolong life” and (b) “where there is inadequate

hospice”¹⁸ care (Gillett et al., 1996, p. 43). Neither condition exists in New Zealand although it is acknowledged that even adequate hospice facilities do not always address terminal suffering successfully.

Authors of this paper do not recommend changing the law to accommodate the few patients affected by intractable suffering. However, while wishing to maintain the status quo, the difficulties of the patient with intractable pain are acknowledged. These authors recommend that the response should be to (a) “educate the profession and develop the skills to manage such problems” and (b) empower “the patient in the New Zealand health care system” (Gillett et al., 1996, p. 43-44).

The empowerment of patients is encouraged by a commitment to educating the public about their “rights and responsibilities” related to the health care system and their own health. The resulting “partnership” between professional and patient would increase autonomy in decision-making, particularly related to end of life care (Gillett et al., 1996, p. 44).

The authors conclude that the provision of “good” palliative care, the right of the patient to decline treatment¹⁹, the principle of double effect allowing doctors to treat at the risk of hastening death, and guidelines about futile treatment are sufficient to address almost all end of life dilemmas. For the small numbers who still suffer, it is questioned whether the good of society is best served by adopting a euthanasia policy to address need (Gillett et al., 1996, p. 44).

However policy adopted by the New Zealand Medical Association would be unlikely to reflect the views of all in the profession (Dryburgh, 1994; Henneveld, 1994; Simcock, 1990). Such policies may also not be reflective of the wishes of the wider public. Polls in 1982 and 1992 indicate that over 70% of the general public would like the option of euthanasia to be available in New Zealand (Heylen Poll, 1982; Roy Morgan Poll, 1992)

¹⁸ Restricting palliative care (comfort care of the dying) to “hospice” here is arguably unnecessarily reductionist of an approach to care that is increasingly being accommodated in existing medical institutions.

¹⁹ “Everyone has the right to refuse to undergo medical treatment” under Section 11 of the New Zealand Bill of Rights Act, 1990. See also (The withdrawal of food and fluids, 1994) and (Advance Directives, 1995).

COMPARISON BETWEEN OREGON, NETHERLANDS, NORTHERN TERRITORY AND NEW ZEALAND OF PREREQUISITES/PROPOSED PREREQUISITES FOR ASSISTED DEATH

Recently the Netherlands became the third country to legalise physician-assisted death after tolerating the practice for many years (CNN NewsNet, 2000; Gordijn & Janssens, 2001; Wise, 2001), (although the Northern Territory legislation was over turned). The laws controlling assisted death in Oregon and Australia were predicated on the patient being terminally ill and this was also proposed in the Death with Dignity Act authored by Michael Laws in New Zealand in 1995 (NZPD 549, 1995; Oregon Health Division, 1997; Rights of the Terminally Ill Regulations 1996, 1996). In Holland the patient does not have to be terminally ill (Griffiths et al., 1998), but compares with the other three countries in that the patient must be experiencing unbearable suffering. Conditions under which elective death is/was supported in Oregon, Australia and Holland are compared with the proposed guidelines in the Death with Dignity Act proposed in New Zealand (see Table 4.1, p. 67). These guidelines share similarities with those proposed to cover elective death elsewhere (Emanuel et al., 1998; Helig, Brody, Marcus, Shavelson, & Sussman, 1997).

Table 4.1: Main conditions under which elective death may be given in Oregon and the Netherlands, formerly given in the Northern Territory* and proposed for New Zealand

Oregon(1)	Netherlands (2)	Australia* (3)	New Zealand(4)
<ul style="list-style-type: none"> • Personal, voluntary, written/verbal request • Resident of Oregon • Competent adult • Terminally ill (life expectancy <6months) • Request enduring over time • Understand palliative alternatives • Second independent opinion • Psychiatric assessment if depression suspected • Doctor may be present but cannot administer drug 	<ul style="list-style-type: none"> • Personal, voluntary preferably written and verbal request • Resident of Holland • Competent adult • Request enduring over time • Unbearable hopeless suffering • Know and refuse palliative options • Second, independent opinion • If psychiatric disorder, second opinion must be psychiatrist • Performed by doctor 	<ul style="list-style-type: none"> • Personal, voluntary signed request • Competent adult • Terminal illness • Request endures over time • Unbearable intractable suffering • Understand palliative alternatives • Two further independent opinions • One consultant must be psychiatrist • Doctor required to be present • Interpreter present if ESL** 	<ul style="list-style-type: none"> • Personal, written, voluntary request • Competent adult • Terminal or incurable illness • Request endures over time • Know all palliative options • Second medical opinion • Psychiatric assessment/competency assessment • Performed by doctor

(1) Oregon Health Division, 1997.

(2) Griffiths, J., Bood, A., Weyers, H. (1998). *Euthanasia and law in the Netherlands*. Amsterdam: Amsterdam University Press. pp 89-107.

(3) Rights of the Terminally Ill Regulations, (1996). Northern Territory of Australia. No. 34. Available: <http://www.nt.gov.au/lan/rotti/illregs.shtml>

(4) NZPD 549, 1995

* On March 24, 1997 Australia's National Senate repealed the Northern Territory's 1995 law which permitted euthanasia.

** English as second language

SECTION II

CHAPTER 5

STUDY ONE: PERCEPTIONS ON JUSTIFIABILITY AND LEGALITY OF MEDICAL DECISIONS AT THE END OF LIFE THAT HASTEN DEATH – LAYPERSONS AND GENERAL PRACTITIONERS IN NEW ZEALAND

INTRODUCTION

The issue of medical decisions at the end of life that hasten death (MDELHD) is one that occupies a place in several fields including medicine, law, philosophy, psychology, religion and ethics. Each discipline brings its own set of assumptions and traditions to the subject with varying degrees of flexibility when it comes to interpreting what is acceptable and what is not. There is the question of what is morally desirable, what is ethically possible and what is medically expedient to consider. Such decisions also have legal consequences both for the individuals involved, and for society as a whole. One implication of that is that it would be useful to investigate the attitude of sections of the population on these issues.

The opportunity for MDELs increases with age. As the baby boomer generation reaches middle-age and beyond, and with the ability of medical intervention to maintain life for longer, such decisions will increasingly become part of the end of life experiences of New Zealanders. Given the difficulty and emotional implications of such decision-making, information on the compatibility of attitudes of the general public and their physicians to MDELHDs may assist in planning end of life interventions/non interventions in a way that takes cognizance of a diversity of opinion.

The following study is an attempt to examine the willingness of laypersons and general practitioners in New Zealand to consider justified various medical decisions that hasten death. In addition the study investigates the understanding of laypersons and general practitioners on the legality of those same decisions.

AIM

1. To investigate attitudes of laypersons and general practitioners towards medical decisions at the end of life that hasten death. Specifically

- (i) The justification and legality of physician-assisted suicide for a requesting tetraplegic patient vs the justification and legality of refusing dialysis to a requesting patient.

Rationale: Comparing and contrasting results exposes possible underlying principles that respondents may employ in their end of life decision-making. This could be useful in planning end of life care.

- (ii) The justification and legality of doctors supplying information, drugs, assisting patient to ingest drugs and giving a lethal injection to a requesting terminally ill patient with intractable pain.

Rationale: These decisions were compared to explore level of tolerance for physician-assisted death. These ranged from the "softest" option of doctor supplying information on how to end life to a terminally ill patient who requests it to the "hardest" option of doctor giving the same patient a lethal injection on request. Supplying information to a patient on how to commit suicide is judged under New Zealand law to be "assistance to commit suicide" and carries a lighter penalty than "murder" which would be the charge for a doctor who gives a patient a lethal injection (New Zealand Crimes Act 1961).

- (iii) The justification and legality of physician giving a lethal injection to a terminally ill requesting patient with intractable pain vs physician stopping nutrition and hydration and sedating the same patient until death.
- (iv) Judgments on whether terminal sedation (as described in (iii), above) is deemed to be "euthanasia" or not.

Rationale: These two decisions were compared to explore how respondents judged the "hardest" palliative care option available, terminal sedation, against euthanasia. Terminal sedation is judged to be the "hardest" palliative option given opinions that are frequently proffered that question whether there is in fact any difference between this action and euthanasia (Billings & Block, 1996).

- (v) The justification and legality of withdrawing life support and withdrawing or withholding nutrition and hydration from an adult patient, comatose, with irreversible brain damage, with and without a Living Will.

Rationale: Withdrawing or withholding life-sustaining measures occur with persons who suffer irreversible brain damage. Examining attitudes to withdrawing vs withholding nutrition and hydration may expose biases in support for one action over the other which could potentially be useful in end of life discussions. Similarly examining the effect of a Living Will on such decision-making may give some indication of respondents understanding of the place of such a directive in end of life decision-making.

- (vi) The justification and legality of withdrawing life support or withholding nutrition from a comatose adult vs those same actions for a severely malformed and brain damaged neonate.

Rationale: As above in (v) without the Living Will investigation. Additionally it could be potentially useful in end of life discussions to determine if there is an age of patient bias when considering such decision-making and if respondents are more reluctant to cease one form of treatment over the other for either patient.

- (vii) The justification and legality of increasing pain medication at the risk of hastening death for a requesting terminally ill adult vs the same action without patient consent.
- (viii) The justification and legality of increasing pain medication at the risk of hastening death for a terminally ill child at the request of the parents vs the same action without parent consent.
- (ix) The justification and legality of increasing pain medication at the risk of hastening death for a terminally ill requesting adult vs the same action for a terminally ill child at parental request.

Rationale: Increasing medication to control pain at the risk of hastening death is ethically and legally sanctioned in New Zealand under the principle of "double effect" (New Zealand Crimes Act, 1961). The intent of the physician to control pain is taken as the primary intent and if death occurs it is seen as an unfortunate secondary consequence. There may be differences in how individuals perceive this action for an adult or a child, or differences in opinions on the requirement for consent when considering this medical action.

- (x) Understanding of respondents of the terms "palliative treatment" and "hospice".

Rationale: When engaging in discussions on end of life care, and particularly the care of the dying, medical and nursing personnel frequently use these two terms. It would be useful to determine how well they are understood.

- (xi) Comparing and contrasting judgments on the justification and legality of frequently made end of life decisions between Layperson and doctors.

Rationale: Inherent in effective end of life planning would be a commitment to identify and resolve potential areas of conflict between those who deliver care and those who receive it. Identifying differences in attitude to specific end of life decisions is potentially useful.

METHOD

A vignette questionnaire (see Appendix B) was used in a related samples study where participants acted as their own controls.

Participants were divided into three groups: Psychology students (18-29 years), Grey Power members (55+ years) and general practitioners (≤ 70 years). Comparisons were made on decisions within and between the groups.

Participants and recruitment

Psychology Students

These were laypersons with no apparent medical background, age 18-29 years of age, 96 Males (47%), 109 females (53%), $n = 205$, Stage III Psychology students, University of Auckland. Participants were spoken to at the end of three lectures, questionnaires were handed out and completed in class.

Grey Power Members

Grey Power is an organisation involved in activities that represent the interests of those 50+ years of age. Recruitment was via the monthly newsletter to members in the Howick/Pakuranga (East Auckland) chapter of Grey Power. Members were asked to take part in the research by completing an enclosed questionnaire and returning in the reply paid envelope supplied. One mail-out only.

General practitioners:

General practitioners aged 25 -75 years, 63 (52%) males, 57 (48%) females, $n = 120$.

Questionnaires and reply paid envelopes were sent to 300 Auckland general practitioners, randomly selected from a database of all Auckland GPs. One mail-out only.

Measures

Vignettes representing 16 different medical decisions at the end of life (MDELS) were presented in a questionnaire (see Appendix B) and comparisons were made within the groups between different scenarios. Two additional questions related to respondent understanding of the terms "palliative care" and "hospice".

The vignettes related specifically to medical decisions at the end of life that hasten death. Some of the actions described are legal in New Zealand and some are not. Each vignette was developed to cover medical decisions that occur fairly routinely in medicine and that involve shared decision-making by patient and/or family and doctor. Decisions related to emergency procedures were not included because these would be subject to emergency regulations pertaining to each individual case and may therefore not reflect the decision-making process that this thesis is occupied with.

Respondent judgments were sought on the justification and legality of each action proposed, and whether or not the proposed action constituted "euthanasia".

Answers to questions were dichotomous, ("Yes"/"No") for questions related to justification of actions and whether the action was judged to be euthanasia or not. Questions on legality offered the response options "Yes", "Unsure" and "No". When considering the issue of respondent understanding of the legality of actions, "Unsure" was included to provide respondents with a "soft" option given that the correct answer could require expert knowledge of the area. It was considered that for the purpose of this questionnaire, knowing an action is illegal or thinking it might be illegal, might produce similar psychological reactions within a person if they witnessed,

participated in or agreed to an act to hasten death. It is considered that this psychological reaction may differ if the action to hasten death was deemed to be legal (and therefore sanctioned).

Details were also sought from participants on age, gender, whether or not the participant was a doctor, nurse or other health worker, ethnicity and strength of personal religious beliefs on a five point Likert scale from "Extremely religious" to "Not religious at all".

A pilot study of 20 respondents identified difficulties with understanding certain terminology. Respondents required clarification on the terms "life support" and "living will". Explanations were inserted.

Strength of religious beliefs was used as the measure for religion. Past research indicates that the denomination or type of religion has less impact on attitudes to elective death than the strength of belief, or frequency of religious observance (Beswick, 1978; Singh, 1979).

Laypersons who indicated they were a nurse or doctor or other health care worker were excluded from the study. After data were collected from Laypersons, data were collected from Doctors. Three doctors stated that the wording in vignette 2 (d) (see Appendix B) was ambiguous and it was unclear what "act" the question referred to. The question was discarded from analysis.

Completed questionnaires were collected and analysis proceeded using SPSS (Statistical Package for Social Sciences Version 9).

ANALYSIS:

Frequencies are reported as percentages, and the effect of question on respondent decision-making was tested using the SPSS McNemar test (SPSS Inc, 1998; Siegel, 1956, p. 63).

Where more than two decisions were being compared (see Chapter 7), decisions were ranked according to level of seriousness (as determined by prior research). A conservative approach was adopted to setting the significance level with a Bonferroni adjustment to take account of repeated testing. Each section was treated as a separate group of analyses and the adjustment was limited to repeated tests of each variable within each section.

A marginal homogeneity test was used for judgments on legality. As the response options included "Yes", "Unsure" and "No", a McNemar test, (which assumes binary data) was not appropriate. The SPSS Marginal Homogeneity test was used which is an extension of the

McNemar test from binary responses to multinomial responses and uses a chi-square distribution, (SPSS Inc, 1998, p. 349).

When between group analyses were done, a normal chi square analysis was used with continuity correction reported (Statistical Package for Social Sciences Version 9). When chi square analyses were done by hand a Yates correction was incorporated into the calculations (Coolican, 1990, p. 180).

CROSS-STUDY RESULTS

Results for individual segments of the study will be presented in turn: the following however relate to all segments.

Response rates

There was an 80% response rate with students. These respondents are called Young Laypersons²⁰ in the study. There was a 30% response rate from Greypower members. This response-rate is low and a follow-up may have increased response rate but resources did not permit this. This sample was restricted to respondents 55+ years with no medical background, 218 (37%) males, 377 (63%) females, $n = 595$. These respondents are called Older Laypersons. There was a 40% response rate from general practitioners who are called Doctors in the study. Demographic breakdown is shown in Table 5.1, (p. 75).

²⁰ It is acknowledged that the three groups in this study may not be representative of all younger or older laypersons or doctors, however these signifiers are used for convenience throughout this section.

Table 5.1: Table showing demographic breakdown of age, gender, ethnicity and strength of religious beliefs of Young and Older Laypersons and Doctors.

		Young Laypersons (18-29) years		Older Laypersons (>55 years)		General Practitioners (<75 years)	
Mean age in years		21.19 years (N = 205)		70.74 years (N = 595)		46.23 years (N = 120)	
		%*	n =	%*	n =	%*	n =
Gender	Male	47	96	37	218	52.5	63
	Female	53	109	63	377	47.5	57
Ethnicity	European/Pak	67	137	99	587	82	98
	NZ Māori	2	4	.5	3	1	1
	PI/Polynesian	5	11	0	0	0	0
	Chinese	13	26	.2	1	7	9
	Japanese	1	2	.2	1	0	0
	Korean	2	5	0	0	0	0
	Indian	2	4	.2	1	6	7
	Other	8	16	.2	1	3	4
Missing	-	-	.2	1	1	1	
Religiosity	Extremely	3	7	3	18	5	6
	Very	10	21	7	41	14	17
	Moderately	24	49	42	251	26	31
	Slightly	25	52	26	156	21	25
	Not	36	74	21	123	34	41
	Missing	1	2	1	6	-	-

*% may not total 100 due to rounding.

CHAPTER 6

RESULTS: 1.

PHILOSOPHICAL PRINCIPLES UNDERLYING DECISION-MAKING

Two scenarios were chosen to explore the decision-making approach of Young and Older Laypersons and Doctors (see Table 6.1, below). These two conditions were chosen for comparison because neither patient is deemed to be dying, although underlying morbidity is potentially life-threatening (testing the Sanctity of Life principle), both patients would be using valuable health care resources (testing the Utilitarian principle) and both patients have made requests (testing the Autonomy principle). In the case of the tetraplegic patient, fulfilling the request is illegal and in the case of the dialysis patient there is no legal imperative to comply with the request (testing the Status Quo principle).

It was considered that identifying the principles used in decision-making would assist in planning interventions in end of life care by exposing possible areas of conflict between doctors, patients and family members when MDELs were proposed.

Table 6.1: Table showing two vignettes compared to investigate possible philosophical differences in how Young and Older Laypersons and Doctors approach decision-making.

<p>Patient D is an elderly person who has suffered for many years with kidney disease. Recently physical deterioration necessitates commencing on dialysis (a daily outpatient treatment where blood is circulated through a machine to purify it). Without treatment the patient will die. There is a long waiting list for dialysis so it is decided that because of age and other complicating medical decisions, treatment will not be offered, <u>despite the patient's requests</u>. Three months later, Patient D dies.</p>	
<i>IN YOUR OPINION, is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR OPINION is this action legal in New Zealand</i>	<i>Yes/No</i>
<p>An accident leaves Patient J permanently disabled with no movement in the legs and with only partial movement in the arms. After two years in a rehabilitation unit the patient is discharged into the community with assistance from a full-time caregiver. Patient J has not adjusted to this new way of life and requests the doctor for assistance to die.</p>	
<i>IN YOUR OPINION if the doctor agrees, would this action be justified?</i>	<i>Yes/No</i>
<i>IN YOUR OPINION is this action legal in New Zealand</i>	<i>Yes/No</i>

From these two scenarios, there were four possible combinations available to respondents. Percentage responses by each group to these combinations were used as the basis for identifying and naming the underlying principles employed in decision-making.

Combinations

1. No it is not justified to deny dialysis to the patient/Yes it is justified to grant a request for assisted death to the tetraplegic patient. *Both options follow the stated wishes of the patient, testing the Autonomy principle.*
2. Yes it is justified to deny dialysis to the patient/No it is not justified to grant a request for assisted death to the tetraplegic patient. *Both options reflect the medico-legal position in New Zealand testing the Status Quo principle.*
3. No it is not justified to deny dialysis to the patient/No it is not justified to grant a request for assisted death to the tetraplegic patient. *Both options aim to preserve and maintain life for the patient, testing the Sanctity of Life principle.*
4. Yes it is justified to deny dialysis to the patient/Yes it is justified to grant a request for assisted death to the tetraplegic patient. *Both options preserve valuable resources available for health care in the community, testing the Utilitarian principle. The Haemodialysis centre in Auckland for example dialyse patients 24 hours a day and an additional unit has been opened recently to accommodate inpatients from Auckland Hospital who require dialysis. Resource constraints have been identified as one of the reasons why patients have been refused dialysis in the past (Carroll, 1997). In the second scenario, providing 24 hour assistance in the community to a totally dependent tetraplegic patient would cost in excess of \$1,000 per week, depending on what services were required.*

Justifiability

Table 6.2, (p. 78) gives a breakdown of percentage responses to various comparisons. Within group analyses suggest evidence of a difference in judgments on justifiability between the two actions for Young Laypersons ($p = .001$) and Doctors ($p < .001$). There was no evidence of a difference in judgments for Older Laypersons ($p = .190$) (see Table 6.2 p.78 & Figure 6.1, p. 80). Although Sanctity of Life principles were ranked highest within this group (31%) there was only a 13% range in the four underlying principles for Older Laypersons (18% - 31%). This compares to Younger Laypersons who were more polarised in their decision-making principles

with a range of 53% (4% - 57%) and a similar picture for doctors with a range of 50% (4% - 54%) (see Table 6.2, p. 78).

Table 6.2: Table showing summary statistics for Laypersons and Doctors on judgments of justifiability and legality of assisted death on request for a tetraplegic patient and denying dialysis to a requesting patient.

JUSTIFIABILITY OF ACTION	YOUNG LAYPERSONS (N = 205)		OLDER LAYPERSONS (N = 595)		DOCTORS (N = 120)							
	Yes	No	Yes	No	Yes	No						
Deny dialysis to patient?	Yes	4% (n = 8)	12% (n = 24)	28% (n = 149)	18% (n = 95)	12% (n = 13)	54% (n = 60)					
	No	27% (n = 53)	57% (n = 114)	22% (n = 115)	31% (n = 165)	4% (n = 5)	30% (n = 34)					
	N = 199, $\chi^2 = 10.182$, P = .001*, df 1		N = 524, $\chi^2 = 1.719$, P = .190*, df 1 NS		N = 112, $\chi^2 = 44.862$, P < .001*, df 1							
LEGALITY OF ACTION	Y	Un	No	%	Y	Un	No	%				
Deny dialysis	30	48	22		42	39	19		78	14	8	
Assist death tetraplegic	2	35	64		2	33	65		1	7	92	
	N = 200, z = 7.914, P < .001*, df 4				N = 533, z = 13.521, P < .001*, df 4				N = 118, z = 10.053, P < .001*, df 4			

NB % may not equal 100 due to rounding

* p = .01

Between group analysis suggest that Young Laypersons ($\chi^2 = 23.42$, $p < .001$, $df 1$) and Older Laypersons ($\chi^2 = 18.79$, $p < .001$, $df 1$) were significantly more likely to make judgments according to proposed Autonomy principles than Doctors. There was no significant difference in judgments on Autonomy between the two groups of Laypersons ($\chi^2 = 1.71$, $p < .2$, $df 1$) (see Figure 6.2, p. 80).

Doctors were significantly more likely to make judgments according to the Status Quo than either Young Laypersons ($\chi^2 = 62.35, p < .001, df 1$) or Older Laypersons ($\chi^2 = 62.24, p < .001, df 1$). There was no significant difference in judgments according to the Status Quo between the two groups of Laypersons ($\chi^2 = 3.99, p < .05, df 1$) (see Figure 6.2, p. 80).

Young Laypersons were significantly more likely to make judgments according to proposed Sanctity of Life principles than either Older Laypersons ($\chi^2 = 40.35, p < .001, df 1$) or Doctors ($\chi^2 = 20.74, p < .001, df 1$). There was no significant difference in judgments according to Sanctity of Life principles between Older Laypersons and Doctors ($\chi^2 = .071, p > .2, df 1$) (see Figure 6.2, p. 80).

Older Laypersons were significantly more likely to make judgments from the proposed Utilitarian perspective than Young Laypersons ($\chi^2 = 50.92, p < .001, df 1$) and Doctors ($\chi^2 = 14.02, p < .001, df 1$). There was no significant difference in judgments according to Utilitarian principles between Young Laypersons and Doctors ($\chi^2 = 6.25, p < .001, df 1$) (see Figure 6.2, p. 80).

Legality

Although the action that was legal in the scenarios provided (denying dialysis) was more likely to be judged legal than the illegal action (assisting death), there appeared to be considerable error and uncertainty in judgments on legality. For the scenario provided, 30% of Young Laypersons correctly recognised that refusing dialysis was legal and 64% correctly recognised that assisted death was not legal (see Table 6.2, p. 78).

Less than half of Older Laypersons (42%) correctly judged it legal to refuse dialysis but 65% correctly judged that assisted death was illegal (see Table 6.2, p. 78).

Doctors appeared more certain in judgments on legality, with 78% correctly judging that refusing dialysis was legal (under the circumstances) and 92% of Doctors correctly judging that it was illegal to grant assisted death (see Table 6.2, p. 78).

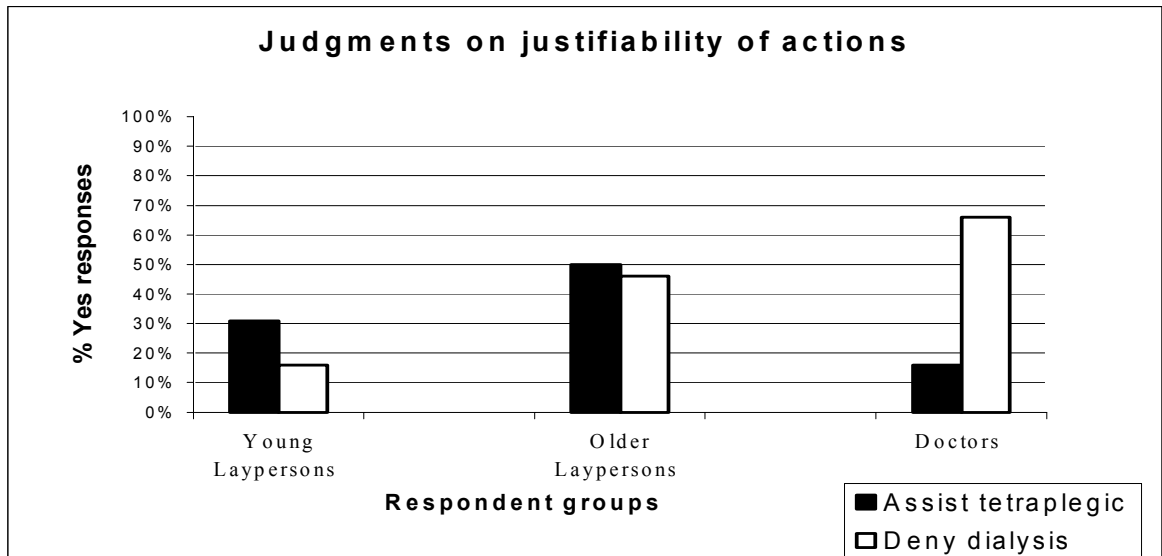


Figure 6.1: "Yes" responses of three groups on justifiability of granting tetraplegic patient request for assisted death and denying requests for dialysis to elderly patient.

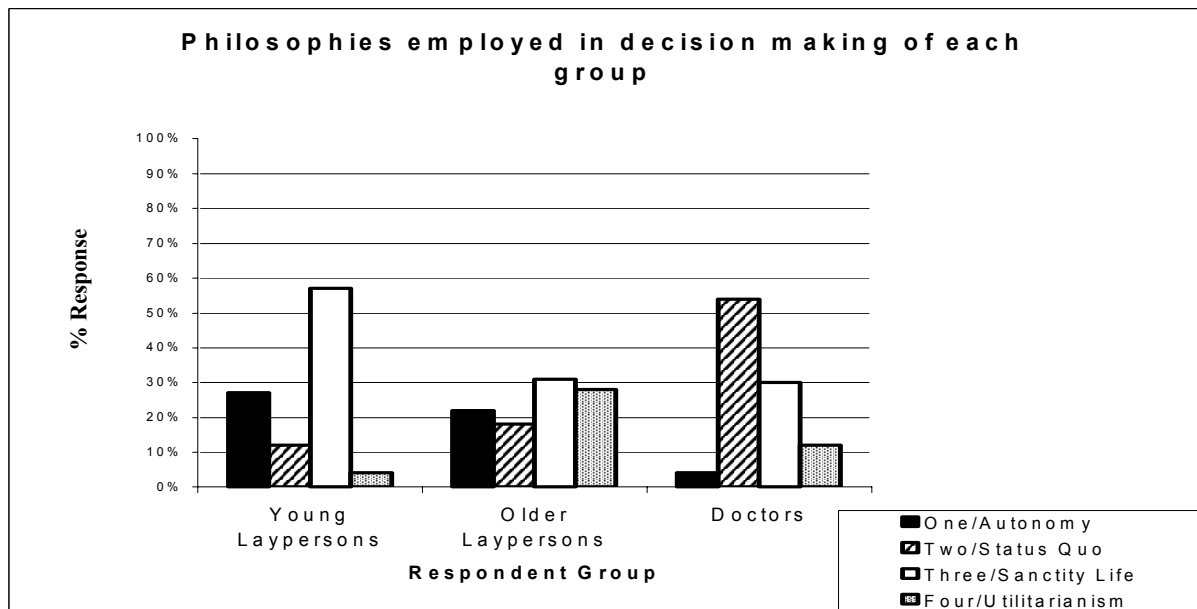


Figure 6.2: Combinations of principles employed by Laypersons and Doctors when comparing the justifiability of assisted death of a requesting tetraplegic patient or denying dialysis to a patient who has requested it.

DISCUSSION

The relationships between the way questions are answered suggested that individuals may invoke different philosophical principles when making choices. Moreover there are significant differences in the combination of choices between groups with the majority of Young Laypersons preferring Sanctity of Life principles and the majority of Doctors preferring the Status Quo. Older Laypersons do not show a clear preference for any one combination over the others although they were more likely to make judgments from a Utilitarian stance than the other two groups (see Figure 6.2, p. 80).

Young Laypersons were significantly more likely to base decisions on the proposed Sanctity of Life position than the other two groups. However of the minority (31%) of Younger Laypersons who thought it was justified to grant the request to die from the tetraplegic patient, 87% thought refusing the patient dialysis was not justified. This suggests that respondents who are pro-choice when it comes to granting requests for elective death may also be pro-choice when it comes to honouring requests for treatment. This suggestion runs counter to the claims of some who oppose the right to die movement, expressing fears that patient wishes not to have death hastened could be ignored (Hendin & Klerman, 1993).

An alternative explanation to the Sanctity of Life motivation for this group may be related to respondent judgments on legality. The majority of Young Laypersons (69%) judged it unjustified assisting the tetraplegic patient to die, the Sanctity of Life stance. However given that 64% recognised this action as illegal, respondents may have been motivated in their decision-making by the illegality of the action rather than the Sanctity of Life ethic per se. It is interesting however that 30% correctly judged the legality of denying dialysis, but only 16% judged it to be justified (see Table 6.2, p. 78). This suggests that actual motivating principles are related to something other than legality and may be related to either Autonomy or the Sanctity of Life ethic. Autonomy had the second highest score for this group at 27% (see Figure 6.2, p. 80).

There is no clear majority of Older Laypersons for any combination although the Sanctity of Life and Utilitarian combinations score the highest (see Figure 6.2, p. 80). This suggests that these respondents were not driven by one clear overriding principle, but based their decision-making on subjective views possibly related to life experiences. Alternatively, the other groups may also use subjective experiences on which to base their decision-making but the experiences of Older Laypersons may be more varied and/or influential when it comes to health care.

Half of Older Laypersons consider it justified assisting the death of a tetraplegic patient on request despite 65% recognising this as illegal, suggesting the principles of Autonomy (22%) or Utilitarianism (28%) as a motivation (see Figure 6.2, p. 80). Given the age of these respondents (mean age 70.7 years, see Table 5.1, p. 75) they may be influenced by psychologically identifying with the struggle of dependency and infirmity expressed in the vignette, having personally experienced some degree thereof or observed it in those close to them. Those who have not had their dependency needs met, or who are having difficulty adjusting to aging may judge that personal choice in resolving such problems should be respected, notwithstanding those who are philosophically committed to autonomy in principle. Cohort effects may also be at play here. During the 1950s and 1960's the views of this group would have developed and matured encompassing the concept of personal freedom and autonomy in decision-making.

This may reflect the role of personal experience affecting decision-making and suggests a need to consider the effect of previous life experiences, both within the family group and incorporating the wider context of personal development when MDELs are being considered. By identifying any unresolved issues around unmet needs or fear of ongoing dependency it may be possible to meet patient needs before they become acute and unbearable. Previous research has shown that fear of being a burden to loved ones is a factor in treatment decision-making by older persons (Schneiderman, Kronick, Kaplan, Anderson, & Langer, 1994) and has been implicated in requests for assisted suicide (Chin et al., 1999).

Nearly half of Older Laypersons (46%) consider it justified to deny dialysis to the patient, a decision in line with a Utilitarian stance (resource conservation) (28%). However 42% of Older Laypersons correctly judged this action to be legal which suggests decision-making influenced by the law, a Status Quo motivation (18%) (see Figure 6.2, p. 80).

The reasonably comparable scores for all combinations by Older Laypersons (see Figure 6.2, p. 80) suggest a philosophically varied approach to end of life decision-making by this group.

Doctors were more likely to judge it justified denying a request for dialysis (66%) than either group of Laypersons, in line with a Utilitarian ethic. However certainty on the legality of the action (78%) suggests a further motivation for this decision-making in line with the high Status Quo score for Doctors (54%) (see Figure 6.2, p. 80). Not all doctors who correctly judged this action as legal considered it to be justified however, which suggests that they could be influenced by either an Autonomy or a Sanctity of Life ethic.

In New Zealand, a decision to refuse dialysis to James McKeown on similar grounds to those proposed in the vignette was vigorously challenged by the patient. The issues relating to the medical decision received wide media attention. The decision was reversed and McKeown received the treatment he requested (Carroll, 1997). In a similar case in Northland, New Zealand, Rau Williams requested dialysis but was refused. His whanau²¹ challenged the decision on his behalf and again the resultant court case received wide media attention (Gregory, 1997; Lewis, 1999; Mager, 1997). The family were not successful in overturning the decision, which the courts ruled was a clinical decision that included considerations of limited resources (Shortland v Northland Health Ltd, 1997). Such cases may create uncertainty in the minds of some general practitioners about what is legal in such situations which could explain why 8% judged it illegal to deny dialysis and 14% were unsure (see Table 6.2, p. 78).

There was little uncertainty by Doctors over the illegality of assisting a tetraplegic patient to die (92%) and 84% of this group judged this to be unjustified (see Table 6.2, p. 78). This suggests a Status Quo motivation, decisions in accordance with the law, which scored high at 54% (see Figure 6.2, p. 80). Alternatively, some Doctors may be responding to a Sanctity of Life ethic when considering it unjustified to either assist the tetraplegic to die or to refuse dialysis to a patient who requests it. This combination scored high at 30% (see Figure 6.2, p. 80). Some doctors could have been influenced by being exposed to tetraplegic patients who have successfully adjusted and/or patients who have benefited from dialysis when this had been given despite medical contraindications.

Using Developmental theory as a theoretical framework within which to view differences in decision-making

There is an evident difference in the decision-making approaches between the groups. One explanation for at least some of the variation might be found in developmental theory and moral developmental theory. Kohlberg's theory of moral development (Kohlberg, 1967; Kohlberg, 1968) and Erikson's developmental theory (Erikson, 1963) will be employed to examine differences.

Kohlberg described moral development in terms of three levels of moral thinking – Pre-conventional, Conventional and Post-conventional. Each level had two stages (Kohlberg, 1967).

²¹ New Zealand Maori term for “family” which incorporates the extended family as well as immediate family.

Pre-conventional Level.

Stage 1 & 2 involved an obedience/punishment orientation. Motivation to do "good" is to avoid punishment. There is a burgeoning awareness of the needs of others but an incomplete understanding of shared standards of conduct (Kohlberg, 1967).

Conventional Level

Operating at Stage 3, Kohlberg suggested we conform to the stereotypical image of the majority. There is a good person/bad person orientation, pleasing and helping others. Although the ethnocentric view of Stages 1 and 2 are replaced by a more integrative view at Stage 3, this is still mainly focused on relations between individuals. At Stage 4, justice is defined in terms of formal rules and the perspective of justice now rests in relations between the individual and the community. Maintaining the social structure through obeying laws becomes a priority (Kohlberg, 1967). Emlar and Hogan suggest this stage acknowledges that the social system has a "superordinate legitimate authority" (Emlar & Hogan, 1981, p. 308).

Post-conventional

Stage 5 is a law-making rather than a law-observing perspective which suggests laws should reflect the will of society and considerations of overall utility gain prominence. Individual rights are important and may take precedence over law. At Stage 6 this develops to go beyond ordained social rules to consider principles of choice based on mutual respect and trust. Personal conscience becomes a directing agent. Kohlberg maintained that very few people achieve this stage (Kohlberg, 1967).

Kohlberg's theory has been criticised on the basis of gender differences (Gilligan, 1982). However others found no gender differences in moral reasoning using Kohlberg's method (Gleitman, 1991, p. 601).

Using the proposed prescriptions, Personal Autonomy and Sanctity of Life were located at Stage 3 of Kohlberg's theory (see Figure 6.3, p. 85). Reasoning at this level is focussed more on the individual and less on the individual as part of the community. Both principles suggest conforming to what is seen as morally good behaviour (life is sacred) and personal freedom (autonomy). Both principles are important according to the majority in New Zealand society, which is strongly individualistic (Hofstede, 1991).

Philosophical Principle					
Personal Autonomy					
Sanctity of Life					
Status Quo					
Utilitarianism					
Stage of Development	1	2	3	4	5
	Pre-conventional		Conventional	Post-conventional	

Figure 6.3: Suggested location of underlying philosophical principles used in decision-making according to Kohlberg's theory of moral development (Kohlbergh, 1967).

The principle of Status Quo is placed at Stage 4 where Kohlberg maintained moral judgments are premised on the relationship between the individual and society and the interest of the individual is in maintaining order as socially prescribed. Operating at Stage 4, moral judgments would emphasise the preservation of life within the legal and ethical framework established in society.

It is not until Stage 5 that a commitment to maintaining the legal and ethical structure of society gives way to a perspective that suggests that such a structure could or should be changed to best meet the changing needs of people. At this Post-conventional level, the moral view looks at the best possible outcomes for society as a whole. The Utilitarian principle is located here.

It could be argued that Personal Autonomy and Sanctity of Life could be located at the Post-conventional level of Kohlberg's theory with its emphasis on personal conscience as the guide to moral decision-making. Overall however, the utility of outcomes seems inherent in Kohlberg's theory at this level, which may preclude some autonomous decision-making premised on the desire to maintain life at all costs. Giving dialysis to the patient who requests it may not be the

best use of community health resources²². This indicates that Autonomy and Sanctity of Life may be better located at the Stage 3 level with its emphasis on individuality.

Erikson's developmental theory, proposed a series of eight crises that each required resolution to achieve a successful progression through the stages of development. The last four occupy themselves with the crises of adolescence, early adulthood, middle age and later years. In adolescence, the crisis is Identify vs Role Confusion. The individual must resolve issues to do with establishing personal standards separate from parents and establishing a sense of identity, their role in life. In early adulthood the crisis is Intimacy vs Isolation where the young adult establishes bonds of love and friendship. In mid-adulthood the crises related to fulfilling life goals, Generativity vs Stagnation. Here the individual brings family and community goals to fruition and contemplates the kind of world that will be left for future generations. Finally, Integrity vs Despair in old age challenges the individual to look back over life with acceptance and a sense of meaning for one's existence (Erikson, 1963).

The crises that require resolution according to Erikson's theory suggest that Older Laypersons may be more likely to be thinking of the effects of their decision-making on the community as much as on themselves individually. The tasks to be met at the stages designated as Generativity vs Stagnation (middle age) and Integrity vs Despair (old age) are in line with a Utilitarian perspective that takes account of wider contributing perspectives on decision-making and the far reaching consequences of decisions. Older Laypersons seem to be pragmatic about decision-making that hastens death in these two scenarios with 50% judging it justified to grant hastened death to the tetraplegic patient and 46% judging it justified to deny dialysis (see Figure 6.1, p. 80).

Younger Laypersons on the other hand are much more conservative in their decision-making related to hastening death with only 31% considering it justified to assist the tetraplegic to die and only 16% considering it justified to deny dialysis (see Figure 6.1, p. 80). According to Erikson, young adulthood is occupied with creating relationships and establishing enduring bonds with loved ones. A belief that life is sacred and that there should be enough resources to meet the needs of individuals may fit with a youthful idealistic view of the world.

²² It is acknowledged that “use” would relate to different priorities depending on the cultural perspective of the recipient – a point that was acknowledged in the Rau Williams case. A value judgment on the basis of most benefit/least harm may be deemed medically appropriate when choosing “suitable” dialysis recipients. However a cultural, religious or personal commitment to “fight” death to the end could arguably be judged to be as important a “use” of resources as that which considers such use justified on physical outcome alone.

In summary, there is a variation in approaches to decision-making between the groups for the scenarios presented. According to the prescriptions proposed, a strong majority of Younger Laypersons used Sanctity of Life principles in their decision-making. It is suggested that this decision-making be placed at Stage 3 of Kohlberg's theory of moral development with its emphasis on the importance of the individual life for its own sake. Such a worldview also seems indicative of Erikson's developmental theory for young adulthood.

There is no significant difference between the combinations used by Older Laypersons in their decision-making, however this group was significantly more likely to make their decisions based on a Utilitarian ethic, than the other groups. It is suggested that this decision-making is placed at Stage 5 of Kohlberg's theory of moral development with its emphasis on the importance of the individual as part of society but not necessarily morally constrained by societal dictates that do not best meet needs. This also seems reflective of the stages of generativity and integrity that exemplify successful aging according to Erikson's theory of development.

Doctors were significantly more likely to make decisions based on the Status Quo than Laypersons, and this was their highest within group percentage. It is suggested that this decision-making be placed at Stage 4 of Kohlberg's theory of moral development with its emphasis on the importance of the individual adhering to and supporting the social structure.

Laypersons are unsure of the legality of either action and it is unclear how much this may impact on their decision-making. Conversely, doctors were more confident in their legal judgments, which may impact on their decision-making.

Caveat

The application of ethical/philosophical labels to these combinations is used for the purpose of convenience and discussion. They should be taken to apply only to the actions described when conclusions are being made about the decision-making processes of each group. Similarly, it is not suggested that the philosophical principle being represented by each combination is necessarily the only principle being invoked in the decision-making that is thus labelled. One of the hallmarks of any philosophical discussion is the premise that almost everything is contentious and open to debate (Rachels, 1993). It was considered that principles that seemed representative of the supposed decision-making process, or at least a part of it, would facilitate comprehension for the purpose of discussion only.

For example, in this context, Combination One is taken to pertain to issues of Autonomy given that both patients have made a request notwithstanding that the issue of autonomy in such situations can be called into question. From a behavioural perspective (Skinner, 1974), it is not hard to understand why the tetraplegic may be requesting death (to avoid suffering) or the dialysis patient is requesting treatment (to avoid death). However, the coercive element introduced by the aversive stimuli (suffering and death) calls into question the autonomy of the request (Campbell, 1999) and even questions whether the patient who is making the request perceives it to be autonomous (Owens, 1995).

Similarly, Combination Two is taken to be that which pertains to the law in New Zealand in relation to taking life or stopping treatments. However, these decisions are governed by professional Codes of Practice that may seem to run counter to the law. Denying dialysis in the situation described in the vignette is a medical decision that may seem contrary to the legal imperative to provide the necessities of life cited in Sections 151-151.05 of the New Zealand Crimes Act, 1961.

For the present purposes, Combination Three is taken to pertain to the Sanctity of Life ethic founded in the Judeo-Christian principles that underwrite our laws and ethical decision-making. Such laws are premised on a prohibition of the taking of innocent life and an imperative to provide for those in need. From a classic Utilitarian perspective however, one could also say that it serves the greatest good to prohibit the intentional taking of innocent life (the tetraplegic patient) even on request, given the potential for abuse. This is subtly different from a Sanctity of Life ethic because the motivation for the decision is the common good of society rather than a judgment that the life itself is sacred.

Lastly, Combination Four is taken to pertain to Utilitarianism, given that both options preserve health care resources. However, seemingly perversely, granting death to the tetraplegic could also be made from a Sanctity of Life perspective. It is suggested that in the light of technological developments we may need to question what "life" is. Respecting the sacred nature of life suggests that the life must be of worth to the person living that life. If they do not regard the life as of a quality to be deemed sacred and worth having, it may be hard to argue that anyone else should either (Dworkin, 1993). This is subtly different from granting death from Autonomy, which may not take into account the quality of the life to be taken.

There appear to be differences in the decision-making between and within the three groups within this very limited range of two decisions. Other scenarios will be examined to see if the apparent

differences in the decision-making of Young and Older Laypersons and Doctors remains robust across other end of life decisions that hasten death.

CHAPTER 7

RESULTS: 2

PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA

The tolerance of Laypersons and Doctors for medical actions that relate to physician-assisted suicide, euthanasia and terminal sedation is explored. The first four actions described in this section have been ranked according to what could arguably be perceived as degrees of severity related to physician involvement in the intentional ending of life.

Setting aside for the moment the issue of the power differential in the doctor/patient relationship, a doctor supplying information on how to end life could be seen as no more than a verbal exchange between two adults (Quill et al., 1997a). A doctor supplying drugs to end life could be seen as a relatively passive action that allows for maximum free choice on the part of the patient with no doctor involvement at the point the decision is ultimately made. Assisting a patient to take drugs and administering a lethal injection seem more severe because the doctor is actively involved in assisting to end the patient's life and in ending the patient's life. Such reasoning has been applied in Oregon.

The Oregon Death with Dignity Act specifically separates the actions of supplying information and drugs to allow a patient to end life from a physician physically assisting a patient to die. The latter is regarded as euthanasia and is illegal in Oregon. Supplying information and drugs is legal provided guidelines are followed (Oregon Health Division, 1997). None of the actions is legal in New Zealand. Under Section 179 of the New Zealand Criminal Code, being found guilty of assisting in a suicide carries a sentence of up to 14 years. Supplying the information when it is not acted upon (an option that may have its uses and will be discussed later) could arguably be deemed to be within the law as it is written.²³

When palliative interventions fail and pain is intractable, a legal palliative intervention that doctors may offer to patients is terminal sedation. Terminal sedation occurs when the patient is sedated and sleeps until death occurs (Cherny & Portenoy, 1994). Food and fluids are not given

²³ Section 179(a) of the New Zealand Crimes Act states that someone is deemed guilty who "incites counsels or procures any person to commit suicide, if that person commits or attempts to commit suicide in consequence thereof" (New Zealand Crimes Act 1961)

during this time. Because this is posited as a legal alternative to euthanasia (Meisel, Snyder, & Quill, 2000) respondent opinions were sought on the justifiability of this action, compared with euthanasia (giving the patient a lethal injection) and whether respondents judged terminal sedation to be “euthanasia”.

The effect of religiosity, gender, ethnicity and age on decision-making is also explored.

Five comparisons were made on the justifiability and legality of actions in four vignettes (see Table 7.1, below).

Table 7.1: Table showing four vignettes compared to investigate level of tolerance of Young and Older Laypersons and Doctors for physician-assisted death.

<p>Patient B has a terminal illness (i.e. no hope of recovery), and <u>pain is a constant problem</u>, not alleviated by drugs. The doctor is requested by the patient to supply information on how to end one's life, and to prescribe enough drugs to make this possible. The doctor agrees to supply the information and drugs to the patient for the patient to use without the assistance of the doctor.</p>	
<i>IN YOUR OPINION, is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p><i>IN YOUR OPINION, is the action of the doctor in supplying <u>the drugs</u> to this patient justified?</i></p>	
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>Some time passes and Patient B deteriorates to the point where taking the drugs that the doctor has prescribed is impossible without assistance. The doctor assists by holding the drinking cup while the drugs are swallowed.</p>	
<i>IN YOUR OPINION, is the doctor's action in assisting the patient to take the drugs, justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>Patient B has difficulty swallowing and requests the doctor to administer a lethal injection to end the suffering. The doctor administers a lethal injection?</p>	
<i>IN YOUR OPINION, is the action of the doctor in giving the patient a lethal injection justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>Patient F has a terminal disease which has reached the end stage. Death will occur within the next few days, but Patient F is suffering unbearably and the drugs being administered are not effective. The doctor explains that the only way to limit suffering is to sedate Patient F <u>who will be kept unconscious until death occurs</u>. Patient F will not be fed during this time, but will receive full nursing care and be kept comfortable.</p>	
<i>IN YOUR OPINION, is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in N.Z.?</i>	<i>Yes/Unsure/No</i>
<i>IN YOUR UNDERSTANDING is this euthanasia?</i>	<i>Yes/No</i>

Knowledge of the function of palliative care and hospice were also tested using multi-choice questions, with frequencies reported (see Table 7.2, below).

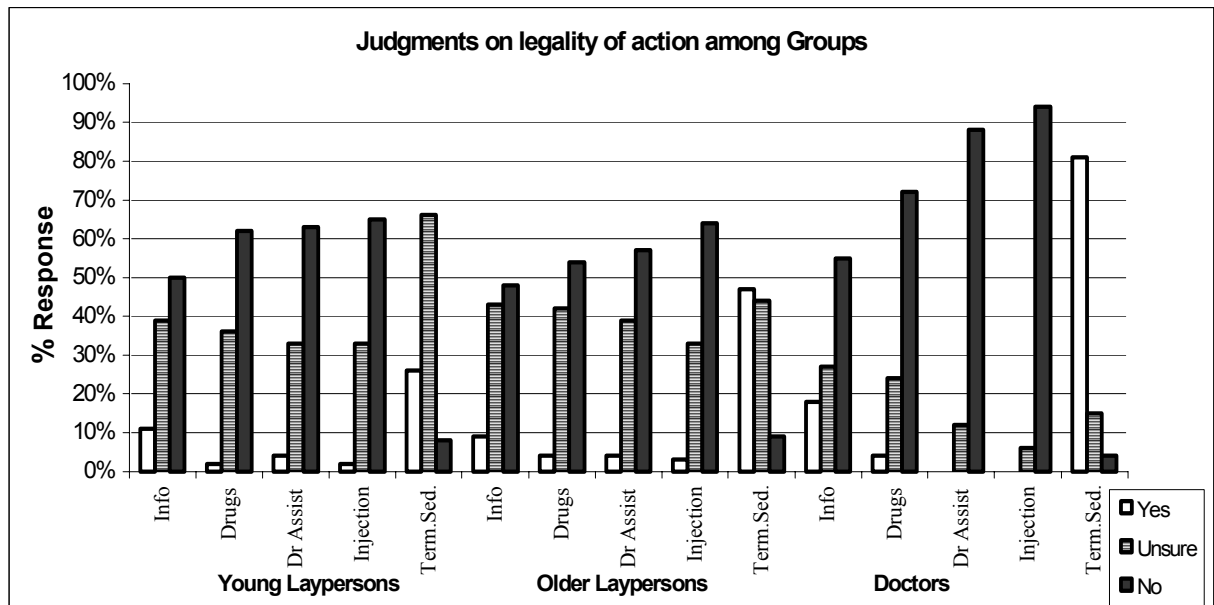
Table 7.2: Table showing questions related to the understanding of the function of palliative care and hospice by Laypersons and Doctors.

<p>Patient K has been diagnosed with cancer. Surgery and chemotherapy are unsuccessful and the cancer spreads. The doctor recommends Patient K start palliative treatment.</p> <p>IN YOUR OPINION, does the term "palliative treatment" refer to</p> <ul style="list-style-type: none"><input type="checkbox"/> experimental treatment<input type="checkbox"/> alternative treatment<input type="checkbox"/> putting her affairs in order<input type="checkbox"/> comfort care to relieve symptoms<input type="checkbox"/> something else <p>After a deterioration in Patient K's condition, the General Practitioner recommends hospice involvement.</p> <p>IN YOUR OPINION, does the term "hospice" refer to</p> <ul style="list-style-type: none"><input type="checkbox"/> an organisation that supports the patient's family<input type="checkbox"/> a place where people get palliative treatment<input type="checkbox"/> a place where people go to die<input type="checkbox"/> a place where the patient can go for a rest and then go home.<input type="checkbox"/> all of the above
--

To test the assumption that respondents concur with the ranking of the first four actions as suggested, frequencies for judgments on the legality of the actions were compared for the three groups. There is a discernible trend evident across the three groups of an increasing confidence in judging the actions as illegal, reflected in decreasing Unsure responses (see Figure 7.1, p. 93). It was considered that for the purposes of analysis, the ranking of these four actions as proposed was justified.

Significance of any observed change in judgments on justifiability was tested in the following comparisons...

- physician supplying information/physician prescribing drugs
- physician prescribing drugs/physician assisting with taking drugs
- physician assisting with taking drugs/physician giving lethal injection.



Key: Info = Physician supplying information to patient on how to hasten death
 Drugs = Physician supplying drugs to patient to hasten death
 Dr Assist = Physician assisting patient to take drugs to hasten death
 Injection = Physician giving lethal injection to patient
 Term. Sed. = Terminally sedating a patient on request (no food and fluids)

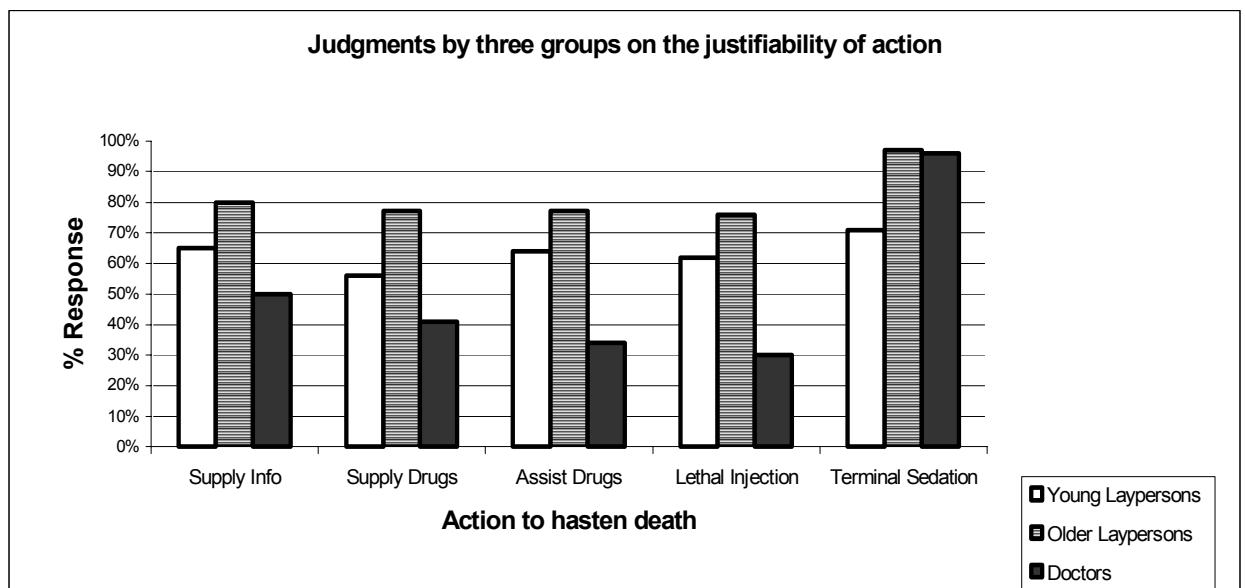
Figure 7.1: Judgments of Young & Older Laypersons and Doctors on the legality of doctor supplying information, drugs, assisting patient to take drugs, administering a lethal injection & terminal sedation of a terminally ill patient with intractable pain, on request.

There was evidence of an effect of action on response in judgments on the justifiability of “Supplying Information” and “Supplying Drugs” for Young Laypersons ($p < .001$), Older Laypersons ($p = .002$) and Doctors ($p < .001$) with each group judging Supplying Information as more justified (see Table 7.3 (1, 2), p. 94).

There was evidence of an effect of action on response in judgments on the justifiability of “Supplying Drugs” and “Assisting to take Drugs (Assisting Drugs)” for Young Laypersons ($p = .003$) with the physician assisting patient to take the drugs judged to be more justified than supplying drugs alone. There was no evidence of a change in judgments on justifiability between these two actions for Older Laypersons or Doctors although the latter judged “Assisting Drugs” to be less justified (see Table 7.3 (2, 3) p. 94).

Table 7.3 **(inserted end)**

There was no evidence of a difference in judgments on the justifiability of “Assisting Drugs” and giving a lethal injection (“Lethal Injection”) for any group (see Table 7.3 (3, 4), p. 94). Over 62% of Young Laypersons, 76% of Older Laypersons and 30% of Doctors judged both actions to be justified (see Figure 7.2, below).



Key:

Supply Info = Physician supplying information to patient on how to hasten death

Supply Drugs = Physician supplying drugs to patient to hasten death

Assisting Drugs = Physician assisting patient to take drugs to hasten death

Lethal Injection = Physician giving lethal injection to patient

Terminal Sedation = Terminally sedating a patient on request (no food and fluids)

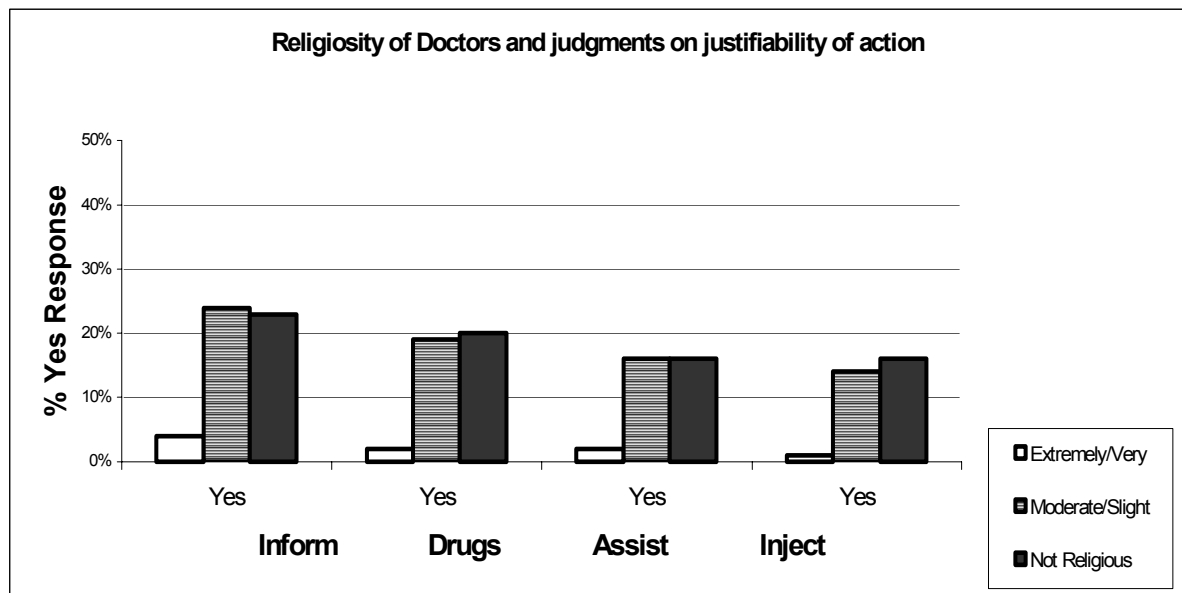
Figure 7.2: Judgments by Young and Older Laypersons and Doctors on justifiability of supplying information or drugs, assisting to take drugs, giving a lethal injection or terminally sedating a dying patient on request.

Effect of religiosity, gender and ethnicity of Doctor on judgments

Religiosity was conflated to three responses, Extremely/Very ($n = 23$), Moderate/Slight ($n = 56$), None ($n = 41$). Religiosity was significantly related to Doctors judging it justified or not justified to supply information ($\chi^2 = 10.105, p = .006, df 2$), supply drugs ($\chi^2 = 13.223, p < .001$,

df 2), assist to take drugs ($\chi^2 = 6.251, p = .044, df 2$) and give a lethal injection ($\chi^2 = 12.629, p = .002, df 2$).

Those who presented as Extremely/Very religious were likely to judge all four actions as unjustified. Those who were Moderately/Slightly religious were evenly divided on Supplying Information but likely to judge the other three actions as unjustified. Those who were not religious at all were more likely to judge Supplying Information and Supplying Drugs as justified, but were evenly divided on Assisting Drugs and Lethal Injection (see Figure 7.3, below).



Key:

Inform = Physician supplying information to patient on how to hasten death

Drugs = Physician supplying drugs to patient to hasten death

Assist = Physician assisting patient to take drugs to hasten death

Inject = Physician giving lethal injection to patient

Figure 7.3: Relationships between Doctors' religiosity and judgments on justifiability of supplying information or drugs, assisting patient to take drugs or giving a lethal injection to a terminally ill patient with intractable pain, on request

There was no significant effect of gender of Doctor on judgments of justifiability of Supplying Information ($\chi^2 = 1.461, p = .227, df 1$), Supplying Drugs ($\chi^2 = 2.515, p = .113, df 1$), Assist Drugs ($\chi^2 = 1.233, p = .267, df 1$) or Lethal Injection ($\chi^2 = 2.530, p = .112, df 1$).

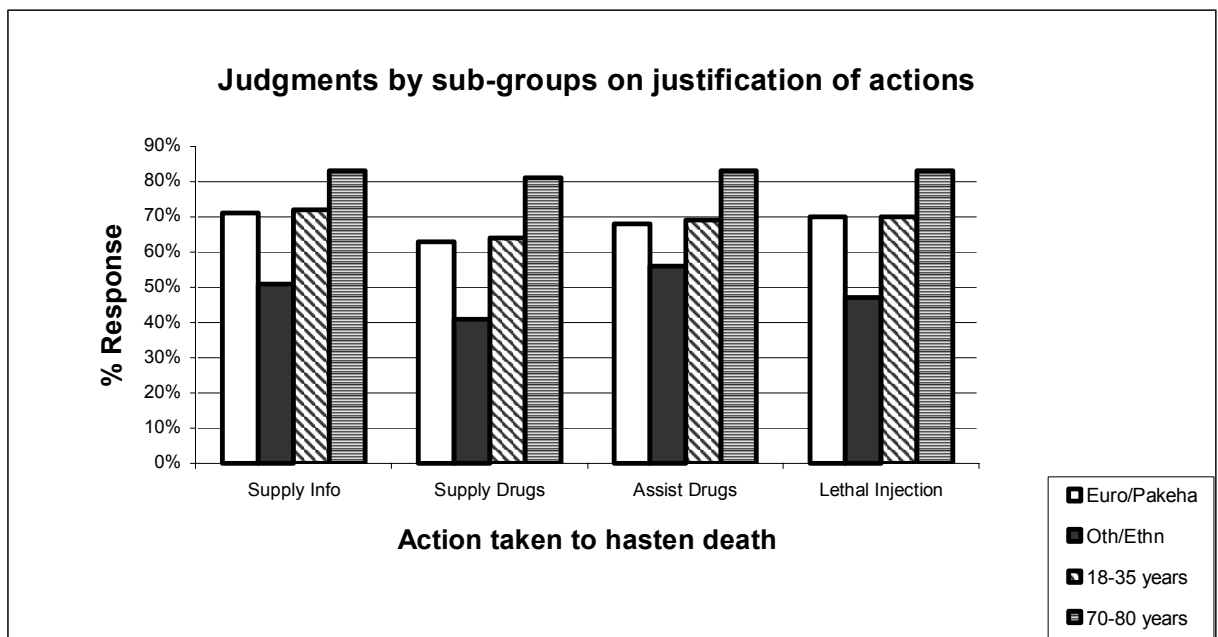
Ethnicity was conflated to two groups, European/Pakeha ($n = 98$) and Others Combined ($n = 22$) due to small numbers in each ethnic group of doctors other than European/Pakeha (see Table 5.1, p. 75). There was no evidence of an effect of ethnicity on Supplying Information ($\chi^2 = .000, p = 1.0, df 1$), Supplying Drugs ($\chi^2 = .047, p = .829, df 1$), Assist Drugs ($\chi^2 = .008, p = .931, df 1$) or Lethal Injection ($\chi^2 = .098, p = .754, df 1$). Given the wide ethnic variation in “Others Combined” and the small number other than European/Pakeha, this result should be viewed with caution.

The age range and distribution was similar between doctors who judged the four actions justified and those who did not.

Exploring Ethnicity and Age in Laypersons

Young Laypersons showed evidence of a discontinuity in the expected regression of support for the justification of actions as they increased in severity. There was a significant difference between support for “Assisting Drugs” and “Supplying Drugs”, a phenomenon that was not evident with the other groups (see Figure 7.2, p. 95). It was considered that ethnicity may have played a part in this trend, given that the ethnic breakdown of this group was varied compared with Older Laypersons who were predominantly European/Pakeha (see Table 5.1, p. 75). It should be noted however, that the ethnic sample in this study may not be typical of other ethnic populations in New Zealand given that they were mainly university students. Young Laypersons were split into two groups, "European/Pakeha" ($n = 137$) and "Other Ethnicities Combined" ($n = 68$).

There is a suggestion of a difference **within** each of the two sub-groups, and significantly present in the **combined** group of Young Laypersons ($p < .003$) for judging “Supplying Drugs” as less justified than “Assisting Drugs” (see Table 7.3 (2, 3), p. 94). Given that the trend is present in both groups, it is concluded that the reason for the difference in judging “Supplying Drugs” as less justified than “Assisting Drugs” is not a product of ethnicity. It is conjectured that it could be a product of age given that Older Laypersons do not show this phenomenon (see Table 7.3 (2, 3), p. 94).



Key: Supply Info = Physician supplying information to patient on how to hasten death
 Supply Drugs = Physician supplying drugs to patient to hasten death
 Assist Drugs = Physician assisting patient to take drugs to hasten death
 Lethal Injection = Physician giving lethal injection to patient

Figure 7.4: Comparisons between European-Pakeha /Other Ethnicities Combined Young Layperson and Age Comparison 18-35/70-80 year old Laypersons on judgments on justifiability of hastening death action ($p = .005$)

Differences **between** the two groups were tested for significance. A χ^2 analysis showed evidence that the European group were more likely than the Other Ethnicities group to judge as justified “Supplying Information” ($p = .009$), and “Lethal Injection” ($p = .002$) (see Table 7.3, (1, 4), p. 94). There was no evidence of a difference between the two groups judging “Supplying Drugs” ($p = .007$) or “Assisting Drugs” as justified ($p = .102$) (see Table 7.3 (2, 3), p. 94) which suggests the groups are relatively (within their within group result) like-minded regarding these two options. Caution should be taken in interpreting this rather tenuous result.

The effect of age on the four actions was explored. Two groups of Laypersons were considered - those aged 18-35 years ($n = 151$) (European/Pakeha) and those aged 70-80 years ($n = 232$) (European/Pakeha). A χ^2 analysis showed evidence that the 70-80 Years group were more likely to judge as justified “Supplying Information” ($p = .019$), “Supplying Drugs” ($p < .001$), “Assisting Drugs” ($p = .003$) and “Lethal Injection” ($p = .004$) (see Table 7.3 (1-4), p. 94 & Figure 7.4, p. 98).

Terminal Sedation and Euthanasia.

There is evidence of an effect of action on response with “Terminal Sedation” judged to be more justified than “Lethal Injection” by Older Laypersons ($p < .001$) and Doctors ($p < .001$). There is no evidence of a difference in judgments on the two options by Young Laypersons ($p = .034$) (see Table 7.3 (4, 5), p. 94). However, of the 62% of Young Laypersons who judged “Lethal Injection” justified, 19% did not judge “Terminal Sedation” justified.

“Terminal sedation” is judged to be "euthanasia" by 32% Young Laypersons, 25% Older Laypersons and 10% Doctors.

Judgments on legality of “Supplying Information”, “Supplying Drugs”, “Assisting Drugs”, “Lethal Injection” and “Terminal Sedation”.

There was evidence of a difference in judgments on the legality of “Supplying Information” and “Supplying Drugs” for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) Doctors ($p < .001$) and the sub-group of European/Pakeha Young Laypersons ($p < .001$) (see Table 7.3 (6, 7), p. 94) with respondents less likely to judge “Supplying Drugs” as legal. There was no evidence of a difference for the Other Ethnicities sub-group of Young Laypersons.

There was evidence of a difference in judgments of Doctors on the legality of “Supplying Drugs” and “Assisting Drugs” with increased support for “Assisting Drugs” being illegal ($p < .001$). There was no evidence of a difference between “Supplying Drugs” and “Assisting Drugs” for Young or Older Laypersons or the sub-groups of Young Laypersons (see Table 7.3 (7, 8), p. 94).

There was evidence of a difference in judgments of Older Laypersons ($p < .001$) on judgments on the legality of “Assisting Drugs” and “Lethal Injection” with increased support that “Lethal Injection” was illegal, although the effect was small. There was no evidence of a difference between “Assisting Drugs” and “Lethal Injection” for Young Laypersons, Doctors or either of the sub-groups of Young Laypersons (see Table 7.3 (8, 9), p. 94).

All groups recognised the legality of terminal sedation relative to “Lethal Injection” ($p < .001$) (see Table 7.3 (9, 10), p. 94).

In judging the legality of terminal sedation, 74% of Young Laypersons, 53% of Older Laypersons and 19% of Doctors were unsure of legality or judged the action to be illegal (see Table 7.3 (10), p. 94).

Characteristics of Doctors who were unsure of legality of terminal sedation

There was no evidence of a difference between Doctors who judged terminal sedation as legal and those who did not, for gender ($\chi^2 = 1.128, p = .288, df 1$), ethnicity ($\chi^2 = 3.031, p = .082, df 1$) or religiosity ($\chi^2 = 1.047, p = .592, df 2$). The age range and distribution of the two groups was similar.

Understanding of the function of “palliative treatment” and “hospice” in the care of the terminally ill.

The function of palliative treatment is comfort care to relieve symptoms and the majority of Doctors (99%) and Older Laypersons (91%) responded correctly. Only 48% of Young Laypersons correctly identified the function of palliative treatment (see Table 7.4, p. 101).

Most Doctors (97%) correctly identified the function of hospice to provide palliative treatment. 10-15% of Doctors did not identify the wider palliative care functions of hospice. A moderate number of Young Laypersons (44%) and Older Laypersons (57%) correctly identified the function of hospice however a large percentage of both groups of Laypersons did not identify the wider palliative care functions of hospice (see Table 7.4, p. 101).

While all of the Doctors (22) who did not judge terminal sedation in the scenario provided as legal correctly identified the function of palliative care, there was confusion among some of these doctors about the role of the hospice organisation.

Five Doctors did not identify hospice as a place for respite care, 3 did not identify hospice as a support for the family, 2 did not identify hospice as a place to go to die and 1 did not identify hospice as a place to go to for palliative care. All the respondents live in the greater Auckland area, which has several hospices including three in-patient facilities. However caution should be taken in interpreting this result. Physicians in an area that has a day stay or volunteer hospice only would not have inpatient facilities for dying patients (place to go to die/respite care) and may not have sufficient resources to offer the wider services identified in the question.

Table 7.4: Table showing judgments of Young (YLP) and Older (OLP) Laypersons and Doctors (DR) on the meaning of the terms "palliative care" and "hospice".

"PALLIATIVE TREATMENT" REFERS TO....	YLP % YES n = 205	OLP % YES n = 595	DR % YES n = 120	"HOSPICE" REFERS TO A PLACE THAT.....	YLP % YES n = 205	OLP % YES n = 595	DR % YES n = 120
Experimental treatment	20%	3%	1%	Supports the patient's family	60%	68%	90%
Alternative treatment	25%	6%	1%	Provides palliative treatment	63%	83%	97%
Putting affairs in order	3%	3%	1%	People go to die	61%	79%	91%
Comfort care to relieve symptoms*	48%	91%	99%	Provides respite care for patient	51%	62%	86%
Something else	6%	2%	2%	All of the above*	44%	57%	85%

*Correct response

DISCUSSION

Doctor supplying information and drugs to end life to a terminally ill patient with intractable pain²⁴.

Most support for "Supplying Information" on how to end life comes from Older Laypersons (80%) (see Table 7.3 (1), p. 94). This may reflect a greater perceived need to know about this issue by this group given their age distribution (mean age 70.74 years) (see Table 5.1, p. 75). Increasing age (either for themselves, spouse or family member) would expose this group to the dying situation more than Young Laypersons (mean age 21.19 years) (see Table 5.1, p. 75). Increased incidence of painful disease, metastatic or otherwise occurs with age and researchers have noted

²⁴ NB: It should be noted that this vignette related to doctor supplying information on how to end life, not the doctor just dealing with a request for hastened death. Dealing with a request for hastened death when it occurs is a normal part of the care of the dying and can occur in conjunction with several factors such as pain, loss of dignity, fear, anxiety or depression. There is no legal impediment, nor is there an obvious moral one, to discussing such a request with patients. What may be an impediment to such a discussion, is fear on the part of the practitioner that a successful resolution of the problem that motivated the request may not be possible. Doctors may fear that in such a situation the patient may persist with the request leaving them wishing that the subject had never been broached in the first place. Part of this thesis is to argue that extensive knowledge of possible palliative interventions provides the practitioner with a freedom to engage in such discussions, confident that the majority of patient needs can satisfactorily be met within the bounds of what is legally and ethically acceptable.

that advanced age is implicated in poor provision of pain relief (Bernabei et al., 1998). However, pain is not the only aspect of suffering implicated in the desire for a hastened death. Unpleasant prior experiences of some respondents who have nursed loved ones who have suffered at the end of life may have influenced responses to the questionnaire on the desirability of hastened death (Seale & Addington-Hall, 1994). In Australia, the first person to avail themselves of euthanasia under the Act (Rights of the Terminally Ill Regulations, 1996) stated that memories of seeing friends die “bloody horribly” motivated him to seek assistance to die before he met a similar fate (Dent, 1997).

There is a higher percentage of Doctors (18%) than Laypersons (Young 11%; Older 9%) who consider that giving information on how to end life to a terminally ill patient, is legal. 18% of doctors stated it was legal to supply information while 26% of doctors were unsure of legality (see Table 7.3 (6), p. 94). With half the doctors judging the action justified (see Table 7.3 (1), p. 94), this suggests that a significant number of the doctors surveyed may see no moral and/or legal impediment to supplying information on how to hasten death to a terminally ill patient with intractable suffering.

The particular problems associated with the power of a physician to influence patient decisions in the clinical relationship have long been recognised (Emanuel & Emanuel, 1992; Szasc & Hollender, 1956). Given this power imbalance, it would generally be regarded as inappropriate for the doctor to initiate discussions on hastening death. A vulnerable patient who is feeling a burden on family and/or professionals could construe this as a directive rather than an invitation to discuss the option. Doctors may recognise this and prefer the issue to be patient driven (Alpers & Lo, 1996). It has been proposed that existing laws prohibiting euthanasia in Australia may discourage doctors from discussing end of life decisions with patients in case these are construed as proposing the intentional ending of life (Kuhse et al., 1997). An approach that relies on patient initiation of euthanasia discussions is in line with protocols controlling euthanasia in the Netherlands (Griffiths et al., 1998).

Anxiety about how the request may be received by the doctor may be an impediment to patient initiation of such a discussion. Approximately 90% of Laypersons judged that supplying information on how to hasten death is illegal or they are unsure of the legality (see Table 7.3 (6), p. 94). Concern about the possible illegality of the action may be perceived by Laypersons as a barrier to initiating discussion. They may be unaware that disclosing and exploring feelings about a desire for hastened death may be welcomed by the physician as a chance to address patient concerns and fears (Chochinov et al., 1995; Emanuel, 1998; Lester, 1996; Muskin, 1998;

Saunders, 1994; Zyllicz & Janssens, 1998). It has been argued that dealing “with death and dying (which includes requests for euthanasia) is an integral part of the practice of medicine” (Hassan, 1996, p. 535).

On the other hand, doctors may be unwilling to discuss the subject, even if the patient broaches it, fearing that such a discussion will be followed by a persistent request for hastened death. If such a request cannot be successfully deconstructed to expose any underlying and reversible motivation for the request such as pain, depression or dependency, the doctor may fear being put in the difficult position of feeling powerless to meet patient need. Similarly a doctor who does identify a pathology that is contributing to such a request but who is unable to address this pathology successfully may feel disempowered if the request for information to hasten death continues but the doctor does not feel able to honour this.

Ambivalence about whether requesting/supplying information is acceptable/legal, may inhibit open communication between doctor and patient on an issue that may need to be addressed and "cleared" to allow for therapeutic interventions that may obviate the perceived need for information on how to hasten death. This is particularly important because information on how to commit suicide successfully is becoming increasingly available on the internet and through books such as “Final Exit” (Humphrey, 1997)²⁵.

It has been said that one of the hallmarks of effective palliative care is open, honest communication between patient and the caring team (Quill, 2000). Receiving a request for information on how to hasten death is a clear signal to doctors that the dying patient's needs may not be being met and that interventions in place need to be reassessed (Chochinov et al., 1995). However, medical training in New Zealand may mirror that of other countries in not routinely preparing doctors for such discussions with their dying patients or with patients who have unbearable chronic diseases.

"Such requests have occurred since antiquity, and physicians today must be able to provide a fully professional response. Tragically, and oddly, physicians do not routinely receive professional training to prepare them to respond to a patient's request for PAS" (Emanuel, 1998, p. 644).

Conversely, it has been suggested that it is not ethical to enter into discussions with patients around hastening death practices if the practitioner has no intention of honouring requests for assistance to die. These authors state that "some patients might be enraged" if they go through

²⁵ Concern has been expressed at the role suicide internet sites play in suicides in several countries. Those contemplating suicide can log onto chat rooms and seek out a suicide partner. David Kerr, director of the pro-regulation Internet Watch Foundation suggests that such sites pose a serious threat to those who are easily influenced (Murphy, 2001)

the process of deconstructing the request only to be told that there was never any intention to comply (Ganzini & Sullivan, 1999, p. 277).

A group of physicians opposed to physician-assisted suicide in Oregon have proposed recommendations that sustain the moral and professional standards of the group including not mentioning suicide as an option to terminally ill patients and not referring on to doctors who will. The group recommends placing a statement of the physician's ethical position in the waiting room as a way of informing patients that assisted suicide is not an option. A criticism of this stance is made from the requirement for openness and honesty in the patient-practitioner relationship. It is argued that inherent in the physician disclosing his or her position, is the premise that the patient should have the same opportunity (Woolfrey & Campbell, 1998). Arguably, knowing the physician's views allows the patient the option of moving on to another doctor. However there may be comfort from discussing the fear of what is to come and the possibility of wanting assistance to die within a long-standing patient-practitioner relationship even if neither party would ultimately take up this option.

Deconstructing the request would incorporate a step by step process during which the doctor and patient can explore alternatives and familiarise themselves with the other's point of view. Such a process would include assessments of patient physical, psychological and emotional situation, cognitive ability to make rational decisions and acceptability to patient of proposed options. Interventions would include palliative care measures appropriate to symptoms and on-going reassessment.

A way of approaching such a process that stops short of supplying information on how to hasten death to the patient has been proposed (Emanuel, 1998). This model restricts responses to the request for assistance to die by proposing a continued deconstruction of the request, and offering palliative alternatives to euthanasia. Their "stopping point" was when they reached "Decline PAS, Explaining Why and Affirming Alternatives" (p. 645).

With the increasing interest in PAS and EU, this approach may no longer be helpful to the patient or practitioner. A decision tree model (see Figure 7.5, p. 106) moves the patient and practitioner through the process of deconstructing the request for information or assistance on how to hasten death. It allows maximum room for the practitioner to move by meeting patient needs and maintaining the preferred personal ethical position for the practitioner. Ultimately assistance to die is not an available option under New Zealand law and the practitioner may decline the persistent request. However, the patient is left with enough information available to them to

pursue their stated wishes even if this is only to know that such information may be accessed with wider investigation. Such an approach seems more flexible than Emanuel's in that it does leave the patient with continued options. Inherent in such an approach is the continued offered support of the practitioner. Those who have proposed guidelines controlling physician-assisted death insist that palliative interventions and alternatives should always be made available, even if the patient pursues options to hasten death (van der Maas et al., 1992).

In determining the steps of the decision tree, the guidelines under which hastening death could be considered in Oregon and The Netherlands and which had underpinned legislation in the Northern Territory of Australia late 1996 until early 1997, were considered. A private member's bill debated and defeated in New Zealand Parliament in August 1995 (NZPD 549, 1995) was also consulted for proposed guidelines for euthanasia practice. There were several points that were common to all sets of guidelines, and these were included in the decision tree (see Figure 7.5, p. 106). If other specific points were regarded as being important, they could be included.

Terminal Illness.

Although this is not a pre-requisite in the Netherlands, (Griffiths et al., 1998, p. 103) it is mentioned in three of the other four countries ("incurable" was also included in New Zealand's Death with Dignity Bill (1995) and could be included under (a) if considered necessary).

Competency.

This was included in the guidelines of each country. The patient is expected to be adult, competent and under no influence from another person or agency.

Comfort.

The issue of patient comfort was evident in every set of guidelines. This centered around palliative care and included physical and psychological comfort.

Enduring Request.

Each country had made provision for assessment that the request was enduring over time. This included mandatory minimum time lapse between request and actioning request from 48 hours (New Zealand), to several days (Northern Territory). The time required to complete the substantive requirements for hastened death in each country would impose an inevitable time lapse between the request and actioning the request.

Other Options.

The requirement to inform about alternative and palliative treatments is a major issue in each set of guidelines. It was not always necessary for the patient to take these up in order to access the euthanasia option.

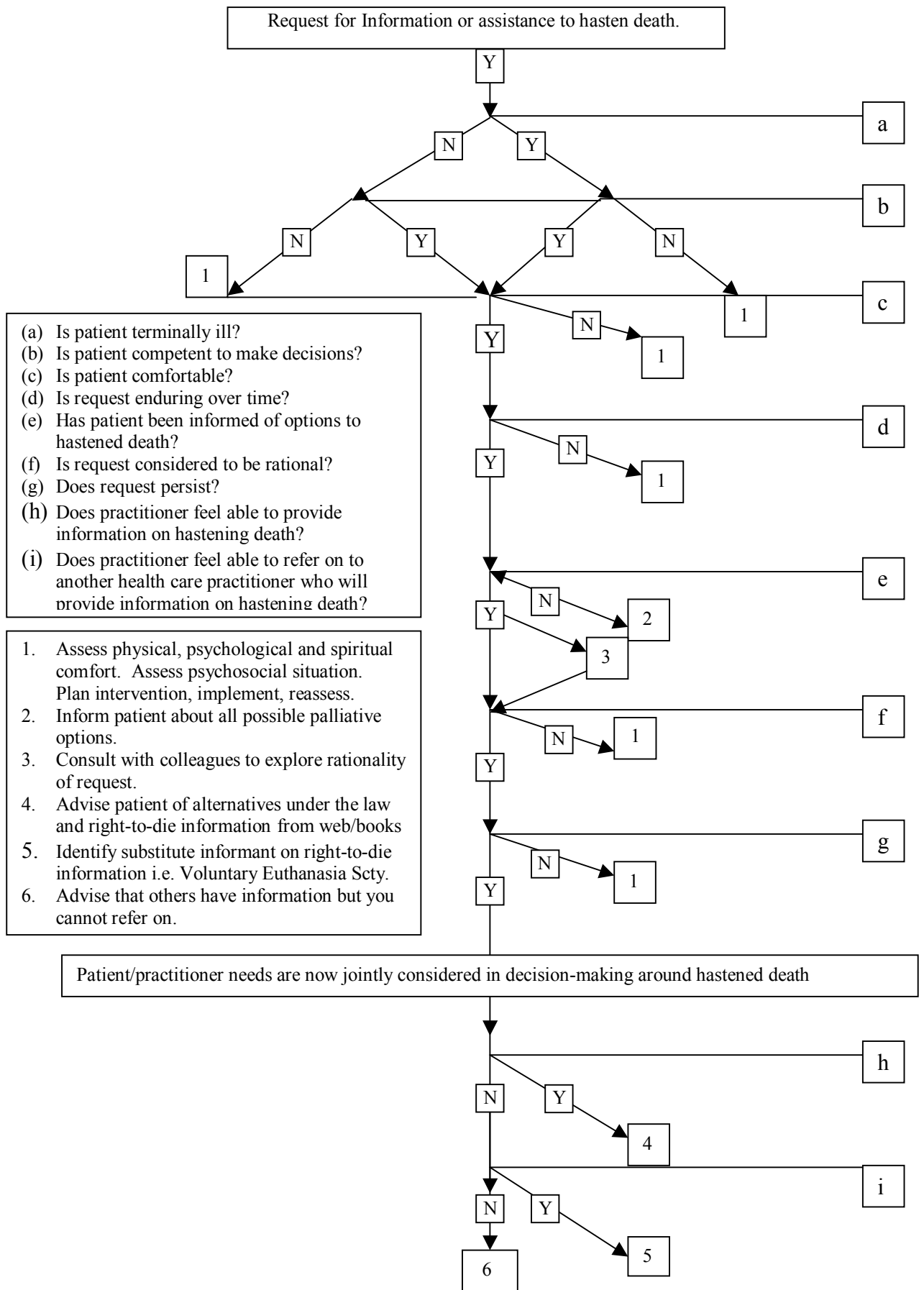


Figure 7.5: Figure showing decision tree approach of physician responding to a request for assisted death.

Rational Choice.

The requirement for psychiatric assessment was included in each set of guidelines to determine patient competency, psychological status (i.e. assess for depression), evidence that decision was well thought through and a rational one.

Over the last decade, studies have shown that a majority of patients with cancer (Emanuel et al., 1996; Suarez-Alamazor, Belzile, & Bruera, 1997; Sullivan et al., 1997), HIV/AIDS (Breitbart, Rosenfeld, & Passik, 1996; Ogden, 1994; Tindall, Forde, Carr, Barker, & Cooper, 1993) and amyotrophic lateral sclerosis (Ganzini et al., 1998) would prefer to have available an option of assistance to die. Concern has been expressed that such requests may not be enduring over time (Chochinov et al., 1995) and guidelines in Oregon specifically address this issue (Oregon Health Division, 1997). Others have found that attitudes to physician-assisted suicide and euthanasia among cancer patients and the general public do endure but that physician attitudes changed over time towards opposing these actions. The authors raised concerns that such discrepancies in attitudes between laypersons and physicians is a potential source of conflict in end of life care (Wolfe, Fairclough, Clarridge, Daniels, & Emanuel, 1999).

In the present study, supplying information on how to end life to a terminally ill patient with intractable pain is considered justified by 80% of Older Laypersons, 65% of Young Laypersons and 50% of Doctors. Considering that over 80% of all respondents recognise that this action is illegal or are unsure of legality this suggests that the current law may not reflect the preferred options of the population in New Zealand (see Table 7.3 (1, 7), p. 94). However it is acknowledged that the respondents may not be representative of the wider population.

Similarly, a doctor providing drugs to end life to a terminally ill patient with intractable pain is regarded as justified by 77% of Older Laypersons, 56% of Young Laypersons and 41% of Doctors. This is despite recognition by over 95% of all respondents that this is either illegal or may be illegal (see Table 7.3 (2, 7), p. 94). This suggests that the law against supplying drugs to a terminally ill person with no hope of recovery may not reflect the opinions of the population on preferred options. Recent research found that 41% of doctors in New Zealand stated that they were in favour of physician-assisted suicide being legalised (McNeill & Schug, 2001 in preparation).

In Oregon it has been noted that supplying information and drugs on how to end life does not necessarily lead to the patient taking action to do so (Oregon Health Division, 2000; Oregon Health Division, 2001a; Oregon Health Division, 2001b). It has been reported that some patients in fact feel a sense of relief and benefit from having control over their death in that they know they have the means to end their suffering if they so wish. Patients often express fear of a future time when they may find their situation unbearable. Having the means of controlling their death may be sufficient to allay some fears and the patient may die without any intervention to hasten death (Quill, 1993; Muskin, 1998).

When involvement in hastening death practice is elevated to the level that the doctor is actively involved in the death by assisting the patient to take drugs it could be expected that respondents may see the action as more problematical, less likely to be legal and therefore less justified.

Doctor assisting a terminally ill patient with intractable pain to take drugs to end life.

The majority of respondents from all groups recognised that the doctor assisting a patient to take drugs to end life is illegal. Despite this, the majority of Laypersons and a third of Doctors judge the action to be justified (see Table 7.4 (3, 9), p. 94).

Older Laypersons judged physician assisting the patient to take drugs and supplying drugs alone as similarly justified, while Doctors judged assisting as less justified than supplying. However, a significant number of Younger Laypersons judged a physician helping a patient to take drugs as more justified than supplying the drugs alone (see Table 7.3 (2, 3), p. 94). One explanation for this result may be respondent belief that the presence and support of the doctor at the time of death is an important and positive factor. A perceived need to have a person in authority (doctor) in control may be linked to this (MacDonald, 1998b). The need for an “authority figure” may be more strongly felt by Young Laypersons given their (probable) decreased experience with the dying situation.

Another explanation is that this is reflective of awareness and concern about lethal drugs being made available in the community that may be used for other than the purpose for which they were intended. This concern may be more acutely felt by Young Laypersons who may be more likely to be exposed to the effects of recreational drug use in the community. Morphine is widely recognised in the community as the drug of choice in treating cancer pain, and has a high street value in illegal drug trafficking.

This latter reasoning is reflective of a concern expressed by the Drug Enforcement Agency (DEA) in the United States. Concern was expressed by the DEA that federally controlled substances should not be available in the community because they could be conscripted into illegal use, specifically for suicide that did not meet the guidelines in place for physician-assisted suicide. In the United States, a private member's Bill, the Pain Relief Promotion Act (Hyde, 1999) was submitted for the purpose of curtailing the use of drugs that could be used for illegal suicide via the 1998 Lethal Drug Abuse Prevention Act. The adoption of the Hyde bill, which is proposed at a federal level, would effectively stop physician-assisted suicide in Oregon. This smacks of artifice in that the bill was proposed by a long time opponent of PAS and was aimed at using federal leverage to overrule the Oregon State legislature²⁶ (O'Keefe & Hogan, 1999; The assisted-suicide ban, 1999). However, the tabling of the Bill had the unusual effect of seeing the Hospice and the Right to Die movements joining forces in the USA to defeat it.

The Hospice movement was concerned that the strong opioids and barbiturates necessary for effective palliation may no longer be available to them. The Right to Die movement have a continued interest in having barbiturates available in the community as this is the preferred drug to hasten death. However, this argument is being further refined by Hospice advocates to separate opioids (as being necessary for palliation) and barbiturates (which do not provide pain relief, only sedation) (Foley, 2000). This attempt by hospice to distance itself from Right to Die advocates could prove untenable since barbiturates are also used in palliative care for terminal sedation when other palliation is not effective.

Assistance of the doctor at the time of death

Assistance of the doctor at the point of death needs to be considered if or when guidelines covering physician-assisted suicide are considered. A review of general surveys on assisted death of the American public over a ten year period revealed a preference for the involvement of the physician at the time the drugs were administered (Caddell & Newton, 1995). Present guidelines used to cover physician-assisted suicide in Oregon state that although the physician may be present when the drugs are taken, the physician is not permitted to be personally involved in administering the drugs to the patient (Oregon Health Division, 1997). This may have tragic consequences as

²⁶ A similar situation occurred with the Northern Territory Rights of the Terminally Ill Act, 1995 (enacted July 1, 1996). A federal ruling overturned the Territorial legislation legalising euthanasia. Those strongly opposed to legalising euthanasia argued that the Northern Territory did not have full statehood and was therefore under the jurisdiction of the Federal Government. This technicality, and strong lobbying by influential Pro-Life advocates including the Church resulted in the Act being overruled by the introduction of the Euthanasia Laws Act, 1997 (Quirk, 1998).

reported in one commentary on the assisted suicides of young AIDS sufferers that happened without a doctor present and willing to intervene (Ogden, 1994).

Policies that exclude doctors from actively involving themselves in the death may not always be workable in practice. There have been no reports of difficulties with patients ingesting drugs successfully to end life since Oregon adopted PAS policies in 1997 and commentary on physician-assisted suicide policies in Oregon suggest that the lack of reporting on "failed" suicide bids that had previously been observed and reported in Holland (Groenewoud et al., 2000), may reflect selective reporting on the part of physician-assisted suicide (PAS) advocates (Nuland, 2000). However, PAS advocates suggest that "botched" attempts have not occurred because of increased knowledge about the correct drugs to use acquired from the Dutch after their experiences and the appropriate dissemination of that knowledge to doctors in Oregon (Rasmussen, 2000). This argument does not hold up however when it is considered that the preferred euthanatic used in Holland is a curare-like drug which is administered intravenously after a sedative to ensure that death is not prolonged (pers com Herb Cohen, Physician, Netherlands). Such physician involvement in the death would escalate the action to euthanasia rather than physician-assisted suicide under the Oregon law and is therefore illegal (Oregon Health Division, 1997).

Having a patient ingest sufficient barbiturates to induce death can result in a wait of up to 38 hours before death finally comes - a period of time that has been described as stressful and frightening by one Oregon family (Smith, 2001). Moves to suggest that the physician should be legally required to be present are criticised on the basis that the family may prefer privacy at this time, although the physician should feel "compelled" to be present if the family request this (Woolfrey & Campbell, 1998, p. 5). It seems obvious that implicit in a request for the physician to be present is the requirement for the physician to facilitate a good dying and to intervene if unfolding events threaten this.

The framing of the Oregon Death with Dignity Act, with its prohibition on active physician involvement is in line with physician preferences (Bachman et al., 1996). It is suggested that the Act may have been formulated to present the least offensive option of limiting active physician involvement, as a way of circumventing physician opposition and getting PAS legalized in Oregon. Such a move may be politically expedient, but is not in line with the preferred options of the public for physician involvement. In the United States, the public show a preference for forms of euthanasia that involve active participation from physicians and suggest "a desire for authoritative control over the procedure of voluntary euthanasia" (MacDonald, 1998b, p. 79). In

the Netherlands, "physician-assisted suicide" and "euthanasia" are both regarded as euthanasia for procedural and legal purposes (Griffiths et al., 1998, p. 79).

Doctor administering a lethal injection to a terminally ill patient with intractable pain.

The present data show there is no evidence that any group judges differently the justifiability of assisting a patient to take drugs or giving a lethal injection. Older Laypersons and Doctors show some evidence of increased confidence in judging Lethal Injection as illegal over Assisting Drugs (see Table 7.3 (8, 9), p. 94). Despite 64% of Older Laypersons recognising the illegality of a Lethal Injection, 76% of them judge this to be justified, a similar response to the other three options for this group.

Over three quarters of Older Laypersons consistently judged all PAS and EU actions as justified. Further, the sub-group of increased age, 70-80 years, is more strongly in favour of these actions (see Table 7.3 (1-4), p. 94). Elsewhere research has suggested that older members of the population may feel under threat by more liberal attitudes towards hastened death in the younger section of society, age being seen as marginalising (Koenig et al., 1996). Given that these results do not support this finding, this suggests that the Older Laypersons in the study may not see increased age per se as marginalising. Alternatively, they may see age as marginalising in relation to accessing adequate end of life care and would therefore prefer the option of assisted death if necessary.

A belief in Autonomy could also be motivating the liberal result from Older Laypersons. The sample was comprised of individuals sufficiently motivated to join Grey Power, a pro-age activist group, situated in a high socio-economic area and predominantly identifying themselves as European. Research into the demographic profile of members of the Hemlock Society, an organisation that promotes assisted dying, show that older, white, wealthy, highly educated, economically and politically active women are prominent in the right to die movement. Such attitudes were related to wider health and social policy concerns (Wilson, Fox, & Kamakahi, 1998). This supports research from Oahu which suggested that increasing age and higher education which the authors suggested were indicative of increased life experience, were indicators of positive attitude towards euthanasia (Littlejohn & Burrows-Johnson, 1996).

Young Laypersons have consistently been more conservative in judging all actions related to hastened death as justified than Older Laypersons, but two thirds judge Lethal Injection to be justified, despite recognising this as illegal (see Table 7.3 (1-4 & 9), p. 94).

With respect to the Doctors' judgments, there was a progression in support from "Lethal Injection" through to "Supply Information". However, it is worth noting that even the hardest option, doctor giving a lethal injection to a terminally ill patient with intractable suffering, was seen as justified by 30% of doctors (see Table 7.3 (4), p. 94). This is in line with research in America which cites 45% of Oncologists judging PAS justified and 22% judging EU justified for intractable pain in a terminal patient (Emanuel et al., 1996). Research in Australia indicates that 28% of medical practitioners in New South Wales have participated in euthanasia and 7% have participated in PAS (Baume & O'Malley, 1994). In Canada, 20-40% of physicians support PAS and EU (Suarez-Alamazor et al., 1997) and in Italy 9-25% of GPs strongly agree that a terminal patient with intractable pain should have assistance to die (Grassi, Magnani, & Ercolani, 1999). The research from Grassi et al. identifies that lack of experience with dying patients and burnout are correlated to positive attitudes to PAS and EU (Grassi et al., 1999). This supports the view that patient need and a perceived inability to meet that need may prove a persuasive factor for doctors when requests for assistance to die are made.

It appears that some New Zealand doctors may be signalling that they are prepared to condone actions covering assisted death to patients who are terminally ill and in intractable pain despite the illegality. Whether this translates to a desire to see the law changed to accommodate this practice has not been explored in this study. However research from Michigan indicates nearly a third of doctors surveyed supported physician-assisted suicide but not a change in the law to accommodate it. Preferences were for the issue to be left to the doctor/patient relationship or for the medical profession to provide regulations and guidelines (Bachman et al., 1996). A similar system existed in the Netherlands until the recent legalisation of PAS and EU in that country.

The Other Ethnicities sub-group of Young Laypersons was significantly less likely to judge Supplying Information and Lethal Injection as justified than the European/Pakeha sub-group (see Figure 7.3, p. 94). Previous research suggests that minority ethnic groups have more conservative views on the justifiability of PAS or EU (MacDonald, 1998a; Singh, 1979) and populations who oppose these practices are viewed as particularly vulnerable to abuse (Koenig et al., 1996). This sub-group is more uncertain over the legality of actions and appear likely to judge these as illegal compared to the European/Pakeha group (see Table 7.3 (6, 9), p. 94). This raises the issue of those in society who are marginalised by recent immigration and/or familiarity with language or social norms. Confusion over what may be acceptable ethical practice could place these people at risk when considering end of life care options. Television and newspaper coverage about end of life decision-making (Daniels, 1998; Editorial, 1999; Family weep at

cancer boy verdict, 2000; Gregory, 1997; Gregory, 2000b; Horwood, 1998; Larkin, 2000; Lewis, 1999; Masters, 1999; For Casey's Sake, 1998) is often emotive and may increase anxiety about what is legal in end of life care. This could prove inhibiting to open disclosure in the doctor/patient relationship. Elsewhere it is acknowledged that those who are marginalised by language can have scant understanding of the complexities of the euthanasia debate (Sanson et al., 1998).²⁷

Ethnicity and Age among Laypersons

There is a greater willingness of the European/Pakeha sub-group of Young Laypersons to tolerate two actions related to hastened death over the Other Ethnicities sub-group (see Table 7.3 (1-4), p. 94). This is in line with research that supports increased tolerance of physician-assisted suicide by those who endorse individualistic values (Kemmelmeier & Burnsten, 1999). The Other Ethnicities group were comprised of collectivist cultures (see Table 5.1, p. 75). However Kemmelmeier & Burnstein also argue that those who identify with collectivism may be likely to endorse euthanasia, citing cultures where such practices have traditionally been tolerated for the greater good of societies with limited resources (Kemmelmeier & Burnsten, 1999).

In this present study, data were not collected on the length of time respondents had been in New Zealand. Auckland University has a strong presence of overseas students who are temporary residents. It may be that the students in the Other Ethnicities sub-group of Young Laypersons are influenced by their collectivist cultural background but this is moderated by other factors (Kemmelmeier & Burnsten, 1999). A clear understanding of how ethnicity affects attitudes to physician-assisted death is not possible here but would benefit from future research, particularly given the multi-cultural make-up of New Zealand society.

The between-group analysis for Young vs Older Layperson shows that the older group are significantly more likely to support all four decisions. Moreover, there is a trend evident that the 70+ years sub-group of Older Laypersons may judge the decisions more liberally than the whole group of Older Laypersons. This strengthens the argument that increased support for medical decisions that intentionally hasten death was associated with increased age.

²⁷ Although the sub-group of Young Laypersons are Auckland University students and may be expected to have a good understanding of the culture and language, this is not necessarily the case. Over 80 countries are represented in the student body. Many recent immigrants who pursue University studies have English as a second language, a fact acknowledged by the Student Learning Centre who provide assistance to students who are experiencing difficulties (pers com Dr Emmanuel Manalo, Director, Student Learning Centre)

Doctor sedating a terminally ill patient with intractable pain.

When pain is intractable in terminal disease and the patient is willing, doctors may sedate a patient maintaining sedation without food and fluids until death occurs. There has been lengthy debate on the ethics of this treatment option with some likening it to "slow euthanasia" (Billings & Block, 1996; Brody, 1996; Cherny & Portenoy, 1994; Dickens, 1996; Fainsinger, 1998; Kenny & Frager, 1996; Mount, 1996; Quill et al., 1997b; Quill et al., 2000). Although undoubtedly some practitioners find it ethically challenging, it remains a palliative care option that is legal in New Zealand today when the practitioner judges this to be the best option for the patient, and the patient agrees to the action.

Almost all Older Laypersons and Doctors judged terminal sedation as justified. In line with their more conservative views, Young Laypersons were less likely to judge the action justified. Of the 65% of Young Laypersons who judged Lethal Injection justified, 19% did not judge Terminal Sedation justified (see Table 7.3 (4, 5), p. 94). These respondents may consider a lethal injection is more justified than terminal sedation in the scenarios presented, possibly responding negatively to the concept of withdrawing nutrition and hydration.

Laypersons were unsure of the legality of Terminal Sedation, with less than half the Older Laypersons and a quarter of Young Laypersons judging this legal (see Table 7.3 (10), p. 94). In comparison, 81% of doctors judged the action to be legal. This leaves 19% of doctors judging the action to be illegal, or being unsure of legality. This seems to be a high number of doctors who may not understand that the option of terminal sedation is available for them to offer to patients when the situation warrants it. Given the suggestion that doctors are more likely to premise decision-making on what they perceive to be legally and ethically acceptable (Status Quo principle, see Chapter 6), patient care could be compromised by lack of information and guidelines on what is legally permissible end of life care. If a physician is not aware that terminal sedation is an available palliative alternative for a patient, a request for assistance to die to escape unbearable pain would present the doctor with a difficult ethical dilemma. This is particularly relevant when it is considered that the majority of Laypersons do not judge terminal sedation as legal (see Table 7.3 (10), p. 94), with 32% of Young Laypersons and 25% of Older Laypersons judging this action to be "Euthanasia". Concern over the legality and ethical status of such an action could prove inhibitive for patients or families who perceive the need for sedation when nutrition and hydration is stopped, but feel constrained from broaching the subject. A doctor who is unsure of the legal status of the action may be unlikely to offer it. The negative

effect of inhibitions on open discussion around end of life decision-making has been previously discussed.

Although research suggests that dying by dehydration need not be painful (Printz, 1992), this research pertains to patients who are at the end stage of their disease when the thirst response becomes depressed. A recent case of a woman in her eighties dying by elective starvation in a New Zealand hospice demonstrated the difficulty of dying this way, without sedation. This patient was not close to death but chose to die rather than endure ongoing painful treatment for invasive cancer. Prior to her admittance she had tried to commit suicide at home following methods described in Derek Humphrey's book, "Final Exit" (Humphrey, 1997). This involved ingesting sleeping pills and pulling a plastic bag over her head as she fell asleep. The suicide failed because she pulled the bag off before achieving her goal. According to patient report, ceasing food intake was not difficult. However, increased confusion secondary to dehydration was unpleasant and unacceptable for the patient, who then took in water to reduce this. She expressed frustration with her attempts to commit suicide by dehydration but hospice staff were reluctant to sedate her, possibly feeling that by doing so they were colluding in her suicide. This has not been the function of hospice who affirm life and traditionally do not condone any form of assisted death. Patient elected death by dehydration may increasingly be an issue being faced by hospice staff.

"Palliative treatment" and "Hospice"

An understanding of the function of palliative treatment and hospice is a requirement in the care of the terminally ill. Although hospices are not available in all areas, wider Auckland is serviced with six hospices that provide services ranging from medical advice and nursing assistance, volunteer assistance with meals and transport and day stay units. Three hospices, St Joseph's Hospice, South Auckland Hospice and North Shore Hospice provide in-patient unit (IPU) services including respite care. All hospice care is provided free to the patient.

Doctors and Older Laypersons have a good understanding of the function of palliative treatment, but the majority of Younger Laypersons are confused about this. This is probably a reflection of inexperience with dying, and the requirement for palliative care. Older Laypersons, because of increased age, would be more likely to have heard the term in relation to the care of aged family members or even for themselves. Similarly, Young Laypersons appear not to be well informed regarding the function of hospice. This highlights the potential for increased vulnerability of this age group.

While Older Laypersons may be familiar with palliative concepts and services, Young Laypersons may require more information on these. Research from Oregon indicates that Laypersons are largely ignorant of options in end of life care. Increased knowledge was associated with being white, having a college education, having experienced the illness or death of a loved one and having been a proxy decision-maker in the past. These authors emphasised the need for education of the public on end of life issues, particularly in a society that has legalised physician-assisted suicide (Silveira et al., 2000).

Some palliative treatments may seem to be aimed at curing the patient, such as radiotherapy or chemotherapy given palliatively for pain, blood transfusions given palliatively for breathlessness and even surgical procedures to relieve discomfort. Similarly, being told that a family member is to receive palliative treatment could be confusing given that some Young Laypersons judge this to be Experimental Treatment (20%) or Alternative Treatment (25%). Careful explanations may be required to correct any misunderstanding that could lead to a false hope that a cure is being sought or may be possible.

Temporary visits to a hospice in-patient unit (IPU) occur when the patient or family requires respite or when the patient needs admission to adjust pain or symptom control. This was the least understood of the hospice functions, with 14% of Doctors, 38% of Older and 49% of Young Laypersons failing to recognise the service. This could be due to an IPU unit not being available in the area in which the Doctor or Laypersons lived. However 91% of doctors identified hospice as a place to go to die which suggests that the concept of an IPU may be there. Some Doctors may not be aware that respite care is a palliative intervention that is available and can contribute to patient and family comfort. Ultimately the majority of people prefer to die in the security of their own homes (Charlton, Dovey, Mizushima, & Ford, 1995). Having respite when needed is a coping strategy which can contribute to a family "staying the distance" when fatigue and grief threaten to undermine the resolve to have a home death. If Laypersons are unaware of this option they cannot ask for respite when this is needed. Being fully aware of services and palliative care options contribute to a sense of control in the dying situation. A sense of control has been identified as contributing to a successful dying (Kastenbaum, 1978) and may reduce the desire for hastened death (Muskin, 1998).

In summary:

- the current law does not reflect the preference of over 56% of Young Laypersons and 76% of Older Laypersons to have information, drugs and physician assistance to die in the case of a

terminal illness with intractable pain. Nor does it reflect the preference of Doctors to supply information (50%), drugs, (41%) and assistance to die (30-34%) to the same patient.

- Supplying drugs to a patient is judged less justified or equally justified by Laypersons to the physician actively assisting suicide (in the vignette the doctor held the cup for the patient) or giving a lethal injection.
- There is evidence of an effect of increasing age on positive attitudes towards all options related to physician-assisted suicide and euthanasia.
- There is evidence that Young European/Pakeha Laypersons have more positive attitudes towards physician-assisted death than Young Laypersons of Other Ethnicity.
- Laypersons were confused over the legality of all PAS and EU options. Doctors were confident in judging the four actions as illegal although only 56% judged Supplying Information as illegal.
- Less than half of Laypersons recognised that terminal sedation is legal and 19% of doctors are unsure of legality or judge the action illegal.
- Terminally sedating a patient in the scenario provided was judged justified by almost all Older Laypersons despite 25% judging it to be “euthanasia”. 32% of Young Laypersons judge terminal sedation to be “euthanasia” which may account for 29% not judging it justified.
- Laypersons are not fully aware of the wider palliative care functions of hospice, and some Doctors may be unaware of respite care as a palliative care option.
- Older Laypersons understand the purpose of palliative treatment but the majority of Young Laypersons do not, a significant percentage judging this to be experimental or alternative treatment.

CHAPTER 8

"Why did I eat? I needn't have eaten. That's a possible way to die, starvation, but I remembered the mayor of Cork who had survived for more than fifty days, wasn't it?" (Potok, 1972, p. 111).

RESULTS: 3

WITHDRAWING/WITHHOLDING LIFE-SUSTAINING TREATMENT

This section explores the effect of the presence of a Living Will on judgments on justifiability and legality of withdrawing Life Support (LS) and withdrawing or withholding nutrition and hydration (N&H). In the previous section some Younger Laypersons appeared to express concern over the prospect of terminal sedation with removal of food and fluids. Of the 62% who judged a lethal injection justified, 19% did not judge it justified to terminally sedate the patient (see Chapter 7). Given that the scenario stated that food and fluids would be removed in the terminal sedation scenario, it was conjectured that these respondents may be expressing concern about this. No such effect was noted with Older Laypersons or Doctors.

The three medical decisions used in this section for the purpose of comparison are examined under two conditions, with a Living will (LW) and with no Living Will (NLW) (see Table 8.1, p. 119).

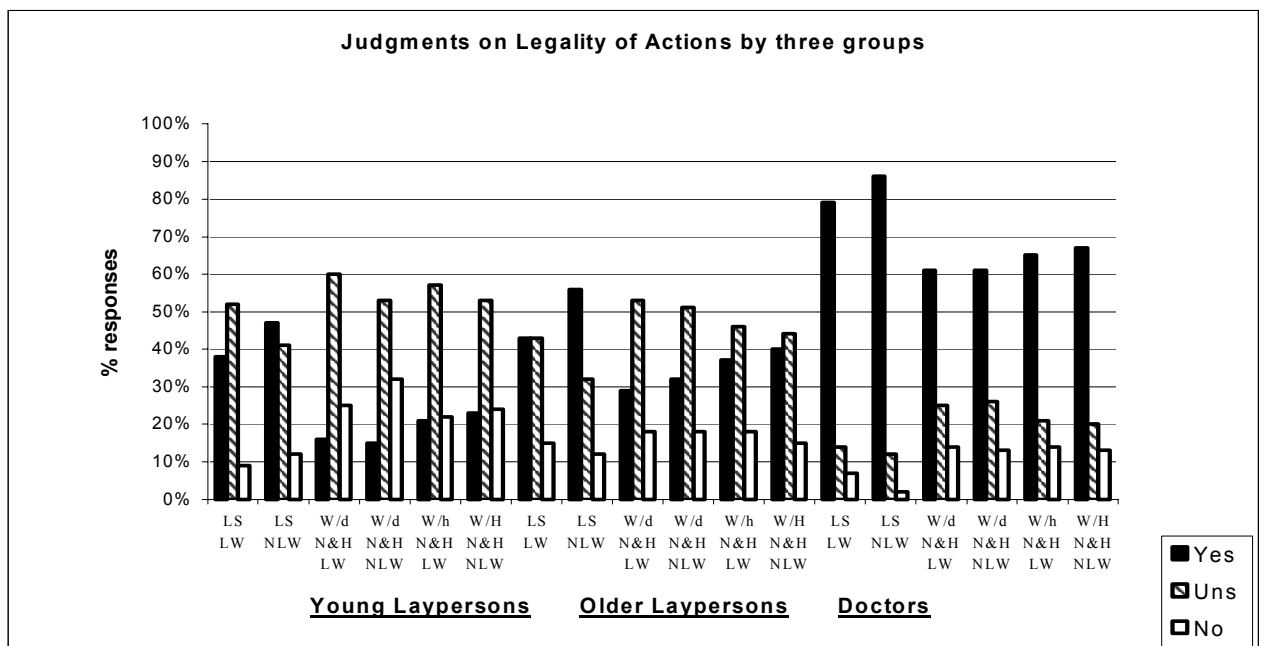
The three actions were arranged according to difficulty of decision-making. Previous research indicated that Laypersons judged withholding food and fluids to be less justified than withdrawing food and fluids (Mitchell, 1995). This runs counter to commentary that there is no ethical difference between the two actions (British Medical Association, 1999a) and indications that withdrawing may be judged more onerous by doctors given that a purposeful action was involved (Micetich, Steinecker, & Thomasma, 1983). Withdrawing N&H was judged to be more serious than withdrawing LS given that some respondents in the previous chapter seem to have responded negatively to starving the patient.

Table 8.1: Table showing three vignettes compared to investigate effect of a Living Will on the decision-making of Young and Older Laypersons and Doctors on justifiability and legality of actions.

<p>Patient A has been admitted to Department of Critical Care at the local hospital following an accident. Unfortunately injuries sustained necessitate the patient being placed on a Life Support System.* <u>Irreversible brain damage</u> is diagnosed, and doctors say <u>the patient will never regain consciousness</u>. After consultation with the family, the doctors switch off Life Support.</p>	
<i>IN YOUR OPINION, is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>If the patient had left a Living Will** stating that all <u>treatment</u> should be stopped in such an event,</p>	
<i>IN YOUR OPINION, would the act be justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>* Mechanical assistance to maintain breathing. ** A document prepared by the patient at a prior time stating preferred treatment in the event of a life-threatening event.</p>	
<p>Patient A commences to breathe independently when Life Support is removed. However brain function loss is such that it is certain the patient will <u>never regain consciousness</u> and will be in life long <u>total dependent care</u>, including being fed by a naso-gastric tube (artificial feeding). Given the patient's condition, a decision is made not to put a feeding tube down the patient but to allow the patient to die. Patient A dies 10 days later.</p>	
<i>IN YOUR OPINION, is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>If the patient had left a Living Will stating all <u>treatment</u> should be stopped in such an event,</p>	
<i>IN YOUR OPINION, would the act be justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>Patient C is unconscious following a stroke, receiving full 24 hour nursing care, and being fed by a nasogastric tube. A scan shows irreversible <u>brain damage</u> and the doctors say there is no hope of the patient regaining consciousness. The family visit daily, but Patient C does not respond to them. A decision is made to <u>withdraw the feeding tube</u> and allow the patient to die.</p>	
<i>IN YOUR OPINION, is this act justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>
<p>If the patient had left a Living Will stating that all <u>treatment</u> should be stopped in such an event,</p>	
<i>IN YOUR OPINION, is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR UNDERSTANDING, is this action legal in New Zealand?</i>	<i>Yes/Unsure/No</i>

There is no evidence that a Living Will affected judgments on the **justification** of withdrawing life support for Young Laypersons ($p = 1.0$), Older Laypersons ($p = .824$) or Doctors ($p = 1.0$) (see Table 8.2 (1), p. 121). The presence of a Living Will affected judgments on the **legality** of withdrawing Life Support for Older Laypersons ($p < .001$) with significantly increased support that the action was legal without a Living Will. A Living Will had no effect on judgments of legality by Young Laypersons ($p = .159$) or Doctors ($p = .009$) (see Table 8.2 (6), p. 121 & Figure 8.1, below).

There is evidence that a Living Will affected judgments on the **justification** of withdrawing N&H for Young Laypersons ($p < .001$). There is no evidence of an effect for Older Laypersons ($p = .006$) or Doctors ($p = .125$) (see Table 8.2 (2), p. 121). There was no evidence of an effect of a Living Will on judgments of **legality** of withdrawing nutrition and hydration for Young Laypersons ($p = .901$), Older Laypersons ($p = .008$) or Doctors ($p = .549$) (see Figure 8.1, below & Table 8.2 (7), p. 121).



Key:

- LS LW = Removing life support from comatose patient with Living Will
- LS NLW = Removing life support from comatose patient with no Living Will
- W/d N&H LW = Withdraw nutrition/hydration from comatose patient Living Will
- W/d N&H NLW = Withdraw nutrition/hydration comatose patient/no Living Will
- W/h N&H LW = Withhold nutrition/hydration from comatose patient Living Will
- W/h N&H NLW = Withhold nutrition/hydration comatose patient/no Living Will

Figure 8.1: Judgments on the legality of withdrawing life support and withdrawing or withholding nutrition and hydration from a permanently comatose patient with and without a Living Will.

Table 8.2: Table showing summary statistics for Young and Older Laypersons and Doctors on judgments on justifiability and legality of actions with and without a living will.

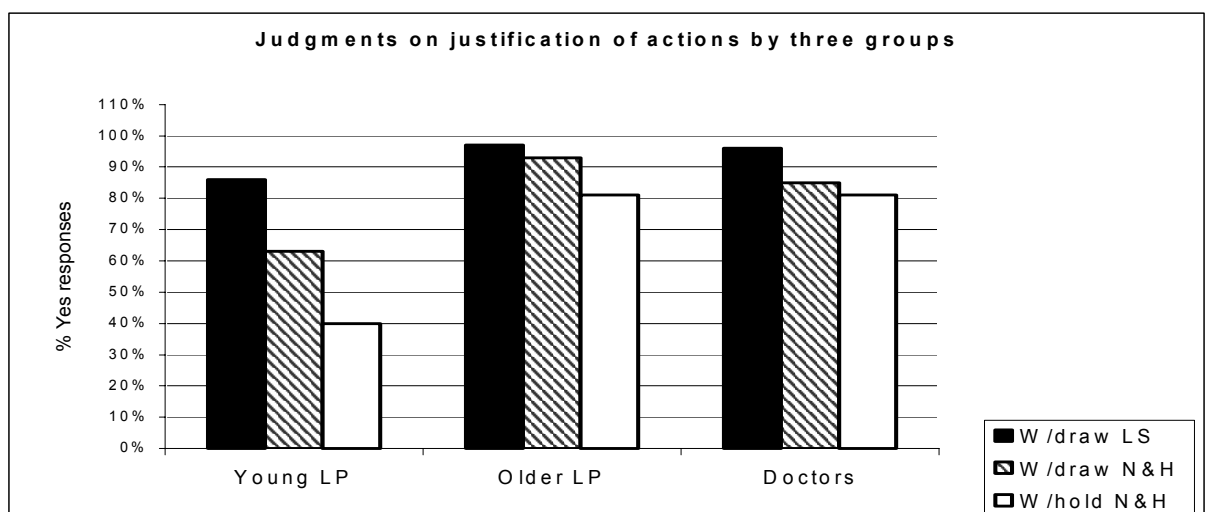
(inserted end)

There is evidence that a Living Will affected judgments on the justification for withholding N&H for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) and Doctors ($p = .004$) (see Table 8.2 (3), p. 121). There was no evidence that a Living Will affected judgments on the legality of withholding N&H for Young Laypersons ($p = .028$) Older Laypersons ($p = .622$) or Doctors ($p = .808$) (see Table 8.2 (8), p. 121).

There was evidence that withdrawing N&H (NLW) was judged less **justified** than withdrawing LS (NLW) for Young Laypersons ($p < .001$), Older Laypersons ($p = .001$) and Doctors ($p = .001$) (see Table 8.2 (4), p. 121; Figure 8.2, below).

There was evidence that withholding N&H (NLW) was judged less **justified** than withdrawing N&H (NLW) by Young Laypersons ($p < .001$) and Older Laypersons ($p < .001$) but no evidence of an effect for Doctors ($p = .388$) (see Table 8.2 (5), p. 121; Figure 8.2, below).

There was a significant difference on judgments on **legality** with no Living Will between withdrawing LS and withdrawing N&H for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) and Doctors ($p < .001$) (see Table 8.2 (9), p. 121). There was a significant difference on judgments on legality between withdrawing N&H and withholding N&H for Young Laypersons ($p = .001$) and Older Laypersons ($p < .001$) but no such difference for Doctors ($p = .178$) (see Table 8.2 (10), p. 121).



Key: W/draw LS = Withdraw life support comatose patient
W/draw N&H = Withdraw nutrition/hydration comatose patient
W/hold N&H = withdraw nutrition/hydration from comatose patient

Figure 8.2: Judgments of justification by Young and Older Laypersons and Doctors of withdrawing life support and withdrawing and withholding nutrition and hydration with no Living Will from a comatose patient with no hope of recovery.

DISCUSSION

Approximately one third of Doctors were unsure of the legality or judged it illegal to withdraw or withhold N&H from a comatose patient with no hope of recovery, with or without a Living Will (see Table 8.2 (7, 8), p. 121). Similarly, less than a quarter of Young Laypersons and 40% of Older Laypersons judged the actions legal with or without a Living Will (see Table 8.2 (7, 8), p. 121). This may reflect the difficulty respondents encountered in decision-making from vignette scenarios that cannot do justice to the complications of real life situations. However, it may also reflect the lack of direction and guidelines available to doctors for such cases.

Fewer doctors (12%) were unsure of the legality of withdrawing Life Support (NLW) (2% judged the action was illegal) (see Table 8.2 (9), p. 121). This suggests that it may be the conditions under which MDELS are usually made, and who is involved in the decision-making that creates confidence in correctly judging whether the action is legal or not. If decisions are being made in a controlled environment i.e. experienced staff, shared decision-making and institutional protocols, knowledge of the legal implications of actions may be more likely to be known.

Place of care impacting on understanding of legality of actions.

Withdrawing life support takes place in Departments of Critical Care that have procedures and guidelines set up for this which may increase confidence in physicians judging this as legal.

Similarly, a team of health professionals would be involved in the decision-making.

Withdrawing or withholding N&H may take place in less formalised surroundings such as nursing homes or even patient's own home. The practice may not be subject to guidelines. Few nursing homes have formalised guidelines for withdrawing nutrition and hydration in New Zealand, dealing with these on a case by case basis. In the case of the patient at home, the doctor may make the decision without professional consultation but with the patient and/or family.

Ambivalence by doctors and family about the legality of stopping food and fluids may increase anxiety surrounding the action and the protracted death that can accompany such an action (Quill & Byock, 2000). This may complicate grieving for the family and be uncomfortable for the doctor.

There is currently no national professional policy available for doctors for withdrawing or withholding nutrition and hydration. The New Zealand Medical Association have released guidelines for Advanced Directives which cover this contingency for people planning their EOL care in advance (Advance Directives, 1995). Draft guidelines have been proposed that cover

withdrawing nutrition and hydration (The withdrawal of food and fluids, 1994) but these have never been formalised. Recently, the British Medical Association published formal guidelines for withdrawing and withholding treatment (British Medical Association, 1999d) following increased pressure from doctors to do so.

"Michael Wilks, Chairman of the BMA medical ethics committee, said that "it was obvious that we were getting increasing reports from doctors who were uncertain on all levels - clinical, legal, and ethical - about the circumstances in which they could withdraw treatment from patients" (Ashraf, 1999, p. 2220)

In New Zealand, the conditions under which withdrawing nutrition and hydration is acceptable for the purpose of Advance Directive planning according to the NZMA (Advance Directives, 1995) could be extrapolated to possible proxy decision-making without an Advance Directive. This is not satisfactory because without formal guidelines the position of the doctor, and patient, will remain insecure.

Effect of being unsure of legality of actions.

If a person is unsure of the legal status of these actions and the doctor recommends such an action for a family member, the layperson may feel inhibited about challenging the legal or ethical status of the action due to the power differential between doctor and layperson. If the family feel unable to openly discuss the circumstances of the dying and the subsequent death this could complicate grieving. It has already been noted that the hallmark of a palliative relationship (which includes the family) is open communication (Dugan, 1987; Kissane, Spruyt, & Aranda, 2000).

On the other hand, if the doctor recognises this dilemma and initiates a discussion on the legality of the action, this may privilege the role of "the law" in the decision for the family rather than "medicine". This may call into question whether this is primarily the most compassionate medical decision for their loved one or one based on medico-legal expediency. Doctors in New Zealand have been challenged on such grounds in the past when family has not agreed with their decisions to withhold treatment (Auckland Healthcare Services Ltd v L & L, 1998; Shortland v Northland Health Ltd, 1997). Such conflicts decrease trust between Laypersons and doctors and make it difficult for families to accept physician recommendations for treatment or non-treatment of patients (Goold et al., 2000). The presence of a Living Will would provide a point of communication between doctor and family and privileges the voice of the patient in the decision-making.

When patients are in a protracted moribund state, family often desire the waiting to be over, and for death to occur. If these feelings are being experienced at the time the decision to remove food and fluids is considered, the guilt felt about wanting the dying to be over (to be differentiated from wanting the patient to be dead) may further confuse families and complicate the decision-making process for them. The presence of a Living Will may assist the family to reassess their feelings in the light of the stated wishes of the patient.

There was an inverse relationship between presence of a Living Will and judgments on the legal status of withdrawing LS. All groups were less likely to judge it legal to withdraw LS in the presence of a Living Will significantly so for Older Laypersons ($p < .001$) (see Table 8.2 (6), p. 121).

Impact of wording in Living Will on decision-making.

The wording in the vignette about "all treatment should be stopped in such an event", may have created difficulties in judging whether the word "treatment" covered life support. Respondents may have questioned, in the light of the voice of the patient being made available in the Living Will, whether their interpretation of what constituted "treatment" reflected what the patient meant by this. This suggests that it is important the wording in Living Wills is unambiguous and reflects the spirit of what the person wants to convey. It is acknowledged that it is impossible to cover every possible contingency that may affect end of life decision-making and it has been argued that advance directives should be submitted for "testing" for validity using psychometric practices (Emanuel, 1994b). Until validated and stable measures of preference instruments are available, it seems that the concept of a Values History (see Appendix C) may be more useful as a tool to access patient wishes than a standardised and more inflexible format.

It is possible for people to write their own Living Wills. Discussing the Living Will with relatives and the doctor at the time of writing will increase understanding by proxies about what was in the mind of the person when they wrote it. It is important that the Living Will is revisited over time and circumstance to ensure that it currently reflects the writer's position on treatment withdrawal (Advance Directives, 1995). Copies should be lodged with the doctor, person who will be the proxy decision-maker, and lawyer.

The Living Will is not a legally binding document in New Zealand. Results here suggest that doctors may be unsure about the legal status of the Living Will in some situations. Moves to establish clear legal guidelines pertaining to advance directives are unclear. The New Zealand Medical Association stated in a report on advance directives in 1995,

"...although there is no local precedent, there is reason to believe that a suitably worded advance directive could be effective in New Zealand law. The NZMA would welcome legislation which removed any remaining doubts, and would give guidance about difficulties which may arise." (Advance Directives, 1995, p. 4).

However, a report submitted a year later warned of the danger of legalising advance directives (for similar reason to those discussed in Chapter 3) and outlined a contrary position.

"This accords with the NZMA view that advanced directives cannot be made legally binding and must be subject to interpretation in the light of the patient's presumed best interests or those of a reasonable person in the patient's position" (Gillett, Bloore & Ngata, 1996, p. 25).

The British Medical Association support that an advance directive has standing in law and suggest that doctors who do not honour such a directive may face legal action.

"A valid advance refusal of treatment has the same legal authority as a contemporaneous refusal and legal action could be taken against a doctor who provides treatment in the face of a valid refusal. (Section 10.3)" (British Medical Association, 1999c)

In the light of seeming conflicting advice from the New Zealand Medical Association, it is not surprising that some doctors may be unsure of the legality of advance directives.

Effect of Existence of Living Will on Judging Action Justified

There was no evidence to support the presence of a Living Will having an effect on the judgments of any group on the **justifiability** of withdrawing LS. This is interesting in the light of a trend suggesting that a Living Will affects judgments on the legality of withdrawing LS. This may add weight to the suggestion that the voice of the patient may be deemed to be the legal authority perhaps over-ruling what is deemed by some respondents to be a justified action. A large majority of all respondents judged withdrawing LS justified with or without a living will.

The presence of a Living Will had an effect on judgments of Young Laypersons on the justifiability of withdrawing and withholding N&H (see Table 8.2 (2, 3), p. 121). The Living Will also affected judgments by Older Laypersons and Doctors on the justification of withholding N&H (see Table 8.2 (3), p. 121). The effect of the patient's wishes known via the Living Will may be deemed to be more relevant to respondents when nutrition and hydration is involved, given that there was no effect for withdrawing life support. This raises the issue of the emotive content of removing food and fluids that will be addressed shortly. All respondents were less likely to judge the scenarios related to nutrition and hydration as legal compared with life support (see Table 8.2 (6 - 8), p. 121).

Medical staff invariably initiate proposing to remove Life Support and this may be reflected in respondent judgments that a Living Will does not affect the justification for withdrawing this²⁸. Similarly, because Life Support is an important health resource, once the decision is taken, it is implemented immediately²⁹. However, removal of food and fluids would not be subject to the same urgency and could be taken weeks or months down the track. Such an extended time frame allows for more input and discussion with wider family, which can create difficulties.

Removing food and fluids would involve discussion with the family and would only be taken when they were satisfied that this action was in the patient's best interests and family members were in agreement. Given the potential for conflict, having a Living Will available to meet this possible eventuality seems to be practical. Researchers have noted that the accuracy of proxy decision-making can be variable (Alpert & Emanuel, 1998; Koenig et al., 1996; Ouslander et al., 1989; Uhlmann et al., 1988). Research indicates that families identified that the presence of an advance directive would have reduced stress when proxy decision-making (Tilden, Tolle, Nelson, Fields, & Tilden, 2001). Patients acknowledge the potential stress of proxy decision-making for close family. Of 17 people living with their spouse, five did not choose the spouse as the proxy when completing an advance directive. The reason given was that “it was not fair to expect them to make these types of decisions; they would be too emotional to be rational and they would not make the decision the participant would have wanted.” (Schiff et al., 2000, p. 1640).

The potential for conflict in removing life sustaining treatment

The case of Hugh Finn, television anchorman, husband and father to two daughters provides a graphic illustration of the discord that can accompany the proposed withdrawal of nutrition and hydration from a patient (see Table 8.3, p. 128). On March 9th 1995, Finn was involved in an automobile accident that left him severely brain damaged. He was subsequently diagnosed by six independent doctors as being in a permanent vegetative state (Palmer, 1998). In June, 1998, after Finn showed no signs of responding to rehabilitation, Finn's wife, Michele informed Finn's parents and siblings that she was invoking her guardianship and having her husband's gastrostomy tube removed. The strongly Roman Catholic family objected, filing a lawsuit against Michele and the resultant acrimony was widely reported in the media for three months

²⁸ It is acknowledged that family would always be consulted when Life Support is to be withdrawn (pers com Dr R. Trubohovich, Department of Critical Care, Auckland Public Hospital).

²⁹ Notwithstanding delays to allow for family members being present or harvesting of organs if the patient is a donor. Even so in New Zealand, support would be withdrawn within days. When there is doubt as to the permanency of the comatose state, a diagnosis of persistent vegetative state can be made if there is no improvement in condition for one year and one day, after which treatment may be withdrawn. This protocol was invoked in the case of Mr L, discussed elsewhere.

Table 8.3: Excerpts from media reporting on the Hugh Finn case showing the polarity of opinion from several sections of society on the withdrawal of nutrition and hydration in this case.

Finn's mother was opposed to her daughter who supported Michele Finn's decision to withdraw the gastrostomy from her husband. When Finn's sister expressed her opinion that he was not going to get better, her mother questioned whether his state was irreversible.

"Are you God? ... I just can't say it's OK, this is it, we'll put you in the grave ... once they put you in the grave there is nothing you can do" (Judge upholds right to die decision, 1998).

Michele's mother, Finn's mother-in-law also questioned what Michele proposed.

"You just can't euthanize the man ... where does it go if we allow this to happen?" (Hopper, 1998).

Members of the Roman Catholic clergy were split in their responses. Archbishop Thomas Kelly of Louisville maintained that,

"The spiritual side of this is that everything inside of Hugh Finn calls for him to be reunited with God. While he remains in this state, it's like suspending that union. If Hugh goes to the Lord, then that's a gift to everyone" (Hopper, 1998).

However The Reverend Daniel Gee, associate pastor of All Saints disagreed.

"...everyone has the right to die naturally ... to remove Finn's feeding tubes would be nothing more than to starve him to death" (Hopper, 1998).

The dilemma posed by removing feeding tubes was expressed by yet another member of the clergy Reverend Philip Keane, medical ethics professor at St. Mary's Seminary in Baltimore. Pointing out that the issue had not been resolved at the National Conference of Catholic Bishops in their 1994 directives, he stated,

"If the matter is not clear, sincere people have to make their mind up the best way they can once they've gathered up all the facts" (Hopper, 1998).

However Reverend Paul de Laudurantaye, secretary of education for the Diocese of Arlington is reported as stating "Mr Finn has not yet reached the point where death is imminent. To withdraw (food and water) now would be homicide, for it is the adoption, by choice, of a proposal to kill him by starvation and dehydration. Such killing can never be morally right and ought never to be permitted" (Paris, 1998).

Demonstrators outside the nursing home where Finn was staying carried banners

"Don't Kill Hugh" and "Let Hugh Live" (Hopper, 1998).

Government officials politicised the case. State representative Delegate Robert B. Marshall maintained that reversing the gastrostomy would be illegal and unethical.

"...it would be against the teachings of the Catholic faith. To me the law doesn't allow it ... he's not on life support. He's not on a respirator. He's not brain dead. To me it is active euthanasia" (Paris, 1998)

When the family finally resolved their differences and all agreed that withdrawing the gastrostomy was in Finn's best interests, Governor James S. Gilmore III of Virginia stepped in and proposed a motion to stop the withdrawal.

Assistant Attorney General William Hurd, acting for the Governor is reported as saying,

"Finn is not dying, any more than a baby who cannot feed himself is dying" (Feeding tube removal upheld, 1998).

However the Virginia Supreme Court rejected the Governor's appeal on October 2. The tube was withdrawn and Hugh Finn died on October 9th (Masters, 1998). The struggle for the family was acknowledged and it was suggested that this situation could be repeated more frequently in the years to come.

"Their private agony has become a pitched battle that has pitted in-laws, sisters, brothers and parents against one another ... (and) underscores the moral and emotional conflicts that roil families whose loved ones are saved - and perhaps cursed - by medical technology that keeps them sitting upright, eyes open, mute, physically alive but mentally and emotionally frozen. ... 'This is nothing compared to how difficult it is going to be in 10 years to make these kinds of decisions', said Dr Ron Cranford, a Minnesota neurologist and expert witness in the Cruzan case. Hugh Finn is completely unconscious. What will happen when we start to see people who are just outside the vegetative state, severely brain-damaged with a little bit of consciousness?" (Palmer, 1998).

(Masters, 1998). It is unclear from reports whether Hugh Finn had written a Living Will. One report stated, "Finn had not left written instructions" (Masters, 1998), while elsewhere it was stated that he had instructed his lawyer to draft a living will stating he would not like to be kept alive in such a condition (Palmer, 1998). Instructions to draft the living will had reportedly come after Finn had reported on similar cases, in particular that of Karen Ann Quinlan and Nancy Cruzan (Paris, 1998) and a "similar case" in Kentucky ('Right to die' subject dies, 1998).

Even allowing for the possible inaccuracy of reporting, it is clear from the Finn case that end of life decision-making can be difficult for families, and others, when the medico-legal interface is blurred, with best medical decisions apparently contradicting ethics and law. The United States is a litigious nation, and such decisions may become more acrimonious. However in Northland, New Zealand the decision to deny a gastrostomy to 81 year old Nancy Witehira, who could not tolerate oral hydration following a series of strokes, was highlighted in the media (Gregory, 2000b). The whanau contacted the news media to publicise her case, reminiscent of a similar occurrence with another Northland family when dialysis was denied to a requesting patient (Gregory, 1997). Mrs Witehira's case was considered by Northland Health and the Health and Disability Commissioner and was quickly resolved with a statement that "any issues surrounding any miscommunications" were resolved (Gregory, 2000b).

The results of the present research demonstrate that the known wishes of the patient via a Living Will did have an affect on respondents when considering withdrawing/withholding food and fluids. The potential for conflict in difficult end of life decisions has been argued and examples given. It is concluded that a Living Will is useful to access the wishes of the patient and to provide a point of discussion when end of life decisions that may hasten death are being considered.

Increasing awareness of advance directives

Given the apparent advantage in having an appropriately worded Living Will on which to base proxy decision-making, any initiative to increase consumer awareness of such a document would be helpful. Positive attitudes by doctors and patients towards advance directives have been reported in past research (Sam & Singer, 1993; Hughes & Singer, 1992). Other research found that young and healthy subgroups were as interested in completing an advance directive as outpatients but lack of physician initiative had been identified as a barrier to completion (Emanuel et al., 1991). However cognisance should be taken of patient preference in death planning. Research on a senior Chinese-Canadian population indicated that advance directives were rejected as a planning option (Bowman & Singer, 2001).

Doctors were more likely than the other two groups to judge all actions as legal in New Zealand today with or without a living will (see Table 8.2 (9, 10), p. 121). Doctors were also the least affected by the presence of a living will. They may be more likely to be aware that a Living Will is open to challenge from the family and other concerned persons.

Doctors are also familiar with end of life decisions and may have greater confidence when making decisions on behalf of others, being less reliant on the presence of a Living Will (which is not to say that a Living Will would be disregarded). This group may feel more confident in making decisions based on known legal and professional standards as practiced in medicine today and known through training or professional or personal experiences. This suggests that such decision-making would privilege Status Quo rather than Personal Autonomy principles when making such decisions and is in line with the proposed decision-making for Doctors discussed in Chapter 6.

Any initiative to increase the profile of and availability of Living Wills, may have to come from quarters other than the medical profession, given that they may not perceive a need for or be as reliant on these to the extent of some laypersons.

MDELS may be more difficult when "starving" the patient is involved

Overall there was statistical evidence of decreasing levels of support for the justifiability of actions with no Living Will in all three groups from withdrawing LS to withdrawing N&H, and with Laypersons, to withholding N&H (see Figure 8.2, p. 122 & Table 8.2 (4, 5), p. 121). Given that all actions would result in the hastened death of the patient this may reflect an emotional response to planned starvation (although this terminology was purposely not used in the vignette). The vignette specifically stated that the patient would take ten days to die. Such protracted dying can be stressful for all involved (McHaffie, Lyon, & Fowlie, 2001; Quill & Byock, 2000) Some respondents expressed concern that “starving” the patient caused suffering.

“Not feeding a person is said to be very painful” (84 year old layperson)

which suggests that such issues may be discussed among laypersons with possibly distressing anecdotes affecting consumer attitudes (Goold et al., 2000)

Greater reluctance by Doctors to withdraw N&H than life support (see Table 8.2 (4), p. 121), suggests that doctors may have a similar emotional response to starving the patient. However, Doctors judged withdrawing and withholding N&H (NLW) as similarly justified, unlike both groups of Laypersons (see Table 8.2 (5), p. 121). Research suggests that the majority of US health professionals agree there is no ethical difference between withdrawing and withholding life-sustaining treatment (Dickenson, 2000) although interestingly commentators suggest it is easier in practice to withhold rather than withdraw treatment (Winter & Cohen, 1999). It is argued that this

may be due to the psychological "bonding" that takes place between patient and practitioner when something is "done" (Micetich et al., 1983, p. 977). This is supported in research of young and older laypersons in the USA who attributed greater culpability when treatments are withdrawn rather than withheld. Withholding treatment was judged to be conventional while withdrawing treatment was seen as highly unconventional and suicidal and associated with greater staff responsibility (Wellman & Sugarman, 1999). Although these findings are the opposite of present findings, weight is lent to the argument that withdrawing and withholding treatment are viewed as different by laypersons in contrast to the views of physicians.

Guidelines for withdrawing or withholding nutrition and hydration from a comatose patient with no hope of recovery are available in a report to the Medical Council of New Zealand, (Campbell, 1993 as cited in Henneveld, 1994). In part, this states that nutrition and hydration may be withdrawn if the diagnosis is certain, if family agrees and if the action is in accordance with patient wishes. As previously stated, the New Zealand Medical Association (NZMA) has released guidelines for advanced directives which cover withholding nutrition and hydration for people planning their EOL care in advance (Advance Directives, 1995). The conditions under which this is legally acceptable for the purpose of advance directive planning could be extrapolated to possible proxy decision-making without an advance directive. However, only approximately 50% of New Zealand general practitioners belong to the NZMA (pers com Shani Naylor, NZMA, November 2001) so such recommendations may not be available to many practitioners. These physicians appear to be left to their own best judgment in such matters

Similarity in physician judgments between withdrawing and withholding N&H (see Table 8.2 (5), p. 121) is possibly due to the physicians' professional judgment that putting a feeding tube down will not benefit the patient. However it is interesting to note that the presence of a living will significantly increased doctors' judgments that withholding N&H was justified. This effect was not present in withdrawing N&H. The increased difficulty of decision-making in withholding nutrition may be related to the immediacy of the decision-making – when *withdrawing* a feeding tube the decision can be taken at leisure after wide consultation. This suggests in part that doctors may find the presence of a living will helpful and influential when making decisions at the end of life that may be deemed to be more difficult. This result is supported by previous research which indicates that when advance directives are in accord with accepted medical practice, doctors find them helpful with more difficult decisions (Waddell et al., 1997).

Greater reluctance by both groups of Laypersons to withholding N&H over withdrawing N&H (see Table 8.2 (5), p. 121), may reflect the need to give the patient a chance to recover if they will by providing nourishment. It could also reflect a need to give the family time to adjust to the patient's

inevitable death. This seems counter intuitive because the withdrawal of a feeding tube involves a purposeful action that would hasten the death of the patient (if they don't die of a pre-morbidity) while withholding the tube is a passive action (although the result will be the same) (Micetich et al., 1983). A study of elderly patients' preferences for therapy indicated that a majority would prefer short-term ventilation (88%) or tube feeding (65%, $n = 287$) if there was a chance of recovery and less than 5% would want interventions if there was not (Murphy & Santilli, 1998). Some laypersons in this study may have less confidence that there would be no chance for the patient and preferred aggressive therapy (see Prologue). Doctors may not be aware laypersons may perceive a need for time to adjust to the patient's imminent (or actual brain) death, or that laypersons may need to feel they have given the patient a chance to recover if they will by putting a tube down, and therefore judged the actions equally.

Alternatively, judging withholding as less justified than withdrawing N&H could be motivated by judgments of legality of actions. There was evidence that Young and Older Laypersons judged withholding N&H as less likely to be legal than withdrawing N&H (see Table 8.2 (10), p. 121). Doctors judged the legality of the two actions similarly, in line with their judgments that the actions were similarly justified (see Table 8.2 (5, 10), p. 121), possible reasons for which have been previously discussed.

Young Laypersons are significantly less likely to judge withdrawing and withholding N&H as justified than Older Laypersons. This is further evidence that this age group may find proxy decision-making difficult. Older Laypersons judge the decisions similarly to Doctors suggesting experience may play an important role in seeing the actions as justified (see Figure 8.2, p. 122).

To summarize.

The presence of a Living will did not affect decision-making of any Groups when judging the justifiability of withdrawing Life Support, and withdrawing Life Support was judged to be more justified than withdrawing or withholding N&H by all groups for vignettes given.

The presence of a Living Will increased judgments of Young Laypersons that withdrawing N&H was justified and increased the confidence of all groups that withholding N&H was justified.

Withholding N&H (NLW) was judged to be less justified than withdrawing N&H (NLW) by Laypersons but not by Doctors.

There was some evidence that the presence of a Living Will may *decrease* confidence in the legality of withdrawing Life Support which may reflect (a) ambivalence over the legal status of a

Living Will and/or (b) concern that the wording in the Living Will may not be reflective of the action proposed (and therefore, patient wishes).

The majority of Laypersons were confused over the legality of withdrawing LS and withdrawing and withholding N&H in the scenarios provided.

A third of doctors were unsure of legality of, or judge it to be illegal to withdraw or withholding N&H from a comatose patient with no hope of recovery. This is an option available to patients that can be instructed in a Living Will to cover instances such as those that are outlined in the vignettes.

CHAPTER 9

RESULTS: 4

AGE OF PATIENT & CONSENT IN DECISION-MAKING

The issue of differences of age of patient affecting end of life decision-making was investigated. The effect of age of patient on a proposal to switch off life support was explored in the event of severe, irreversible, permanent brain damage of a comatose adult and an extensively brain damaged baby with multiple organ malformation and limited prognosis (see Table 9.1, p. 135).

A further comparison examined the effect of age of patient on a proposal to withhold nutrition and hydration from the same two patients, after life support is withdrawn and breathing continues independently (see Table 9.1, p. 135).

The issue of age of patient and effect of consent/non-consent on decision-making was investigated by examining judgments on the decision to increase pain medication knowing that death may be hastened as a result, the principle of double effect. Four scenarios were compared.

The first two scenarios examined the effect of consent/non-consent on treatment decision-making for a terminally ill adult. The second two scenarios examined the effect of consent/non-consent on the decision-making for a terminally ill child (see Table 9.2, p. 136).

Table 9.1: Table showing vignettes compared to investigate effect of age of patient on the decision-making of Laypersons and Doctors on justifiability and legality of withholding nutrition and hydration.

<p>Patient A has been admitted to Department of Critical Care at the local hospital following an accident. Unfortunately injuries sustained necessitate the patient being placed on a Life Support System. Irreversible brain damage is diagnosed, and doctors say the patient will never regain consciousness. After consultation with the family, the doctors switch off Life Support.</p> <p><i>IN YOUR OPINION is this action justified?</i></p> <p><i>IN YOUR OPINION is this action legal?</i></p>	<p><i>Yes/No</i></p> <p><i>Yes/Unsure/No</i></p>
<p>After consultation with the family, the doctors switch off Life Support but the patient continues to breathe independently. Given the patient's condition, a decision is made not to put a feeding tube down the patient, but to allow the patient to die.</p> <p><i>IN YOUR OPINION is this action justified?</i></p> <p><i>IN YOUR OPINION is this action legal?</i></p>	<p><i>Yes/No</i></p> <p><i>Yes/Unsure/No</i></p>
<p>Baby G is born with malformation in many organs, including extensive brain damage. The baby's condition suggests mechanical assistance is necessary for survival and the baby is placed on life support. After full investigations, it becomes clear that there is nothing doctors can do to save Baby G, and they propose switching off life support.</p> <p><i>IN YOUR OPINION is this action justified?</i></p> <p><i>IN YOUR OPINION is this action legal?</i></p>	<p><i>Yes/No</i></p> <p><i>Yes/Unsure/No</i></p>
<p>Baby G continues to breathe when life support is switched off but is not expected to live for more than a few days and the decision is made not to commence feeding.</p> <p><i>IN YOUR OPINION is this action justified?</i></p> <p><i>IN YOUR OPINION is this action legal?</i></p>	<p><i>Yes/No</i></p> <p><i>Yes/Unsure/No</i></p>

Table 9.2: Table showing vignettes compared to investigate effect of age of patient and consent on the decision-making of Laypersons and Doctors on justifiability and legality of actions.

<p>Patient E has a terminal disease which has reached the end stage. Unfortunately, pain is a problem, and the doctor has had to increase medication to keep pain controlled. The doctor explains to Patient E that the large doses of medication being administered could hasten the end of the patient's life. <u>At the patient's request</u> the doctor administers sufficient drugs to maintain comfort, despite the effect of hastening death.</p>	
<i>IN YOUR OPINION is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR OPINION is this action legal?</i>	<i>Yes/Unsure/No</i>
<p>In a similar case to Patient E, the doctor increases the drugs to control pain, knowing that hastened death could result, without discussing this with the patient or family, first.</p>	
<i>IN YOUR OPINION is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR OPINION is this action legal?</i>	<i>Yes/Unsure/No</i>
<p>Toddler H is diagnosed with cancer and undergoes treatment. The treatment is unsuccessful and Toddler H is dying. Believing Toddler H to be in pain, despite receiving pain relieving drugs, the parents ask the doctor to increase the drug dose, even though they know that doing so may hasten the toddler's death. The doctor agrees to increase the drugs to relieve pain despite the effect of hastening death.</p>	
<i>IN YOUR OPINION is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR OPINION is this action legal?</i>	<i>Yes/Unsure/No</i>
<p>In a similar case to Toddler H, the doctor administers increased drugs to ease the toddler's pain, which results in hastening death. In this case, the doctor does so <u>without the stated wishes of the parents.</u></p>	
<i>IN YOUR OPINION is this action justified?</i>	<i>Yes/No</i>
<i>IN YOUR OPINION is this action legal?</i>	<i>Yes/Unsure/No</i>

Comparisons were done to test effect of

- age of patient on judgments that withdrawing life support or withholding N&H was justified and legal.
- age of patient and consent on judgments that increasing pain medication at the risk of hastening death was justified and legal.
- judgments on justification of withdrawing life support or withholding nutrition and hydration for baby

There was no evidence of age of patient affecting the judgments of any group on the justifiability or legality of withdrawing LS (see Table 9.3 (1), p. 138). There was no evidence of age of patient affecting the judgments of any group on the justifiability of withholding N&H (see Table 9.3 (2), p. 138) however age of patient had a significant effect on Young Laypersons in judgments on legality with respondents increasingly unsure for the baby (see Table 9.3 (8), p. 138). There was no such effect for Older Laypersons or Doctors.

Consent had a significant impact on judging it **justified** to increase drugs that may hasten death for an adult for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) and Doctors ($p < .001$) and for a child for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) and Doctors ($p < .001$) (see Table 9.3 (4, 5), p. 138 & Figure 9.1, p. 139).

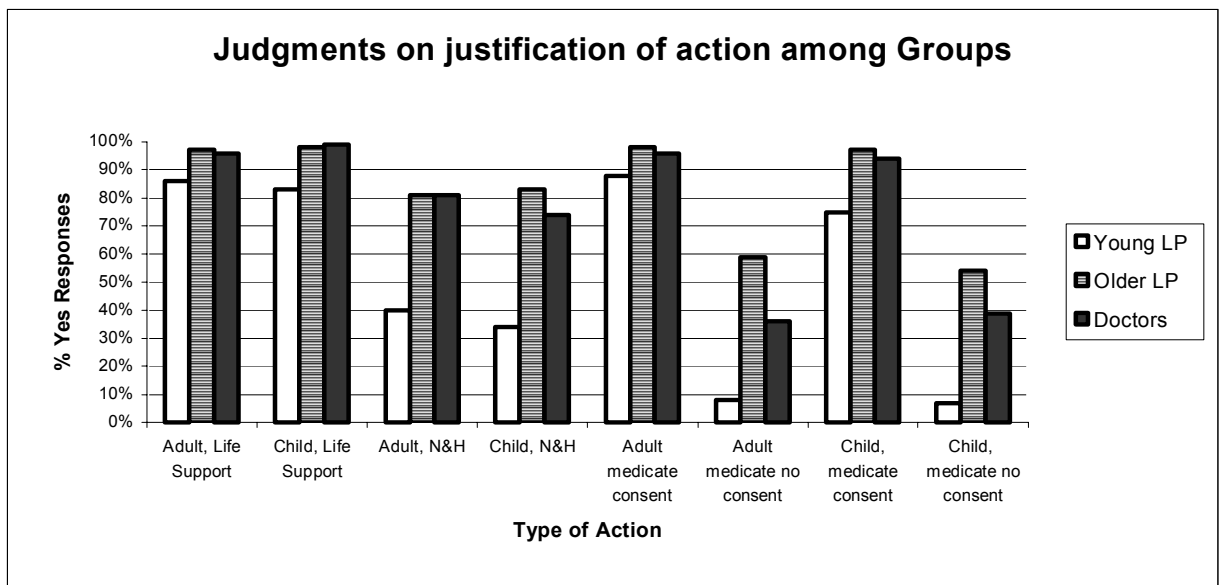
Consent had a significant impact on judging it **legal** to increase drugs that may hasten death for an adult for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) and Doctors ($p < .001$) and for a child for Young Laypersons ($p < .001$), Older Laypersons ($p < .001$) and Doctors ($p < .001$) (see Table 9.3 (10, 11), p. 138 & Figures 9.2 & 9.3, p. 140 & 9.4, p. 141).

Age of patient had a significant effect in judging it **justified** to increase pain relieving medication on request at the risk of hastening death for Young Laypersons ($p = .002$) with less support for medicating the child. Of the 87% of Young Laypersons who thought it justified to increase medication for the adult with consent, 21% changed their minds (18% of sample) and said it was not justified to do the same for the child, with parental consent. There was no significant effect of age of patient on the decision-making for Older Laypersons or Doctors (see Table 9.3 (3), p. 138 & Figure 9.1, p. 139).

Table 9.3: Table showing summary statistics for Young and Older Laypersons and Doctors on judgments on justifiability and legality of end of life actions as a function of consent and age of patient

(inserted end)

There is evidence that age of patient affects judgments on **legality** of increasing medication at the risk of hastening death with consent for Young Laypersons ($p < .001$) and Older Laypersons ($p < .001$) with respondents less sure of legality in the case of the baby. There was no evidence of an effect with Doctors (see Table 9.3 (9) p. 138; Figures 9.2 & 9.3, p. 140 & 9.4, p. 141).



Key: Adult Life Support = Withdrawing life support from adult
 Child Life Support = Withdrawing life support from child
 Adult N&H = Withholding nutrition & hydration from adult
 Child N&H = Withholding nutrition & hydration from child
 Adult medicate consent = Increase medication risk hastening death adult/consent
 Adult medicate no consent = Increase medication risk hastening death adult/no consent
 Child medicate consent = Increase medication risk hastening death child/parental consent
 Child medicate no consent = Increase medication the hastening death child/no parental consent

Figure 9.1: Comparisons for Laypersons and Doctors between judging it justified to withdraw life support, withhold nutrition & hydration and increase pain relief with or without consent at the risk of hastening death for an adult or child.

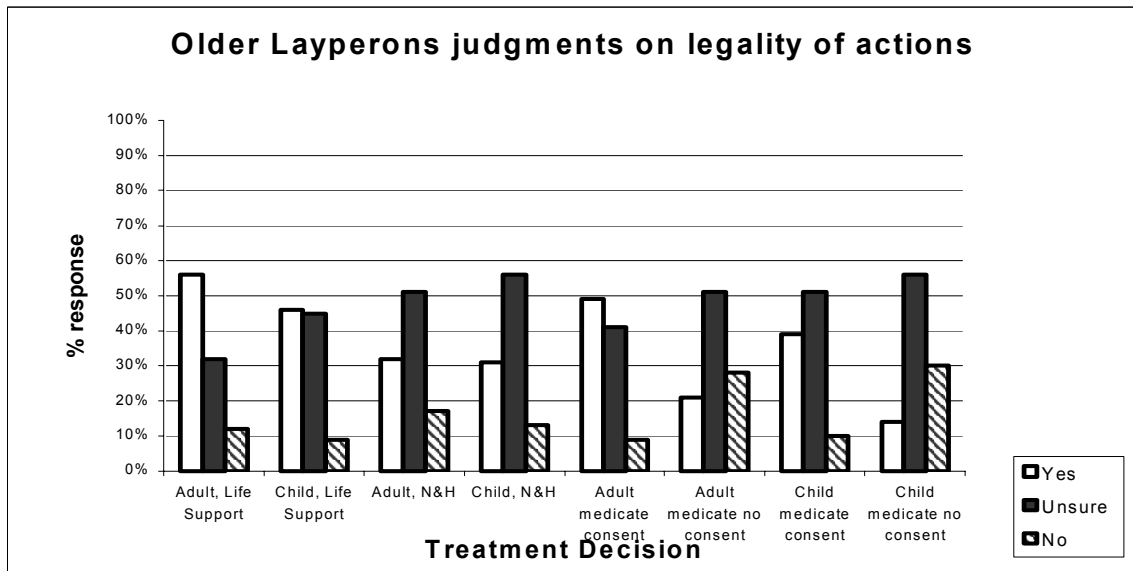


Figure 9.2: Responses of Young Laypersons on judging legality of withdrawing life support, withholding nutrition and hydration and increasing medication at the risk of hastening death for an adult and baby

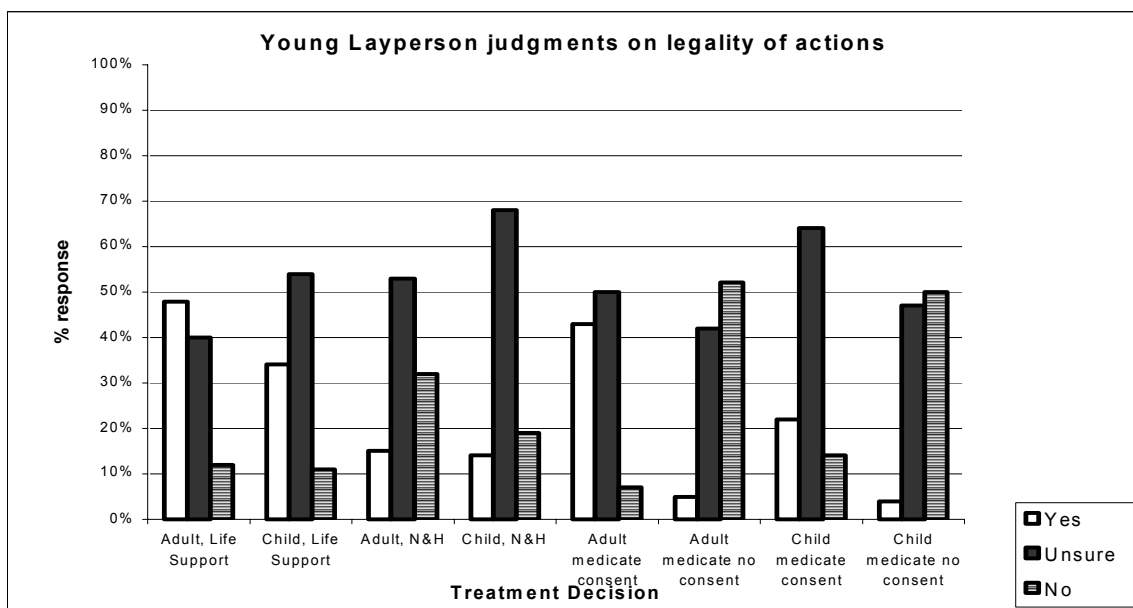


Figure 9.3: Responses of Older Laypersons on judging the legality of withdrawing life support, withholding nutrition and hydration and increasing medication at the risk of hastening death for an adult and a baby.

Key: (Figure 9.2 & 9.3)

Adult Life Support = Withdrawing life support from adult

Child Life Support = Withdrawing life support from child

Adult N&H = Withholding nutrition & hydration from adult

Child N&H = Withholding nutrition & hydration from child

Adult medicate/consent = Increase medication risk hastening death for adult, consent

Adult medicate/no consent = Increase medication risk hastening death adult, no consent

Child medicate/consent = Increase medication risk hastening death child/parental consent

Child medicate/no consent = Increase medication risk hastening death child/no parental consent

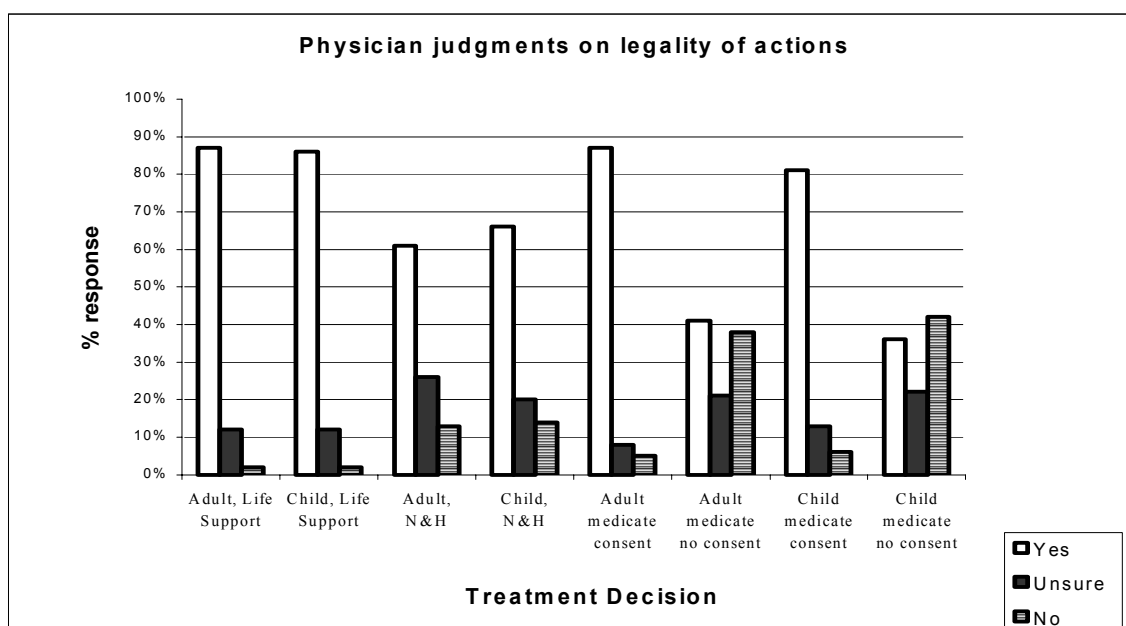


Figure 9.4: Responses of Doctors on judging the legality of withdrawing life support, withholding nutrition and hydration and increasing medication at the risk of hastening death for an adult and baby.

Key: Adult Life Support = Withdrawing life support from adult
 Child Life Support = Withdrawing life support from child
 Adult N&H = Withholding nutrition & hydration from adult
 Child N&H = Withholding nutrition & hydration from child
 Adult medicate consent = Increase medication risk hastening death adult/consent
 Adult medicate no consent = Increase medication risk hastening death adult/no consent
 Child medicate consent = Increase medication risk hastening death child/parental consent
 Child medicate no consent = Increase medication risk hastening death child/no parental consent

A McNemar test was done to see if the 21% change from adult to child for Young Laypersons was a function of ethnicity. The group was divided into two groups, European/Pakeha (EP) and Other Ethnicities Combined (OEC).

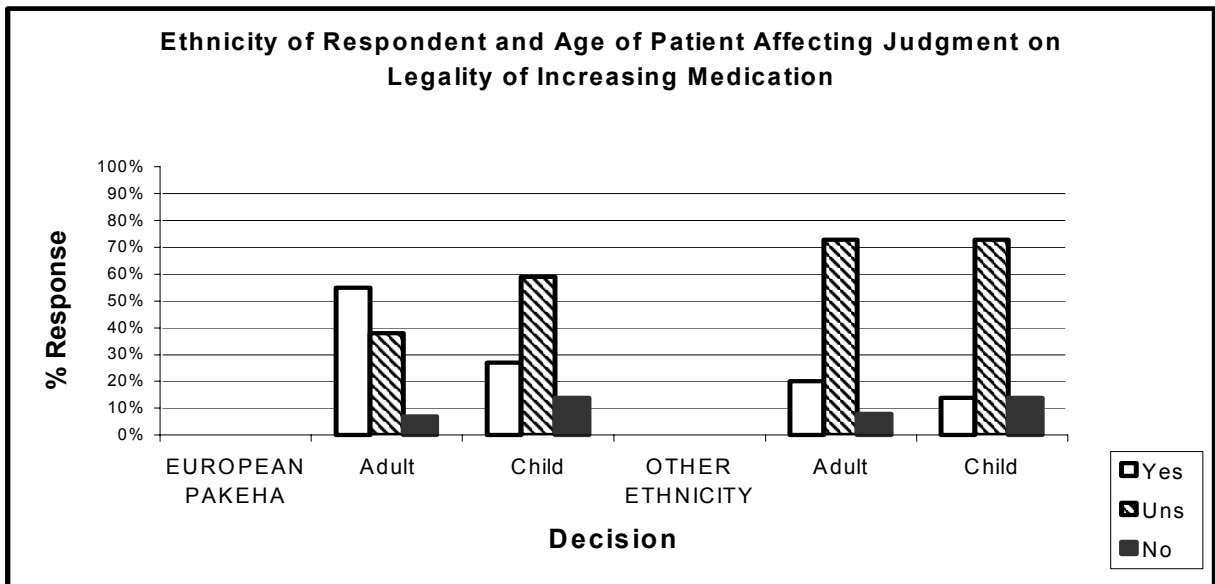
There is an effect of age of patient on judgments of the EP group ($n = 134, p < .001, \chi^2 = 14.700, df 1$) (see Table 9.4, p. 142). Of the 94% of EP/Young Laypersons who judged it justified to increase pain relief for an adult who requests it at the risk of hastening death, 20% judged it not justified to do the same for a child when parents request it. There is no evidence that age of patient affected judgments of the OEC/Young Laypersons ($n = 67, p = 1.00, df 1$).

Table 9.4: Table showing effect of ethnicity of Young Layperson respondent on judging it justified to increase pain relief for a child or adult knowing that death could be hastened.

<u>IS INCREASING PAIN RELIEVING DRUGS JUSTIFIED FOR A TERMINALLY ILL CHILD OR A TERMINALLY ILL ADULT ON REQUEST, KNOWING THAT DEATH COULD BE HASTENED?</u>					
<u>European/Pakeha (n = 134)</u>			<u>Other Ethnicities Combined (n = 68)</u>		
Adult	Child		Adult	Child	
	Yes	No		Yes	No
Yes	75%	19%	Yes	57%	15%
No	3%	2%	No	13%	15%

Ethnicity of Younger Laypersons affected judgments that age of patient affects **justifiability** of increasing medication with consent at the risk of hastening death. A marginal homogeneity test was done to test for differences in judgments on **legality** of this action for EP Young Laypersons and OEC Young Laypersons. There was evidence that age of patient affected judgments on **legality** for the EP group ($n = 135, z = 5.196, p < .001, df 4$) with more support that medicating the adult was legal. There was no evidence of an effect with the OEC group ($n = 68, z = 1.633, p = .102, df 4$) with respondents equally unsure of the legality of medicating both adult and child (see Figure 9.5, p. 143).

This suggests that judging the action to be illegal may be implicated in the finding that 21% of the European/Pakeha sub-group judged it less justified to medicate the baby (see Table 9.4, above).



Key:
 European Pakeha = European-Pakeha Young Laypersons
 Other Ethnicity = Other Ethnicities Combined Young Laypersons

Figure 9.5: Effect of ethnicity of Young Layperson on judgments of legality of increasing pain relief for a child or adult knowing that death could be hastened, with consent

There was strong evidence that withholding N&H from a baby was judged as less **justified** than withdrawing LS by Young Laypersons ($p = <.001$), Older Laypersons ($p = <.001$) and Doctors ($p = <.001$) (see Table 9.3 (6), p. 138 & Figure 9.1, p. 139). The strongest effect was reported by Young Laypersons with only 34% judging it justified to withdraw nutrition and hydration from the baby (see Table 9.3 (6), p. 138). This is in line with their more conservative judgments in previous chapters.

Previous findings that withholding nutrition and hydration is judged as less justified than withdrawing life support (see Chapter 8) remains robust in the case of decision-making for a baby.

DISCUSSION

Legality of withdrawing life support or nutrition and hydration

Both groups of Laypersons were confused over the legality of both actions for adult and baby (see Figures 9.2 & 9.3, p. 140 (see discussion on legality of withdrawing N&H from an adult in Chapter 8).

Confidence in the legality of decision-making for the baby may be affected by media publicity about consent of parents being over-ruled by doctors via the courts. In one report Elaine McCall, Starship³⁰ clinical nurse educator, was quoted as saying that although the parents had the final call on whether life support should be removed from their child, “health professionals could challenge a parent’s decision on the grounds of what was best for the patient” (Young, 1997b). Later the same year, another report under a “Health in Crisis” byline stated that the “Starship children’s hospital considered fighting for custody of a gravely ill patient so it could stop treatment against the parents’ wishes” (Young, 1997a).

Eighteen months later, a former patient right's advocate at National Women's Hospital³¹ was critical that the hospital's intensive care unit had problems with informed consent, the unit remaining isolated from the Cartwright inquiry³² (Johnston, 1999). However Dr David Knight, clinical director of newborn services at the hospital defended hospital policy that did not require consent for ventilatory support or admission to intensive care. He stated that the best approach was one that talked with parents "about the baby or the baby's condition *rather than the treatment that's necessary*. I think parents want to talk about their baby rather than be weighed down with the technique" (Johnston, 1999) (italiacs added).

A report into chest tapping procedures for newborns at National Women’s Hospital in 1999 confirmed that informed consent was a problem at the hospital in that parents were "not asked to consent to many of the procedures their babies are subjected to" (Williams, 1999). This parallels reporting of similar cases in Britain with one writer stating,

"We do not lightly criticise the medical profession. Most of us are still happy to trust our doctors. But this state of affairs will continue only if the profession embraces a sort of medical glasnost. Openness could turn out to be the most valuable clinical experiment of all" (Independent London, 1999).

Because these experts are quoted in the popular press, this may render more problematic for Laypersons, the question of legality and who is ultimately responsible for some MDELs.

Doctors were confident in judging withdrawing life support and withholding nutrition as legal for adult and child although this confidence decreased for withholding nutrition and hydration with approximately one third of Doctors confused over the legality of this action for adult and child (see Figure 9.4, p. 141).

³⁰ Starship Children’s Hospital is a purpose-built hospital for children located in Auckland, New Zealand.

³¹ National Women’s Hospital is a base hospital provider of obstetric and gynecological services in Auckland.

³² The Cartwright Enquiry was convened after National Women's Hospital was involved in allegations of improper treatment of patients with carcinoma in situ for a period until 1988. One of the main outcomes was a commitment to informed patient consent for all procedures (Committee of Inquiry (into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters) & Dame Silvia R Cartwright, 1988).

Judging withdrawing life support and withholding nutrition and hydration as justified

There was no evidence that the age of the patient affected judgments on the justifiability of withdrawing life support or withholding nutrition and hydration, by Laypersons or Doctors (see Table 9.3 (1, 2), p. 138). A large majority of respondents in each group judged withdrawing life support as justified for both the adult and the baby. Previous findings that this is the least problematic option for an adult (Chapter 8) remain robust in the case of the baby.

Similarly, withholding N&H is judged to be less justified than withdrawing life support for both patients, by all groups (see Table 9.3 (6), p. 138). Overall, Young Laypersons continue to be more conservative than the other two groups in their judgments that any decision that hastens death is justified (see Figure 9.1, p. 139).

Given that the death of the baby is inevitable in either the life support scenario or the nutrition and hydration scenario, respondents may be responding emotionally to withholding food and fluids. Several respondents expressed concern about the pain of withholding nutrition and hydration, "too painful, not feeding", "dehydration is a slow painful death", "not feeding a person is said to be a slow and painful death". One doctor expressed concern for the baby. Although he judged it justified to withdraw life support, he did not judge it justified to withhold nutrition and hydration stating,

"(m)ay as well not have the babe hungry as well, if they are sure to die regardless in a few days" (NZ GP)

the implication being that withholding food and fluids would be distressing for the child.

This suggests that a decision to withholding feeding from a neonate could be more distressing for parents and staff than the decision to withdraw ventilatory support. Withdrawing ventilatory support could (and could be expected to) potentially initiate instant death. An instant death may be deemed to be kinder than the potentially drawn out death that can occur with withholding food and fluids. The effect of a drawn out death after nutrition and hydration are discontinued has previously been discussed.

Consent and increasing pain medication at the risk of hastening death

There is a strong majority in all three groups who consider it justified to increase medication at the risk of hastening death (the principle of double effect) with consent, for both adult and child (see Figure 9.2, p. 139). When the decision to increase medication was not discussed with the patient or family however, support for the action dropped significantly (see Table 9.3 (4, 5), p. 139 & Figure 9.1, p. 139).

Decreased support by YLP for increasing medication without consent mirrors the decision-making of Young Laypersons in Chapter 6 which indicated a high Sanctity of Life stance (57%)/moderate Personal Autonomy stance (27%). This stance would support the proposition that lack of consent makes justification for increasing pain relief at the risk of hastening death extremely problematic on the basis of autonomy. This is in line with results from Chapter 8 where the presence of a Living Will (patient wishes known) had most effect on the decision-making of Young Laypersons (see Table 8.2, p. 121). Reasons for this were previously discussed.

Lack of consent had a significant effect on Doctors judging increasing medication as not justified. Doctors reported a high Status Quo (54%)/very low Personal Autonomy (4%) stance in Part One. Although the outcome would be similar between Young Laypersons and Doctors for the question under consideration i.e. consent is judged important, the motivation for this judgment may be different. A high Status Quo/low Personal Autonomy stance is in line with privileging legal and ethical imperatives rather than the wishes of the patient in decision-making that has the potential to hasten death.

It is illegal and considered unethical for doctors to carry out any treatment on a patient for which consent has not been sought and given. It was proposed that only 4% of doctors based their decision-making on Personal Autonomy in Part One (see Table 6.2, p. 78), this suggests that doctors may be basing their decision that consent is important here in legal/ethical terms i.e. Status Quo, rather than patient consent, per se. This is in line with actual medical decision-making practice that recognises that although patient consent is normally a legal imperative, the consent/wishes of the patient in some treatment decisions is not always the primary consideration and may be overruled³³.

Notwithstanding the large majority of doctors who judged consent as necessary before increasing pain medication that could hasten death, 36% judged the action justified without consent from the adult and 39% without consent from the parents in the case of a child. In a case by case comparison, of those doctors who judged the action **justified** without consent, 71% (for adult) and 63% (for child) also judged it **legal** to increase medication without consent. These doctors could also be basing decision-making on the Status Quo as they understand it. They may have been responding to a belief that increasing medication to control pain is part of normal medical practice

³³ Rau Williams was refused dialysis when he asked for it and it was known that such a refusal may be implicated in his death. Doctors recognised the difficulty of the decision and the many impacting variables on the decision, only one of which was the request of the patient (Lewis, 1999). However, Northland Health, who made the decision were criticised by the Health Commissioner for restricting decision-making to clinical considerations without recognising wider cultural and spiritual needs (Lewis, 1999).

in palliative care and therefore within legal and ethical requirements, even without consent or discussion with the patient. Alternatively, these doctors may be motivated by the need to provide a compassionate outcome for the patients, such a belief providing a moral imperative to overrule the normal requirement for consent in some situations.

It was suggested that some doctors in Australia may avoid discussions on end of life decision-making, fearing they could be perceived to be colluding in the intentional hastening of death (Kuhse et al., 1997). Concern that pain relief may be refused because death could be hastened could lead to the implementation of death hastening procedures without discussing this with the patient when the doctor considers this to be the best action for the patient. They may also be expressing concern that the decision could be too hard for some families to make given that death could be hastened. One Dutch doctor interviewed for this thesis indicated that it was better for him to live with the memory of making the decision to hasten death than for the family to do so.

Doctors in New Zealand who sought a court ruling to allow them to withdraw life support from Baby L over the wishes of the parents based their decision-making on the most compassionate outcome for the child given that they believed her to be suffering (Horwood, 1998). Recourse to the courts may be made despite recognising that this is not optimal given that consent is a legal and moral prerequisite for treatment decision-making. Misgivings may be reflected in "the pause" that Grant Gillett speaks of, knowing that the decision about to be made is a momentous and troubling one, but determining to make the decision that has the most compassionate outcome for the patient and hopefully, for the family (Gillett, 1988). Such decision-making may occur even when this may breach what is normally understood to be a legal/ethical imperative, enshrined in a requirement for patient consent. In other words, doctors regard patient consent as important in decision-making, but some seem prepared to use available-to-them legal means to over-ride this when they judge this to be the best medical decision. How much their own discomfort and feelings of helplessness are factored into this decision-making when it involves increasing pain relieving medication at the risk of hastening death is another question.

Older Laypersons have consistently been more pragmatic in their responses to MDELS and this latest decision is no different. While the majority of Young Laypersons and Doctors consider increasing medication to be unjustified without patient/parental consent, the majority of Older Laypersons continue to judge the act as justified without consent (Table 9.3 (4, 5), p. 138).

The effect of consent appears stronger for Young Laypersons than Older Laypersons (see Figure 9.1, p. 139). The older group may be saying that when a decision that is deemed to be the most compassionate for the patient is too hard for the patient/family to make, it is better made by the

doctor than not at all. This may be related to increased life experience that could recognise the difficulty of some decisions and the understanding that such difficulty may undermine rational decision-making. One study reported that some elderly patients chose persons other than a spouse to be their proxy on the grounds that it was too much to expect a close loved one to make a decision that could hasten death (Schiff et al., 2000).

An alternative explanation may relate to cohort effects. Older Laypersons would have had their attitudes towards the medical profession honed in an era where the doctor was assumed to know best and the patient would often unquestioningly follow doctors' advice. In recent years the doctor/patient relationship has assumed more equality with the patient taking an active interest in decision-making (Siegler, 1985; Szasz & Hollender, 1956).

Older Laypersons were unsure of the **legality** of increasing pain medication, even with consent (see Figure 9.2, p. 140) suggesting that the possible constraints of the law were not seen as an impediment to the justifiability of delivering the necessary pain relief. This is in line with the more liberal attitudes towards MDELS by this group noted in previous chapters. Such decision-making may be indicative of Stage 5 of Kohlberg's theory of moral development (Kohlberg, 1967) with its emphasis on moral decision-making that can be independent of the strictures of societal dictates (see Chapter 6).

There was no evidence of an effect of age of patient on the justification of increasing medication, except for the sub-group of European/Pakeha (EP) Young Laypersons. Of the 94% of EP Young Laypersons who thought it justified to increase drugs for the adult on request, 20% changed and said it was not justified to do the same for a child with parental consent (see Table 9.4, p. 142). This sub-group was also significantly less likely to judge this action legal for the child over the adult with consent (see Figure 9.5, p. 143).

Only 7% of the combined group of Young Laypersons said increasing the drugs for the child was justified without parental consent (see Table 9.3 (5), p. 138). This suggests that parental consent is deemed necessary, but may not be sufficient for some European/Pakeha Young Laypersons to judge increasing the drugs as justified.

Confusion on legality may be related to media reporting

The decision by those in the EP Young Laypersons sub-group that increasing medication at the risk of hastening death is not justified for the baby with parental consent may be an effect of confusion over the legality of the action rather than age of the patient per se. Such confusion

may arise from media reporting that occurred around the time data were collected. Elsewhere the impact of media coverage on lay perceptions of euthanasia has been acknowledged (Helme, 1993).

In the case of Baby Liam, parents chose to pursue alternative therapy for their son's cancer against the advice of their medical team (Editorial, 1999). The doctors obtained a court order making Liam a ward of the state so they could enforce their treatment options (Healthcare Otago Ltd v Williams-Holloway, 1999b). The case involved extensive media coverage with the public being asked to inform on the whereabouts of the family when they went into hiding (Healthcare Otago Ltd v Williams-Holloway, 1999a).

In a similar case at this time, a Samoan family chose to honour the wishes of their 12 year old son, Tovia, not to take him to hospital for treatment of an osteo-sarcoma from which he subsequently died. Tovia's parents were charged with manslaughter and were finally convicted of failing to provide the necessaries of life, the lead story of the day (Family weep at cancer boy verdict, 2000). It was reported that hospital authorities had declined to pursue the option of making Tovia a ward of the court and thereby enforcing treatment because of the effect publicity had had in alienating the parents in the Holloway case. Co-operation between hospital and family were seen as of paramount importance (Johnston, 2000; Publicity 'stopped' hospital taking legal action for boy, 2000).

Media coverage that emphasises the superordinate role of the physician and the state over the parents, may have influenced responses on legality and justification of increasing medication at the request of the parents for this sub-group. It is unclear why this apparent effect was restricted to this sub-group and this may be worthy of further research.

Principle of Double Effect and the ethics of hastening death

The principle of double effect provides a legal and ethical safeguard against societal censure if controlling the pain of terminally ill patients by increasing narcotics should be seen to hasten their death. Increasing narcotics to control pain at the risk of hastening death is a medical decision that is frequently taken when caring for the terminally ill and such a decision is deemed to be motivated by compassion (Quill et al., 1997a). As discussed deciding not to discuss such an action with the patient or relatives may also be motivated by compassion for their feelings. However, not appraising the patient/guardian that an action may hasten the death of the patient is problematical.

The report from the Rummelink Commission in Holland indicates that "some thousand cases, (0.8% of all deaths)" are the result of doctors prescribing, supplying or administering a drug to end life. In approximately half of these cases this was done without the request of the patient and without knowing the patient's wishes (van der Maas et al., 1992, p. 182). The report indicates that virtually all of these patients were suffering and unable to express wishes but that discussion would have been possible in a few cases. Similarly, in "several" cases, no discussion took place with relatives or colleagues (van der Maas et al., 1992, p. 182). Doctors in the Netherlands have been criticised on the basis that their permissive euthanasia policy has put them on a slippery slope to accommodating hastening death practices without consent (Hendin, 1996; Keown, 1995; Jochemsen, 1998). Even if the primary intent of the action of increasing medication is to relieve pain, and this absolves a doctor from censure if hastened death occurs (Gillett, 1991; Gillon, 1999), the doctor would still be aware that a hastened death could eventuate from increasing the drugs.

Approximately one quarter of general practitioners in this study considered it justified to risk hastening the death of a terminally ill patient without consent, arguably for compassionate reasons. This appears to be similar to at least some of the 1000 cases reported by the Rummelink Commission that relate to hastened death without the request of the patient (van der Maas et al., 1992).

In summary:

Age of patient did not affect judgments on the justifiability or legality of withdrawing life support or withholding nutrition and hydration for any group. Withholding nutrition and hydration was judged by all groups to be less justified than withdrawing life support for the baby comparing to previous findings in Chapter 8, in the case of the adult.

Consent had a significant effect on judgments by all groups that increasing medication at the risk of hastening death was justified in the scenarios described. However 20% of Young European Laypersons judged it less justified for medication to be increased for the child over the adult.

Young Laypersons have a consistently more conservative approach to all decisions compared with Older Laypersons.

Laypersons are confused over the legality of all decisions, while Doctors are confident in judgments on legality.

The majority of Older Laypersons consider increasing medication at the risk of hastening death is justified without consent, and over 97% with consent, despite less than half judging either action to be legal. This is reflective of decision-making that is not constrained by legal requirements.

Approximately one quarter of Doctors consider increasing medication at the risk of hastening death without consent to be justified and legal.

CHAPTER 10

CONCLUSION

The variations noted in the decision-making of Young and Older Laypersons and Doctors in Chapter 6 have remained constant with other medical decisions at the end of life that hasten death. Table 10.1, p. 153) summarises the differences between the three groups for nine end of life decisions, including elective death.

Young Laypersons are significantly less likely than Older Laypersons to judge all actions that will hasten death as justified (see Table 10.1, p. 153 & Figure 10.1, p. 154). This may relate to their confusion over the legality of these decisions (see Figure 10.2, p. 154). However, the majority recognise the illegality of decisions related to physician-assisted suicide (PAS) and euthanasia (EU) and this has not precluded over 62% of Young Laypersons judging it justified to provide an elective death to the terminally ill patient with intractable pain.

Similarly, uncertainty over the legality of terminal sedation and increasing medication at the risk of hastening death and withdrawing life support has not precluded a strong majority of Young Laypersons judging these actions as justified. This is in line with privileging Autonomy in decision-making, independent of judgments on legality of actions, and suggests that the strong majority who judged it not justified withholding dialysis from the patient who requests it may be doing so from the Autonomy position rather than the Sanctity of Life position. A strong Autonomy position was noted in Chapter 6 for Young Laypersons.

While two thirds of Young Laypersons support elective death for the terminally ill patient only one third of this group judge an elective death for the tetraplegic patient justified. It seems that a commitment to Autonomy is not enough for the majority to judge elective death as justified per se, and suggests that the request should come from someone suffering and actively terminal. This is in line with the strong Sanctity of Life position of Young Laypersons noted in Chapter 6.

Table 10.1: Table showing difference in judgments of Young and Older Laypersons and Doctors on judgments on justifiability of MDEL.

JUDGMENT ON JUSTIFICATION OF END OF LIFE DECISION	YLP (N = 205)	OLP (N = 595)	YLP DRS (N = 205)	OLP DRS (N = 595)
	% YES	% YES	% YES	% YES
(1) Doctor assisting a terminally ill patient, intractable pain to ingest drugs to end life, on request	64 ($\chi^2 = 12.548, p < .001, df 1$)	77 ($\chi^2 = 12.548, p < .001, df 1$)	64 ($\chi^2 = 26.077, p < .001, df 1$)	77 ($\chi^2 = 84.280, p < .001, df 1$)
(2) Doctor assisting a tetraplegic patient who has not adjusted, to end life on request	31 ($\chi^2 = 23.958, p < .001, df 1$)	51 ($\chi^2 = 23.958, p < .001, df 1$)	31 ($\chi^2 = 6.790, p = .009, df 1$)	51 ($\chi^2 = 43.367, p < .001, df 1$)
(3) Doctor administering lethal injection to a terminally ill patient with intractable pain, on request	62 ($\chi^2 = 12.614, p < .001, df 1$)	76 ($\chi^2 = 12.614, p < .001, df 1$)	62 ($\chi^2 = 27.722, p < .001, df 1$)	76 ($\chi^2 = 86.593, p < .001, df 1$)
(4) Sedating terminally ill patient, intractable pain, no food or fluids, until death occurs, with consent	72 ($\chi^2 = 103.975, p < .001, df 1$)	97 ($\chi^2 = 103.975, p < .001, df 1$)	72 ($\chi^2 = 25.818, p < .001, df 1$)	97 ($\chi^2 = .201, p = .654, df 1$)
(5) Increasing pain relief to a terminally ill patient at the risk of hastening death, with consent	87 ($\chi^2 = 31.315, p < .001, df 1$)	98 ($\chi^2 = 31.315, p < .001, df 1$)	87 ($\chi^2 = 5.398, p = .02, df 1$)	98 ($\chi^2 = .702, p = .402, df 1$)
(6) Withdrawing life support from a comatose patient with irreversible brain damage, no living will	86 ($\chi^2 = 31.373, p < .001, df 1$)	97 ($\chi^2 = 31.373, p < .001, df 1$)	86 ($\chi^2 = 7.045, p = .008, df 1$)	97 ($\chi^2 = .109, p = .742, df 1$)
(7) Withdrawing N&H from a comatose patient with irreversible brain damage, no living will	63 ($\chi^2 = 98.928, p < .001, df 1$)	93 ($\chi^2 = 98.928, p < .001, df 1$)	63 ($\chi^2 = 14.970, p < .001, df 1$)	93 ($\chi^2 = 7.686, p = .006, df 1$)
(8) Withholding N&H from a comatose patient with irreversible brain damage, no living will	41 ($\chi^2 = 119.126, p < .001, df 1$)	82 ($\chi^2 = 119.126, p < .001, df 1$)	41 ($\chi^2 = 47.190, p < .001, df 1$)	82 ($\chi^2 = .002, p = .967, df 1$)
(9) Refusing dialysis to a request patient because of age and medical complications, patient dies	16 ($\chi^2 = 58.591, p < .001, df 1$)	47 ($\chi^2 = 58.591, p < .001, df 1$)	16 ($\chi^2 = 74.293, p < .001, df 1$)	47 ($\chi^2 = 10.544, p = .001, df 1$)

Key: YLP = Young Laypersons, OLP = Older Laypersons, DRS = Doctors, N&H = nutrition and hydration.
 $p = .01$

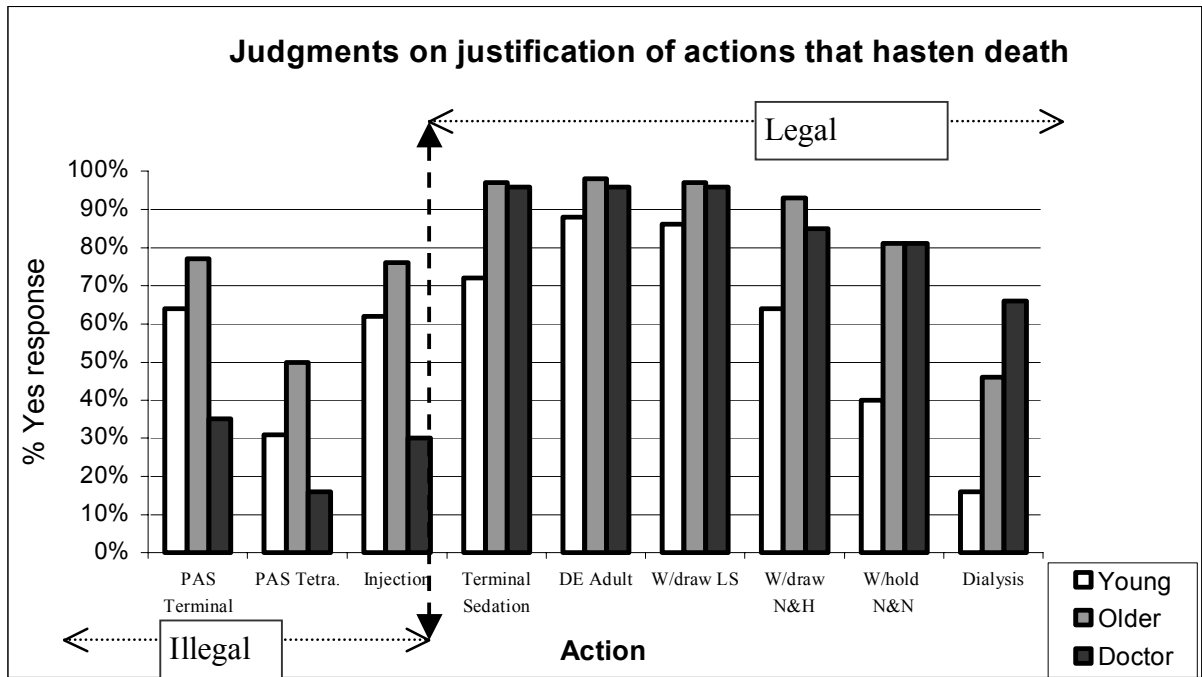


Figure 10.1: Judgments by Young and Older Laypersons and Doctors on justification of medical decisions that hasten death.

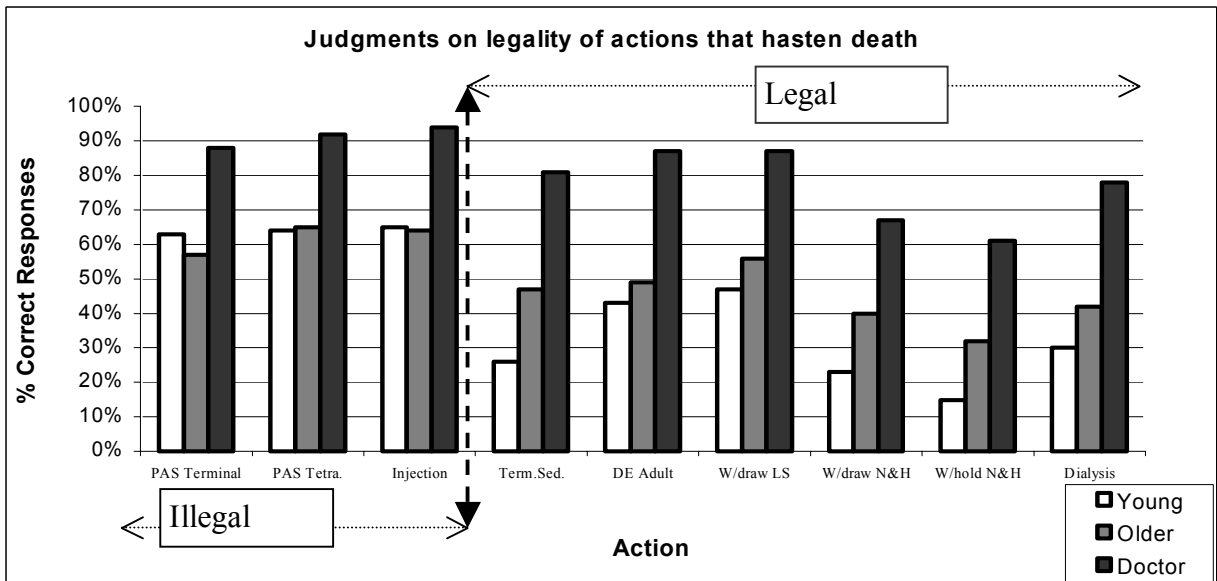


Figure 10.2: Judgments by Young and Older Laypersons and Doctors on legality of medical decisions that hasten death.

Key: (Figures 10.1 & 10.2)

PAS Terminal = Doctor assisting terminally ill patient to take drugs to end life, on request

PAS Tetra. = Doctor providing assisted death to tetraplegic patient on request

Injection = Giving lethal injection to terminally ill patient on request

Terminal Sedation = Providing terminal sedation to a terminally ill patient on request

DE Adult = Increasing medication at the risk of hastening death to address pain

W/draw LS = Withdrawing life support from a comatose patient with no hope of recovery

W/draw N&H = Withdrawing nutrition/hydration from comatose patient no hope recovery

W/hold N&H = Withholding nutrition/hydration from comatose patient no hope recovery

Dialysis = Refusing dialysis to a patient who requests it and patient

Young Laypersons are significantly more likely to judge terminal sedation justified than withholding nutrition and hydration in the scenarios provided ($n = 197$, $\chi^2 = 37.113$, $p < .001$, $df 1$) (see Figure 10.1, p. 154). This is suggestive of decision-making in line with a Sanctity of Life perspective or an Autonomy perspective. Young Laypersons may be influenced by terminal sedation being elective whereas in the withholding N&H scenario the patient could not express preferences, decision-making in line with the Autonomy position. Similarly, this group may also be influenced by the patient in the terminal sedation scenario being terminally ill while the patient in the withholding N&H scenario was irreversibly brain-damaged, but not dying at that time, decision-making in line with a Sanctity of Life position. Alternatively, the use of sedation may be seen as a positive move when stopping hydration is considered. It has previously been suggested that the removal of food and fluids and possibly the length of time it takes to die could be a problem for this group. The decision-making approach of Young Laypersons that was proposed in Chapter 6 seems to remain robust over other medical decisions that hasten death.

Older Laypersons have maintained a liberal stance on medical decisions that hasten death, legal and illegal, being significantly more likely to judge all actions justified than Younger Laypersons. As with Young Laypersons, Older Laypersons were uncertain regarding the legality of the legal actions, except for withdrawing life support. A slight majority recognised that decisions related to PAS and EU were illegal (see Table 10.1, p. 153 & Figure 10.2, p. 154). The strong support of this group for PAS, EU, terminal sedation (despite being uncertain of legality) and slight majority support for giving dialysis suggests a commitment to Autonomy (see Figure 10.1, p. 154). As with Young Laypersons, support for elective death drops in the tetraplegic scenario suggesting a Sanctity of Life position that may reflect a stronger commitment to elective death for those who are actively dying.

The decision-making of Older Laypersons was comparable to that of Doctors for most legal actions but significantly more liberal than Doctors for the illegal actions, despite the majority of Older Laypersons recognising the illegality (see Table 10.1, p. 153 & Figures 10.1 & 10.2, p. 154). This suggests that Older Laypersons may often be influenced by something other than the law when making their decisions.

Two exceptions in the legal scenarios related to withdrawing N&H and withholding dialysis, with Doctors significantly more likely to judge withholding dialysis justified than Older Laypersons and significantly less likely to judge withdrawing N&H justified. However given that 85% of Doctors judge the latter justified this result is less compelling than the dialysis result.

Approximately half of Older Laypersons appeared to be responding to Sanctity of Life principles when judging it not justified granting elective death to the tetraplegic patient. However half judge this to be justified, while half judge it not justified denying dialysis, an Autonomy position.

It has already been argued that half of Older Laypersons judging an elective death for the tetraplegic patient justified and half judging it justified denying dialysis is a position that supports resource conservation and is therefore indicative of Utilitarianism. Other decisions for this group that support a Utilitarian position are suggested by over 82% considering it justified to withdraw or withhold nutrition and hydration or withdraw life support from patients who are irreversibly brain damaged and unconscious but not actively dying (see Table 10.1, p. 153 & Figure 10.1, p. 154). This is despite uncertainty of the legality of such actions (see Figure 10.2, p. 154). However, it may just be that Older Laypersons have a pragmatic approach to such decision-making that recognises the inevitability of death, a position in line with Erikson's theory on the crisis that elderly people must resolve at this stage of their lives for successful aging (Erikson, 1963). The decision-making approach of Older Laypersons proposed in Chapter 6 seems to remain robust over other medical decisions that hasten death but a commitment to Autonomy appears to be stronger than at first indicated.

Doctors are significantly less likely than Laypersons to judge the PAS and EU scenarios justified and a strong majority recognise the illegal status. Similarly over 81% of Doctors judge all legal actions justified with the exception of denying dialysis. Here support for justification drops, possibly in line with the Sanctity of Life position (see Figures 10.1 & 10.2, p. 154).

Stopping food and fluids can have only one outcome, the death of the patient. The three actions that proposed this received almost unanimous support from Doctors in the scenarios presented. Given that these actions are arguably legal in the scenarios provided (and recognised by the majority of Doctors as such although with less certainty than other decisions – to be discussed later), it would appear that the legal status of the action may encourage support for the action. The other actions that would have the inevitable death of the patient as outcome (PAS and EU options) were not judged justified, possibly mainly because doctors recognised that these were illegal.

In the PAS and EU scenarios (illegal), the patient made a request for elective death but Doctors did not judge the action justified. This suggests the Sanctity of Life or Status Quo position. However in the terminal sedation scenario (legal) the physician explained to the patient that death would occur after stopping food and fluids and providing sedation and over 80% of Doctors judged the action justified. This suggests that Status Quo overrules the Sanctity of Life

(Autonomy could not have been the primary motivation because it was not privileged in the PAS/EU scenarios). In the withdraw/withhold N&H and LS scenarios (legal), over 80% of Doctors judged the actions justified. This suggests a Status Quo position as these three actions are legal and recognised as such by over 60% of doctors.

In the dialysis scenario (legal) a request was made and 66% judged a refusal justified, suggesting a Status Quo or Utilitarian position over-rule an Autonomy or Sanctity of Life position. The decision-making approach of Doctors that was proposed in Chapter 6 seems to remain robust over other medical decisions that hasten death.

There appear to be fundamentally different approaches by Laypersons and Doctors to medical decisions that hasten death. The decision-making of Young Laypersons mirrors that of Older Laypersons but Older Laypersons are significantly more liberal than the younger group particularly in scenarios related to removal of food and fluids and denying dialysis. The decision-making of Older Laypersons and Doctors is similar for legal scenarios, but the majority of Doctors do not support illegal options while the majority of Older Laypersons do. Almost all Doctors judge it justified to hasten death by accepted legal means (increasing medication at the risk of hastening death and terminal sedation) but do not consider it justified hastening death by illegal means, on request (PAS and EU). Given that the outcome is the same i.e. hastened death of the patient, it appears that something other than the outcome for the patient per se is motivating decision-making, possibly legality. Laypersons on the other hand appear to be responding positively to the request of the patient in the PAS and EU scenarios.

Laypersons are consistently uncertain of the legal status of medical decisions that hasten death. If they were more aware of the legal status, decision-making may come more into line with that of Doctors if legality is a prime motivation in decision-making. However legality as a prime motivation for Laypersons may be questionable following the results of this study. Alternatively, if PAS and EU were legalised, decision-making of doctors may come into line with Laypersons unless something other than legality is affecting the negative responses of doctors to PAS and EU. This could be the potential psychological effect for the doctor of intentionally killing the patient (and admitting to self that that was the intention – to be discussed further in the next section) and/or a moral aversion to such an action.

The research as undertaken has identified possibly inconsistencies in the decision-making approach of the three groups. Future research could explore these differences more fully to see if they are consistent across populations. Particular reference should be given to heterogeneous populations given the multi cultural aspect of New Zealand society. Similarly, research on

attitudes of Maori to medical decision-making at the end of life is necessary. Two of the cases that have received wide publicity (Rau Williams and Nancy Witehira, discussed previously) highlight the possible difficulties related to cultural aspects of medical decisions that are seen to shorten life.

It would be helpful to determine if planned interventions such as education, advance care planning and increasing awareness in populations of potential differences in end of life care decision-making could reduce the potential conflict such differences may incur in the clinical situation.

Limitations of the study

Limitations of the study relate to three main areas. The first related to the study design.

- (i) The difficulty of making judgments from vignettes, which may not parallel judgments in a real-life situation has been noted by other researchers (Waddell et al., 1996). The difficulty of capturing the complications of decision-making in vignette form may be reflected in the decreased certainty of doctors over the legality of withdrawing and withholding nutrition and hydration. Although over 80% judged the actions justified, Doctors were comparatively (to the other scenarios) uncertain of the legal status (see Figures 10.1 & 10.2, p. 154). This may have been because the vignettes gave scant medical evidence for the irreversibility of patient condition and physicians recognising that such a diagnosis follows exhaustive repeated testing.
- (ii) An attempt was made to explore ethnic differences in the Young Layperson group but given the small numbers within each ethnic group it was necessary to collapse the ethnic groups to European/Pakeha and Other Ethnicities Combined. Although it has been argued that some potentially useful information was obtained caution must be exercised when interpreting these results. Similarly, collapsing European/Pakeha into one group is also questionable. Recent “European” immigrants from Australia, the United Kingdom, South Africa etc may have identified themselves with this group and would arguably not be homogeneous with Pakeha New Zealanders, for instance.
- (iii) An attempt was made to explore ethnic differences in Doctors related to physician-assisted death. As above (ii), ethnicity other than European/Pakeha were collapsed into Other Ethnicities Combined. The usefulness of the conclusion reached (no difference) may be questionable for the reasons already given.

The second area related to sampling. The samples and method of recruitment used in the study may have produced a bias in results.

- (iv) University students would not necessarily be indicative of young laypersons in the general population, tertiary level education possibly producing a bias. The ethnic distribution of this sample was diverse (although uneven) and may not be reflective of the young laypersons in the general population. Students at Auckland University may have a wider ethnic variation than elsewhere given the number of overseas students attending and any ethnic variation may be different from the ethnic variation present in the general population. For example, Maori were poorly represented in the sample.
- (v) Similarly, the older sample were also from a unique population. Persons motivated enough to join Grey Power would almost certainly have strong views one way or the other on the issue of elective death. A belief in freedom of expression has been associated with positive attitudes to elective death (Singh, 1979) and this may influenced the liberal result noted with this group.
- (vi) The geographic area Greypower members were recruited from is a high socio-economic, urbanised area suggesting the sample may not be representative of older populations elsewhere. Positive attitude to elective death has been noted from those in highly urbanised areas (Singh, 1979) and higher socio-economic status (Wilson et al., 1998). Further, the group was ethnically homogeneous with almost all subjects identifying themselves as European/Pakeha. Minority race has been associated with decreased support for elective death (Finlay, 1985; Singh, 1979) and decreased support for elective death was noted in the Young Layperson Other Ethnicities sub-group in this study (see Table 7.3, p. 94) (again, caution should be exercised in interpreting these results).
- (vii) The recruitment methods may also have introduced response bias in the laypersons. Students had a high response rate (80%) possibly because they were approached personally and given class time to complete the questionnaire.
- (viii) Greypower members were approached by mail, in the same envelope as the Greypower newsletter. Only those who opened/read the newsletter would have been aware of the questionnaire. There was no second mail-out and no reminder follow-up. This may have produced a non-response bias (30% response rate). Similarly, members of Greypower who were most supportive of physician-assisted death may have been more willing to complete the questionnaire, introducing bias. A larger sample from Greypower may have

resulted in a less liberal stance on assisted death, possibly more in line with the psychology students.

- (ix) Doctors were approached by mail, one mailout, no follow-up. This may have produced a non-response bias but the reasonably high response rate for this group (given the time constraints on doctors) suggests that the nature of the questionnaire may have encouraged participation.

The third area related to analysis.

- (x) A conservative approach was taken to analysis by making a Bonferroni adjustment when setting the alpha. Each section was treated as a separate analysis and the adjustment was made within the section rather than taking into account all tests on each variable over the five sections. As such, a conservative approach could have been said to have been taken to the Bonferroni adjustment as adjusting for all tests over all sections could have produced false negatives. It could be argued that the approach taken to the Bonferonni adjustment may have resulted in false positives in this study.
- (xi) Differences in power may also be misleading. Significant results for Older Laypersons in the within subject analyses are often associated with a weak effect size due to high N.

In defence

Sampling: The average of the combined group of Laypersons in this study (Older and Young) is 72% in favour of the physician giving a lethal injection on request to a terminally ill patient with intractable suffering. This is comparable to past opinion polls held in New Zealand that indicated 71% of the general public were in favour of such an action in 1982 (Heylen Poll, 1982). Ten years later this number had risen to 73% (Roy Morgan Poll, 1992). This suggests that the populations sampled here may be representative of the wider population in New Zealand, at least on this particular question.

Analysis: All p values are reported for subjective reader judgment.

SECTION III

CHAPTER 11

STUDY TWO: MEDICAL DECISIONS AT THE END OF LIFE THAT HASTEN DEATH - DECISION-MAKING AND PRACTICE BY NEW ZEALAND GENERAL PRACTITIONERS

INTRODUCTION

Results from Study One indicate that approximately one third of general practitioners reported that they considered it justified to offer physician-assisted death to a terminally ill patient with intractable pain despite over 89% judging this action as illegal (see Section Two, Figures 10.1 & 10.2, p. 154).

The following is a descriptive study using the questionnaire from the Death Certificate Study of the Rummelink investigation (van der Maas et al., 1992) to determine the frequency and type of medical decisions and actions at the end of life that hasten death in New Zealand. The Dutch study was used for comparison because of the high impact it has had on the end of life debate world-wide. Similar work using the Rummelink questionnaire has been conducted in Australia (Kuhse et al., 1997) and Belgium (Deliens et al., 2000).

A higher rate of euthanasia/physician-assisted suicide actions from general practitioners was reported in Holland so it was decided to research the actions of general practitioners in New Zealand. In Holland, general practitioners reported an MDEL in a third of the deaths they reported on and were responsible for two thirds of the euthanasia cases reported in 1990 ($n = 2,300$) (van der Maas et al., 1992).

AIMS

- To investigate the incidence and type of medical decisions at the end of life that hasten or had the potential to hasten death that have occurred in the practice of New Zealand general practitioners in the previous 12 months
- To investigate the decision-making process involved in these decisions including request and consent of patient and consultation with colleagues
- To compare results obtained with results from the Death Certificate study of the Rummelink Commission of Enquiry (van der Maas et al., 1992).

METHOD

A survey methodology was adopted partially replicating the Rummelink Death Certificate study of the Rummelink investigation. A questionnaire was administered to general practitioners in New Zealand in August and September, 2000 (see Appendix D for questionnaire, participant information sheet).

Participants and recruitment

In 1998 the Medical Workforce reported 3,159 registered general practitioners (GPs) in New Zealand (Medical Council of New Zealand, 1999). The Royal College of General Practitioners report that approximately 95% of these are practising³⁴. This means there are approximately 3000 practicing general practitioners in New Zealand. A list of GPs was obtained from a commercial source containing 2602 names from all areas in New Zealand. This study thus included 87% of the practicing general practitioners in New Zealand.

Measures

The English version of the Rummelink questionnaire was obtained from the authors of the Australian study Demographics were changed to suit the New Zealand environment i.e. ethnicity and place of practice (see Appendix D).

³⁴ Based on figures cited by the Royal College of General Practitioners in New Zealand: <http://www.rnzcgp.org.nz/> accessed 27/10/01

The Remmelink research classified decisions researched on the basis of physician action, physician intent, patient request and patient competency. Analysis was conducted on the basis of these questions and this has been replicated in the current study.

Question 22 asked for judgments on the role of New Zealand legislation in the care offered. These questions were not part of the Dutch study and had been included in the Australian questionnaire and retained for this present study.

A separate section was included at the end of this present research related to accessibility and use of palliative care in practice.

Confidentiality and Response Rates

Research suggests that when a questionnaire deals with sensitive issues such as illegal behaviour, strong assurances of confidentiality produce higher response rates (Singer, Thurn, & Miller, 1995 (Singer, Hans-Juergen, & Schwarz, 1992)). However there is also evidence that strong assurances of confidentiality are counter-productive, regarded with suspicion by respondents who become concerned that confidentiality could be breached (Singer et al., 1992). Other research found that assurances of confidentiality had no effect on response rates (Dillman, Singer, Clark, & Treat, 1996). There may be mediating variables between confidentiality and response and it is suggested that these may relate to the respondents' perception of the sensitivity of the questions, and the confidence the respondent has in the researcher's assurances (Singer et al., 1995).

It was also determined that a note on the envelope indicating the mandatory nature of the response in a Government survey, increased response rate by 20% (Tulp Jr, Hoy, Kusch, & Cole, 1991). It may be that the message on the envelope elevates the importance of the contents enough to prevent the contents being consigned to the rubbish as junk mail (Dillman et al., 1996). When the questionnaire contains sensitive material, a confidential assurance placed on the outside of the envelope may encourage the recipient to consider the contents more closely. Both the envelope addressed to general practitioners in this study and the reply paid envelope were stamped with "Confidential" in large red letters.

The postcard technique to maintain anonymity of the respondent reduces the total cost of a mailout but has been found to result in a lower response rate. The authors found that using a postcard strategy may lower costs, does not affect quality of results but could lower response rates (Asch, 1996b).

Kuhse et al. used a postcard system for their Rummelink replication study and received a 64% response rate from two mail outs (Kuhse et al., 1997). It was decided not to jeopardise response rates in the New Zealand study so the postcard system was not employed, two mail outs going to everyone in the sample.

Terminology

The term MDEL-action is used in this present study and applied as it was in the Dutch study to refer to a medical decision at the end of life that may involve a purposeful action or a decision not to act, involving

“-the withholding or withdrawing of a treatment, either taking into account the probability that this decision will hasten the end of life of the patient, or with the explicit purpose of hastening the end of life
-the intensifying of the treatment of pain and/or symptoms, taking into account the probability that this will hasten the end of life of the patient or in part with the purpose of hastening the end of life of the patient;
- the prescribing, supplying or administering of drugs with the explicit purpose of hastening the end of life.” (van der Maas et al., 1992, pp. xv-xvi)

Euthanasia was taken to refer to the administration of drugs with the explicit intention of ending the patient’s life, at the patient’s request and death ensued.

Physician-assisted suicide was taken to refer to the prescribing or supplying of drugs with the explicit intention of allowing the patient to terminate their own life and death ensued.

ANALYSIS

Analysis was done using SPSS-Version 9. Frequencies for MDEL-actions Question 3-6 are reported separately and percentages in tables presented represent the frequency of action under each Question. Total percentages for all actions performed across the Questions 3-6 are averaged and reported in the last column of the tables.

Pearson’s chi and Mann-Whitney tests are used for between group comparisons.

RESULTS

Response Rates

There was a 37.3% response rate from the first mail-out. This increased to 48.1% with the second mail-out. One percent (32) questionnaires could not be delivered (unknown at address).

Returned questionnaires numbered 1302 and 47 (1.8%) of these were returned blank, some with comments for non-response (3 were illegible/unintelligible) which left 1255 usable questionnaires. Comments give some indication of concern by respondents about the use of the results and were evident in comments elsewhere in other questionnaires (see Table 11.1, p. 165).

A demographic breakdown of respondents is presented in Table 11.2, (p. 165).

Table 11.1: Table showing reasons given for not participating in study by general practitioners who returned the survey blank.

Reason given for non-response	No.
Illegible/unintelligible response	3
Returned blank – no advice on why	12
“Too busy” to respond	9
Not/no longer in general practice	12
Other opinions:	
<ul style="list-style-type: none"> Do not wish to participate/Not happy to take part/Wish not to participate/Decline participation/Unable to oblige This is far <u>too</u> dangerous to answer. When you publish your results you will destroy palliative care in NZ. For God’s sake leave this topic alone!! Is this questionnaire designed by a narrow-minded “liberal” <u>Not</u> happy to proceed. I am not confident re how <u>media</u> will report result of this study I believe this questionnaire to be designed to support the contention that “euthanasia” should be legalised. Accordingly I refuse to cooperate. Given that I expect to read about the findings of this survey in NZ Herald (sensationalised) the answers must be coloured by a doctors views about law change/no change as issue is already politicised and I see this survey as part of a <u>political</u> process. I feel the subject of ethnography! 	11

Table 11.2: Table showing demographic breakdown of general practitioners participating in study (N = 1255)

Gender	%*	Age	%*	Religion	%*	Ethnicity	%*	Location	%*
Male	64	<35	11	Extremely	4	Pakeha	78	City (>100,000)	45
Female	35	36-45	45	Very	12	Māori	1	Small city (30,000-	
Missing	1	46-55	32	Moderately	22	Pacific Is	.5	100,000)	22
		56-65	9	Slightly	30	Asian	5	Town (<30,000)	15
		>65	4	Not	30	Indian	2	Rural	17
		Missing	.2	Missing	3	Other	12	Missing	1
						Missing	1		

*Percentages may not total 100 due to rounding

The 1998 Medical Workforce survey for doctors in New Zealand indicated that one third were overseas-trained. Maori doctors were 2.3% and Pacific Island doctors were 1% of the general doctor population (Medical Council of New Zealand, 1999). Separate figures for general practitioners are not available and the present study did not ask for place of training.

Occurrence of MDELS

There were 693 cases where a medical decision was made that had the probability of hastening the patient's death. There were three screening questions to identify doctors who had the potential to have made a MDEL. Of the 1100 respondents who had been the attendant doctor at a death in the last 12 months, 3.2% reported first contact after the death, 6.8% reported a sudden and totally unexpected death and 25.4% reported that no MDEL was actioned. There was a non-response to questions 1 or 2 in 1.6% of cases (see Table 11.3, p. 167, Column 1).

A breakdown of the action plus intention and outcome are given in Table 11.3, (p. 167), Column 2.

Following the format of the Dutch questionnaire study, the last "Yes" in questions 3-6³⁵ was treated as the most serious MDEL- action (see Table 11.1, p. 167, Column 3). Thus the last affirmative answer was used as the point of analysis for subsequent questions related to decision-making (van der Maas et al., 1992; p. 128). Later questions (Question 21-25) involved respondents who had known the patient prior to death but had not made a MDEL (37%) (see Questionnaire, Appendix D).

The largest category for an MDEL-action was 3c, intensifying the alleviation of pain and/or symptoms taking into account the probability that the end of life was hastened. This occurred in 84.9% of cases when an MDEL was actioned ($n = 693$) and in 53.8% of cases it was the last action noted (see Table 11.3, p. 167, Columns 2 & 3). In 24.8% of cases medication was increased in part with the purpose of hastening the end of life and this was the last action noted in 13.6% of cases (see Table 11.3, p. 167, Columns 2 & 3).

In 66% of cases where an MDEL was actioned ($n = 693$), treatment was withdrawn or withheld, taking into account the probability that death would be hastened (see Table 11.3, p. 167, Column 2). In 28.9% of MDELS actioned, treatment was withdrawn or withheld with the explicit purpose of hastening death and death was caused by the action (see Table 11.3, p. 167, Column 2). In 5.6% of cases death was caused by a drug prescribed, supplied or administered with that explicit intention (see Table 11.3, p. 167, Column 3). When actions are taken that have the *intent* of killing the patient, the action is illegal under New Zealand law.

³⁵ In the Dutch questionnaire, these were Questions 4-7.

Table 11.3: Table showing medical decision at the end of life (MDEL) performed by general practitioner on the last death attended in the previous 12 months (*n* = 1100)

	<u>Col. 1</u> Deaths attended in the last 12 months (<i>n</i> = 1100) %	<u>Col. 2</u> MDEL as a % of actions taken ¹ (<i>n</i> = 693) %	<u>Col. 3</u> Of which action was last stated MDEL (<i>n</i> = 693) %	<u>Col. 4</u> If 6 = Yes, Drug Introduc ed into body by ¹	<u>Col. 5</u> (<i>n</i> = 39) %
No MDEL actioned	37.0				
First contact after the death	3.2				
Sudden and totally unexpected death	6.8				
No MDEL was performed (No “yes” to Q 3-6)	25.4				
Missing (no response)	1.6				
MDEL actioned	63.0				
Taking into account the probability that end of life hastened by					
3a withholding a treatment		37.2	4.0		
3b withdrawing a treatment		28.8	3.9		
3c intensifying alleviation of pain and/or symptoms		84.9	53.8		
In part with intention of hastening the end of life by					
4 intensifying the alleviation of pain and/or symptoms		24.8	13.6		
With the explicit purpose of not prolonging life or hastening the end of life and death caused by					
5a withholding a treatment		18.7	10.8		
5b withdrawing a treatment		10.2	8.2		
6 prescribing, supplying or administering a drug		5.6	5.6	Patient	12.8
				Doctor	53.8
				Nurse	53.8
				Other	5.1

¹More than one could be answered

Characteristics of physicians who had made an MDEL

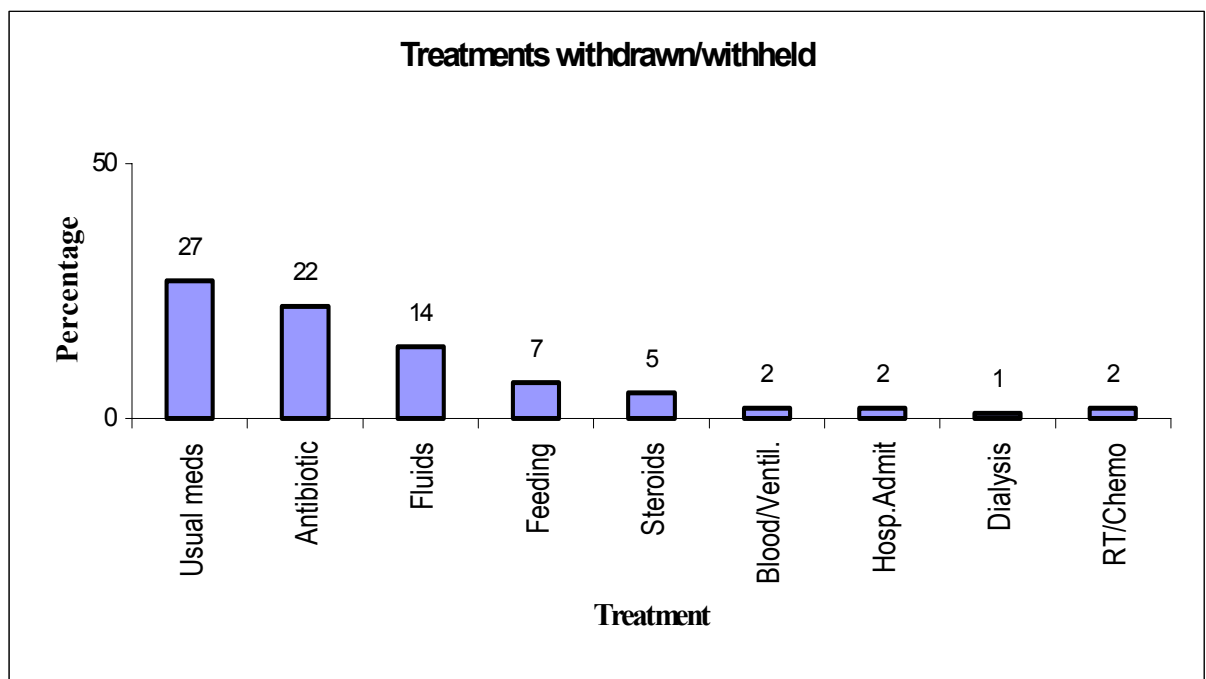
There was a statistically significant gender difference between doctors who had made a MDEL and those who (despite having the potential to) did not ($\chi^2 = 6.422$, *df* 1, *p* = .011) with relatively more males (72.8%) than females (64.8%). There was no significant difference between those who made a MDEL and those who did not for age, ethnicity, religion, place of practice or access to palliative care.

Of the doctors who had performed a MDEL-action, 90.9% were acting as general practitioners, 6.8% were acting as nursing home physicians, 0.9% were acting as specialists and 1.3% were

acting in another capacity. Several participants indicated that they were acting in a double capacity and as the address list was for general practitioners, it is taken for the purpose of this research that the respondents were all general practitioners – with the capability to act in another capacity. As there were too few respondents who identified themselves as working in a capacity other than general practitioner, no statistical analysis was done on the discipline involved.

Characteristics of treatment withdrawn/withheld

Details were sought on the 458 decisions made related to withdrawing or withholding treatment. Not all respondents responded by giving details and some respondents withdrew or withheld more than one treatment. Figure 11.1 (below), may give some indication of the breakdown of treatments withdrawn/withheld by general practitioners in the study and may be useful as an indication of the ratio between decisions. The withdrawal of dialysis for instance, which received marginal support from laypersons in Study One, appeared to occur relatively infrequently compared to other actions.



* More than one treatment could be withheld/withdrawn

Figure 11.1: Frequencies of treatments withdrawn or withheld* by general practitioners making a MDELHD ($n = 458$).

Affirmative answers to Question 6

Despite illegality, 5.6% of cases where a MDEL was made, a drug was prescribed, supplied or administered with the explicit purpose of hastening the end of life and death ensued (see Table 11.3, p. 167, Columns 2 & 3). This compares to 2.7% in the Dutch study ($n = 5197$) (van der Maas et al., 1992, p. 128). In 6 of these 39 cases more than one person was identified as administering the drug to the patient (introducing the drug into the body). In one case the doctor had identified patient/doctor/nurse/other as administering the drug and another identified doctor/nurse/other. In two cases the patient was identified as ingesting the drugs acting alone.

There was a statistically significant difference between doctors who had answered affirmatively to Question 6 and those who had not (but had performed another type of MDEL-action) for ethnicity ($\chi^2 = 14.408$, $df 6$, $p = .025$), age ($z = -3.198$, $p = .001$) and religion ($z = -2.309$, $p = .021$).

There was no significant difference between these two groups for gender ($\chi^2 = 1.684$, $df 1$, $p = .194$), place of practice ($\chi^2 = 5.857$, $df 4$, $p = .210$) or access to palliative care ($\chi^2 = .478$, $df 2$, $p = .787$). Low numbers for some ethnic groups suggest that results should be viewed with extreme caution (see Table 11.4, p. 170). Younger doctors were less likely to reply affirmatively to Question 6 than those over 45 years and respondents who were less religious were more likely than those who were more religious to have responded affirmatively (see Table 11.4, p. 170).

Extent of life shortened when MDEL actioned

There was a 13.6% non-response to Question 7, relating to how much life was shortened by the last mentioned MDEL. There is a clustering of non-response and an indication that life was not shortened around Q. 3a, 3b and 3c and a marked decline in non-response/life not shortened response from Q. 4-6. As the decision becomes more serious as to intent to hasten death, respondents are more likely to acknowledge that life has been shortened (see Table 11.5, p. 170).

Life was shortened by 1-7 days for 26.8% of cases and less than 24 hours for 19% of cases. In 1.2% of cases life was shortened by an estimation of one to six months (once by increasing pain relief, three cases from treatment withheld and four cases from treatment withdrawn). In 7.2% of cases, life was shortened by an estimation of one to four weeks. In 3 cases life was shortened by more than six months (two cases from treatment withheld and one from administering a drug) (see

Table 11.4: Table showing demographic details of doctors who answered affirmatively to Question 6.

Demographic grouping (n = 39)	% Within Group	(n)	Demographic grouping (n = 39)	% Within Group	(n)
Ethnicity *			Age*		
Pakeha	5.9	32	<35	3.0	2
Máori	33.3	2	36-45	3.0	9
Pacific Island	-	-	46-55	7.7	17
Asian	-	-	56-65	12.9	9
Indian	6.7	1	>65	6.7	2
Other (included Australian, English, South African/others) (Missing)	3.5	3 1	Gender		
			Male		
			Female	6.4	31
				3.9	8
Religion			Place of Practice		
Extremely	-	-	City (over 100,000)		
Very	3.8	3	City (30-100,000)	4.7	13
Moderately	2.7	4	Town (under 30,000)	5.4	9
Slightly	6.6	14	Rural	10.1	12
Not (Missing)	7.7	17 1		3.9	5
			Access to palliative care		
			Yes	5.4	34
			No	7.4	5

* Significant difference ($p = .05$) between doctors answering affirmatively to Q.6 and doctors who did not but had performed a MDEL-action ($n = 693$).

Table 11.5: Table showing estimation of shortening life, based on the last-mentioned MDEL taken in the last death attended in the previous 12 months.

	Last-mentioned MDEL ¹							Total N = 693
	3a n = 28 %	3b n = 27 %	3c n = 373 %	4 n = 94 %	5a n = 75 %	5b n = 57 %	6 n = 39 %	
Missing (not answered)	10.7	14.8	22.5	2.1	1.3	-	-	13.5
Not shortened	32.1	55.6	44.2	14.9	12.0	8.8	7.7	31.7
< 24 hours	3.6	3.7	15.5	37.2	17.3	17.5	35.9	19.0
One to seven days	50.0	18.5	15.0	31.9	49.3	43.9	48.7	26.8
One week to four weeks	3.6	-	2.4	13.8	13.3	22.8	5.1	7.2
One month to six months	-	-	0.3	-	4.0	7.0	-	1.2
> six months	-	-	-	-	2.7	-	2.6	0.4
Total								

¹Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

Table 11.5, p. 170). This means that in half of the cases where an MDEL was actioned (with the probability of hastening death) GPs judged that life was either not shortened or was shortened by <24 hours. If the missing values indicate that life was not judged shortened (and several respondents indicated this was the reason for non-response) then this result is strengthened.

Affirmative answers to Question 6 indicated that when life was shortened, this was estimated to have been by less than 7 days in 85% of cases and not shortened in 7.7% cases (see Table 11.5, p. 170).

The authors of the Dutch study combined 3a/3b together for discussion (van der Maas et al., 1992; p. 131). However it should be noted that there is some indication of a larger effect of action on shortening life for 3a withholding treatment than for 3b withdrawing treatment. Further, in two cases where treatment was withheld with the explicit purpose of hastening death (5a) life was shortened by more than six months (see Table 11.5, p. 170).

Decision-making process

The decision-making process that accompanied the MDEL-action was examined. Of the 693 instances where a decision was made that may shorten life, there was no discussion with the patient in 54.8% of cases. This figure parallels results from the Dutch study (54%) (van der Maas et al., 1992, p. 131). In 19.5% of cases a discussion took place some time beforehand and in 13.4% of cases discussion took place at the same time. There was no response to this question in 12.2% of cases, with most missing data clustered in Q.3a-3c. There was nearly twice as much missing data in 3c as 3a or 3b (see Table 11.6, p. 172).

When Question 6 was answered affirmatively, no discussion took place between the doctor and patient before the drug was administered in 43.6% (17) cases. This is two and a half times the figure in the Dutch study of 17% (van der Maas et al., 1992, p. 131).

Discussion with patient

In 76.3% ($n = 228$) of cases where a discussion took place the patient was considered by the doctor to be competent to have the discussion (see Table 11.7, p. 173). The discussion was initiated by the doctor (41.7%) or patient (36%) the majority of the time (see Table 11.7, p. 173). In 21.5% of cases ($n = 228$) the patient was considered not, or not fully, competent to have the discussion and this was more likely to occur in 3a/3b or 5a/5b or when medication was increased with the partial intention of hastening death (Q.4) (see Table 11.7, p. 173).

Table 11.6: Table showing discussion status with the patient about the last-mentioned MDEL.

	Last-mentioned MDEL ¹							Total N = 693 %
	3a n = 28 %	3b n = 26 %	3c n = 373 %	4 n = 94 %	5a n = 74 %	5b n = 57 %	6 n = 39 %	
Discussed at the same time	25.0	14.8	8.6	12.8	18.7	26.3	23.1	13.4
Discussed sometime beforehand	10.7	11.1	12.6	31.9	29.3	29.8	33.3	19.5
No discussion took place	53.6	59.3	58.7	53.2	50.7	43.9	43.6	54.8
Missing (no response)	10.7	11.2	20.1	2.2	1.3	-	-	12.2
Total	May not total 100% due to rounding							

¹Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

The MDEL-action was made at the explicit request of the patient in 39.0% of cases and the patient was judged competent to make the request in virtually all of these cases (see Table 11.7, p. 173). When the physician had judged the patient competent to assess their situation for the purposes of a discussion, there was only one occasion when the patient was judged not fully competent when an explicit request was made. This patient had been judged competent to have a discussion with the doctor at a previous time and had initiated this discussion with the doctor.

Requests to increase pain medication occurred in over half (56%) of the requests and in all cases the patient was considered to be competent to request (see Table 11.7, p. 173). In all instances where a discussion took place this was more likely to be initiated by the doctor when there was a probability that death may be hastened. When the purpose or intention of the decision was to hasten death or not prolong life, the discussion was more likely to be initiated by the patient (see Table 11.7, p. 173).

A written directive was available in only 13 cases and the directive was influential in decision-making in 9 of these cases (see Table 11.7, p. 173).

Table 11.7: Table showing characteristics of discussion with patient about the last-mentioned MDEL.

	Last-mentioned MDEL ¹							Total N = 228 %
	3a n = 10 %	3b n = 7 %	3c n = 79 %	4 n = 42 %	5a n = 36 %	5b n = 32 %	6 n = 22 %	
Patient able to assess situation for discussion	70.0	71.4	81.0	73.8	66.7	71.9	90.9	76.3
Patient not/not fully capable of assessing sit. (Missing)	30.0 -	28.6 -	14.0 5.0	26.2 -	30.5 2.8	28.2 -	9.0 -	21.5 2.2
Decision taken upon explicit patient request	60.0	0.0	31.6	33.3	52.8	43.8	50.0	39.0
Patient able to assess situation for <u>request</u>	60.0	-	31.6	33.3	47.2	43.8	50.0	38.1
Advance directive available	0.0	0.0	2.5	4.8	13.9	9.4	4.5	5.7
Advance directive influential in decision	-	-	1.3	2.4	11.1	6.3	4.5	3.9
Initiative for discussion came from								
Patient	30.0	28.6	24.1	45.2	36.1	46.9	50.0	36.0
Doctor or colleague	60.0	71.4	50.6	31.0	30.6	31.3	45.4	41.7
Partner or relative	10.0	-	13.9	19.0	37.8	18.8	4.5	16.2
Nurse	-	-	5.1	4.8	2.8	3.1	-	3.5
Other	-	-	-	-	2.8	-	-	0.4

¹Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

No Discussion with patient

In the 380 cases where a MDELHD was made and no discussion took place (see Table 11.6, p. 172), the patient was judged not fully competent or not competent to make a decision the majority of the time (71.3%). In 23.1% of cases, the patient was judged by the doctor to be competent to make a decision (see Table 11.8, p. 174).

When no discussion had taken place with the patient there was a wish expressed by the patient at some earlier time to have death hastened in 16.9% of cases. The wish to have death hastened clustered mostly around cases where medication was increased with the partial intention or explicit intention of hastening death (see Table 11.8, p. 174). Verbal advice by the patient was the main means of the wish being communicated to the doctor with relatives the next most likely source. Only one patient used a written directive for this purpose (see Table 11.8, p. 174).

Table 11.8: Table showing decision-making after no discussion with patient about the last-mentioned MDEL.

	Last-mentioned MDEL ¹							Total N = 380 %
	3a n = 15 %	3b n = 16 %	3c n = 219 %	4 n = 50 %	5a n = 38 %	5b n = 25 %	6 n = 17 %	
Patient not capable/not fully capable of discussion	86.7	81.3	60.7	84.0	84.2	88.0	94.1	71.3
Patient competent to discuss (Missing)	13.3	6.3	32.4	14.0	15.8	4.0	-	23.1
	-	12.5	6.8	2.0	-	8.0	5.9	5.5
Patient had expressed a wish to have death hastened	13.4	18.8	11.9	30.0	21.0	16.0	35.3	16.9
Doctor informed of wish by*								
Verbally by patient	-	6.3	10.0	22.0	13.2	12.0	23.5	12.1
Written Directive	-	-	-	-	-	-	5.9	0.3
Partner/Relative of patient	13.3	6.3	2.7	6.0	10.5	12.0	23.5	6.1
Nursing staff	6.7	-	0.9	-	2.6	-	-	1.1
Colleague	-	-	-	-	-	-	-	-
Otherwise	-	-	-	-	-	-	-	-
An explicit request to hasten death made by*								
Partner/relative	6.7	6.3	2.7	16.0	21.1	24.0	23.5	8.9
Colleague	-	-	-	2.0	-	4.0	-	0.5
Nursing staff	6.7	-	0.5	-	2.6	8.0	23.5	2.4
Others	-	-	0.5	-	-	-	-	0.3
No explicit request	86.7	81.3	85.4	70.0	73.7	60.0	52.9	78.9

Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

*>one answer could be indicated

When there had been no discussion with the patient and an explicit request was made by someone else to hasten death, requests clustered around Questions 4-6 where the action is specifically targeted towards the intentional hastening of death (see Table 11.8, p. 174). These cases were mainly associated with requests from partner/relative which raises the issue of vicarious suffering. It should be noted that nurses also made requests (2.4%). Few physicians reported a request from Others (see Table 11.8, p. 174).

Reasons for non-discussion with patient

Reasons given for non-discussion across all MDEL-actions were mostly because patient was unconscious (38.6%), patient was demented (19.9%), this was the best decision for the patient (19.2%) and discussion would have done more harm than good (11.8%) (see Table 11.9, p. 176).

When Question 6 was answered in the affirmative, the strongest reason given for no discussion with the patient was that the patient was unconscious (41.2%), the patient was demented (35.3%) or this was clearly the best action for the patient (29.4%) (see Table 11.9, p. 176).

Representative statements of those included in the “Other” option indicate that the MDEL-action taken was judged to be a normal part of medical practice and this was a reason for discussion not to take place. In many instances the doctor took this opportunity to state that a discussion was not deemed necessary because the primary intention of the action was to relieve the patient, not to hasten death (see Table 11.10, p. 176) or that discussion was unnecessary because the action would not significantly alter the duration of life. Several statements made in this section indicated the intimacy of the doctor/patient relationship e.g. “I do feel much more respect must be made of the wishes of the person dying”, “She was in pain and told me she didn’t want to linger”, “They trust me to keep them comfortable”, “The question of hastening death is in my eyes between the patient and the doctor, sometimes partners”, “very dangerous territory, only the doctor and patient, don’t (underlined heavily) include anyone else”.

Other discussants when no discussion had taken place with patient

In half the cases when no discussion had taken place and there was no known wish expressed by the patient for death to be hastened a discussion took place with others. Unsurprisingly, the main non-professional discussant was a relative (30.1%). The main professional discussant was a nurse (22.4%). Non-discussion was mainly associated with Q3c indicating that physicians may have been more confident in making this decision than other decisions (see Table 11.11, p. 177). The main purpose of the discussion with another professional (colleague/professional caregiver/nursing staff) was to make it a joint decision (67.7%). As the decision becomes more serious there is an increase in exchanging information as a reason for seeking collegial discussion (46.8%) (see Table 11.11, p. 177).

Table 11.9: Table showing reason given for no discussion with patient about the last-mentioned MDEL

	Last-mentioned MDEL ¹ *							Total n = 380
	3a n = 15	3b n = 16	3c n = 219	4 n = 50	5a n = 38	5b n = 25	6 n = 17	
Patient too young	-	-	1.0	-	-	-	5.9	0.8
Patient emotionally unstable	-	-	1.4	4.0	5.3	4.0	5.9	2.4
Clearly best action for patient	33.3	6.3	20.5	20.0	10.5	12.0	29.4	19.2
Would have done more harm than good	-	-	12.8	12.0	18.4	8.0	11.8	11.8
Patient mentally handicapped	-	-	-	-	-	-	5.9	0.3
Patient unconscious	73.3	31.3	29.6	52.0	50.0	56.0	41.2	38.6
Patient demented	20.0	43.8	13.6	22.0	23.7	40.0	35.3	19.9
Patient psychiatrically disordered	6.7	-	0.5	4.0	5.3	-	5.9	1.8
Other	20.0	31.0	34.7	8.0	18.5	4.0	5.9	25.5
No explanation given								5.5

¹Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

* >one reason could be indicated

Table 11.10: Table showing representative statements of reasons given in “Other” option for not discussing possible hastening of death from act or omission with patient (see Table 11.9, above)

Representative statement
“unnecessary, act was not intended to shorten life”
“discussed with patient’s family”
“patient did not like detailed information”
“not seen as shortening but clinical necessity for pain relief”
“language barrier”
“difficult to get patient alone” (away from relatives)
“although elderly and accepting of her diagnosis she was not able to talk about death and dying to myself or her family”
“tube feeding never offered in these circumstances (end-stage cancer) in this institution”
“events overtook the discussion”
“increasing morphine part of normal practice”
“offering tube feeding not an option given her remoteness and resources available” (implying lack of resources in this rural practice inhibit treatment that may otherwise be offered to patients)
“patient wanted a doctor knows best approach without too many details”

Table 11.11: Table showing discussion with others when there was no discussion with the patient and no known wish expressed by the patient

	Last-mentioned MDEL ^{1*}							Total n = 299
	3a n = 13	3b n = 12	3c n = 181	4 n = 34	5a n = 30	5b n = 19	6 n = 10	
No discussion, no known wish expressed, discussed with								
Colleague	7.7	33.3	5.5	2.9	10.0	21.1	20.0	8.4
Nurse	38.5	16.7	14.4	32.4	33.3	26.3	80.0	22.4
Other professional	-	16.7	5.0	5.9	13.3	31.6	10.0	8.0
Someone else	-	-	1.1	-	-	-	10.0	1.0
Relative	53.8	41.7	19.3	44.1	43.3	52.6	50.0	30.1
No discussion	30.8	33.3	63.5	38.2	33.3	5.3	10.0	49.5
Reason for discussion with colleague/nurse or other professional (n = 124)								
Exchange information	33.3	14.4	42.8	44.4	55.6	71.4	50.0	46.8
Consultation (asking/receiving advice)	16.7	42.9	38.8	27.8	16.7	35.7	50.0	33.9
Joint decision-making	83.3	57.1	61.2	77.8	66.7	64.3	83.3	67.7
Fulfil institutional requirements	-	-	2.0	5.6	-	14.3	8.3	4.0

¹Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

* >one reason could be indicated

Do-Not-Resuscitate Orders

Doctors who had actioned a MDEL and doctors who had not but had had contact with a patient before death ($n = 971$) reported on a “Do not Resuscitate” (DNR) decision being made in advance of the patient’s death in 64.8% cases. The DNR decision could be taken with more than one person but was mostly made with a relative (37.6%) followed by the patient (26.9%). Nurses were consulted in 22.4% of cases. An implicit DNR order based on institutional protocols but not explicitly ordered for the patient was reported by 14.3% of doctors (see Table 11.12, p. 178).

Table 11.12: Table showing Do Not Resuscitate (DNR) order for patients for whom an MDEL was made and those for whom death was unexpected but the doctor had previous contact with patient

	(n = 971) %
DNR decision made in advance of death	64.8
DNR decision made in consultation with *	
Colleagues	16.6
Nursing staff	22.4
Patient	26.9
Partner/relatives of patient	37.6
Implicitly based on institutional protocols	14.3
No	28.6
(Missing)	6.7

*Agreement could be with more than one person mentioned

Explicit request to terminate life not carried out.

The majority of doctors who had actioned a MDEL or had the potential to action a MDEL reported that there was no explicit request to terminate life that was not actioned (80%). When a request was made it occurred most frequently from the patient (4.2%). A total of 30 (3.1%) doctors reported that an explicit request to terminate life was actioned (see Table 11.13, below).

Table 11.13: Table showing request to terminate life that was not carried out.

	(n = 971) %
Explicit request not carried out*	
From patient	4.2
From partner/relatives	1.9
From other persons	0.4
From nursing staff	0.3
Request was carried out	3.1
There was no request at all	80.0
Don't know	2.9

*Request could have been made by more than one person

Legislation

The perception of the law as it applies in New Zealand inhibited or interfered with the preferred management of the patient for 60 doctors who actioned a MDEL (8.7%, $n = 693$). Of these, 37 felt that the patient would have received better and more appropriate care if euthanasia had been a legal option (see Table 11.14, below).

Table 11.14: Table showing perceived impact of present legislation in New Zealand on MDEL actioned

	($n = 693$) %
New Zealand law inhibited or interfered with preferred patient management	8.7
In doctor's opinion, a law accommodating assisted death would have enabled patient to have received better and more appropriate care	5.3

Palliative Care

The last section of the questionnaire related to access and use of palliative care or pain management teams. Of the 1255 respondents, 88.9% had access to such a team and 97.8% of these consulted with the team. The majority consulted with the team frequently (50.2%) or always (17.6%) (see Table 11.15, p. 180). Twenty-two doctors (2%) stated that they had access to such a team but did not use them (see Table 11.15, p. 180).

Of the 123 doctors who did not have access to a palliative care or pain team 99 (80.5%) said they would use one if they could. Seventeen doctors (13.8%) said they would not use a team even if access were possible (see Table 11.15, p. 180).

Table 11.15: Table showing access to palliative care and use of palliative care or pain control services by all respondents (N = 1255)

Column A (n = 1255)	%	Column B*	%	Column C**	%
<u>Access to palliative team</u>	88.9	<u>Consult team (n = 1115)</u> Consult with team	97.8	How often consult team (n = 1090)	
				Very occasionally	8.2
				Occasionally	23.3
				Frequently	50.2
				Always	18.0
				(Missing)	0.4
		Don't consult with team ² (Missing)	2.0 0.2		
<u>No access to palliative care</u> (Missing)	9.8	<u>Consult team (n = 123)</u>	80.5	Reason don't/would not consult team (n = 39)^{1, 2}	
	1.3	Would consult	13.8	Sufficient knowledge	38.5
		Would not consult ² (Missing)	5.7	Unhelpful in past	2.6
				Inaccessible	12.8
				Difficulty shared care	10.2
				Other	30.8
				(Missing)	5.1

* Column B figures based on Column A

** Column C figures based on Column B

¹ Could tick more than one answer

² In Column B combined for ² in Column C

Percentages may not total 100% due to rounding

The main reason given for not using or not wanting to use a palliative care or pain management team (those who have access and those who do not, n = 39) was that the physician had sufficient palliative care knowledge. Further reasons are included in Table 11.15, (above), Column C. Statements included in the “Other” option expanded along the theme provided by one of the other options.

There were 39 instances where Question 6 was answered in the affirmative (see Table 11.3, p. 167). In 34 of these cases the GP had access to an interdisciplinary pain management or palliative care team (see Table 11.4, p. 170). In the remaining 5 cases, 3 said they would use a team if available. One of these involved the death of a child. The remaining 2 did not respond.

CHAPTER 12

DISCUSSION

The research conducted on behalf of the Rummelink Commission in Holland in 1990/1991 resisted exploring and analysing incidents of euthanasia and physician-assisted suicide outside of the wider context of medical decisions at the end of life. Structuring their research and field of enquiry in the way they have, they are refusing to polarise euthanasia and other end of life care that could be called palliative only, and instead place it on a continuum with palliative care, albeit on the extreme end of that continuum. Thus we are forced to consider acts of euthanasia (or physician-assisted suicide) within the context of other decision-making that may hasten the end of life including withdrawing or withholding a treatment (including tube feeding) and the administering, supplying or prescribing of drugs. The research also considered that decisions not to resuscitate, or refusing requests for assistance to die were medical decisions (van der Maas et al., 1992).

Several justifications were given for this approach. Firstly, the commission of inquiry asked for the investigation of incidents of “life-terminating acts other than acts upon explicit request of the patient and alleviation of pain and symptoms with shortening of life as a side-effect”³⁶ (van der Maas et al., 1992, p. 5). Secondly, the authors of the study claimed that there were divergent interpretations within the medical profession on what constituted “euthanasia” as legally defined³⁷. It was feared that an investigation “exclusively in terms of euthanasia could have led to estimates that might have been difficult to interpret” (van der Maas et al., 1992, p. 5). Thirdly, the development of medical technology to the degree now routinely employed has led to an increase of incidents where a medical decision to treat or not to treat is more often made. Such decisions may certainly have consequences for the patient related to the timing of death. Additionally, the increase of medications now available to relieve pain and distressing symptoms may also have an effect of shortening life (van der Maas et al., 1992, pp. 5-6).

The original authors also raised the issue of terminology applied to withdrawing or withholding treatment.

³⁶ These are not considered “euthanasia” in The Netherlands which is defined as “the purposeful acting to terminate life by someone other than the person concerned upon request of the latter” (van der Maas et al., 1992, p. 5)

³⁷ The findings of research in America support this view (discussed elsewhere) (Emanuel et al., 1998)

“Concerning withholding or withdrawing treatment it can be commented that the decision was to not prolong life by a certain period of time rather than to shorten life by the same period of time. The correct terminology depends on whether or not the results of usual medical treatment are considered part of human life expectancy” (van der Maas et al., 1992, p. 24).

Such considerations are the stuff of philosophical or medico-legal debate and beyond the scope of this thesis. However for the purpose of analysis and discussion both “not prolonging life or hastening the end of life” (Question 5) were taken to relate to the hastened death of the patient. The authors of the original questionnaire used in the death certificate study did not include “not prolonging life” in this question. This was added by the Australian researchers and retained for this present study³⁸. The Dutch authors reported that some respondents differentiated between “not prolonging” and “hastening” particularly when the patient refused further therapy (van der Maas et al., 1992, p. 120). Only one respondent in the present study stated that there was a difference between “hastening the end of life” and “not prolonging life” (NZ GP 859).

It is important to differentiate between the methods of recruiting participants for this study and the Dutch or Australian studies. Similar approaches to sampling/data gathering were made in the 1990 and 1995 Dutch studies (van der Maas et al., 1992; van der Maas et al., 1996). The Dutch researchers used the questionnaire in two sections of their 1990 study. The first located death certificates for the previous 12 months through the Central Bureau of Statistics where data for deaths of all Dutch residents are collected (van der Maas et al., 1992). Where a decision could be seen to have been made regarding the death i.e. non-accidental death, a stratified sample of doctors was sent the questionnaire in regard to these deaths. Stratification was based on the likelihood that a MDEL was made, from 1 – 4 (accidental death = 0). For bureaucratic reasons it was not possible to access such central records in New Zealand. The second Dutch study was a prospective study where physicians who had already been interviewed in relation to the research were sent 10 questionnaires to be completed over a period of 6 months, one for each death they attended. For reasons of confidentiality and anonymity, such an approach was not possible in New Zealand.

The Australian researchers had access to a Medical Masterfile Database through the Australasian Medical Publishing Company, Sydney (Kuhse et al., 1997). It was not possible to locate a master file of practitioners in New Zealand despite an approach to the New Zealand Medical Council, who declined to make this available. They cited an undertaking to their members that participation in employment census would not result in lists being made available for research purposes other than any conducted by the Council themselves for the purpose of employment

³⁸ The Australian questionnaire was not published (Kuhse et al., 1997) but made available by the authors for this present research.

records. Accessing similar records through a commercial source was not possible because of resource constraints. In this respect this study differs from the Australian study (who also did not conduct interviews for reasons of anonymity). Kuhse et al. selected 3000 participants from 27 medical disciplines to receive the questionnaire (Kuhse et al., 1997).

No data were collected on the characteristics of the patients for whom the last-mentioned MDEL was actioned. Although this provided interesting data in the Dutch study it was considered that this, in combination with demographic data would possibly have been identifying for the doctor and may have affected response rates. One respondent expressed concern that taken together, age, gender, ethnicity and place of practice could identify a doctor. Given the potentially sensitive nature of the data being collected it was decided not to collect patient information beyond details of the actions taken.

This study restricts itself to the incidents reported by general practitioners in New Zealand as laid out in the questionnaire (see Appendix D). Results draw upon information about the last death the practitioner has attended as the treating or attendant doctor in the last 12 months. This rigid methodology was frustrating for some doctors who expressed a wish to report on incidents where they had more actively participated in hastening the patient's death, believing this to be the most appropriate and compassionate action in that particular case.

Restricting cases to the "last" case in the last twelve months implies that this is a random sampling of end of life cases. This was not necessarily correct for the Dutch study given their sampling of many disciplines. The authors caution that a physician "who often takes a certain type of decision probably deals with a kind of case that differs from that treated by physicians who very rarely take that decision" (van der Maas et al., 1992, p. 248). The present study was intra-discipline given that it sampled general practitioners only. In this respect at least, the sample was homogeneous and could reasonably be expected to be dealing with similar cases.

Incidence of MDEL-actions

A medical decision at the end of life that had the probability of hastening the patient's death was made in 63.0% of cases where there was an opportunity. The most frequently occurring action was intensifying medication to relieve pain and/or symptoms with the probability that this would hasten death (Q.3c) and this frequently occurred along with withholding or withdrawing a treatment. In over half the cases increasing medication was the last MDEL-action taken and in 13.6% of last-mentioned cases this action was taken partly with the intention of hastening death (see Table 11.3, p. 167). The original authors of the questionnaire had stated that the actions were listed according to increasing seriousness. If frequency of action is an indicator of decreased

seriousness, this result suggests that physicians may disagree with the order of severity. Increasing medication to alleviate symptoms (Q.3c) appears to be the most frequent, and therefore arguably accepted action. This was also noticed in the Dutch results (van der Maas et al., 1992) (see Table 12.1, p. 185), although not to such a great extent.

In 5.6% of cases where an MDEL was actioned the last action mentioned was prescribing, supplying or administering a drug with the explicit purpose of hastening the end of life or enabling the patient to end his or her own life (Q.6). There is clearly a huge difference between respondents reporting increasing medication with the probability that death would be hastened and increasing medication with the partial or explicit intention to hasten death.

Death was also associated with withholding or withdrawing treatment with the explicit purpose of not prolonging life or hastening the end of life and this occurred more often than the same action taken with the probability that this would hasten death (the less serious option) (see Table 11.3, p. 167). This suggests that withdrawing and withholding treatment is a purposeful action taken by physicians explicitly to hasten the death of the patient. This can be justified on medical grounds and may therefore be conducted without the scrutiny of the law³⁹. It has been suggested that this makes such MDELs more liable to abuse than physician-assisted death available under strict guidelines (Brock, 2000).

In Holland, general practitioners (33.9%) are less likely to make an MDEL than either specialists (40.4%) or nursing home physicians (55.9%) (van der Maas et al., 1992, p. 139). However, general practitioners (3.7%) were more likely to answer affirmatively to Question 7 (Question 6 here) than specialists (2.8%) or nursing home physicians (0.4%) and more often than the national average of 2.7% (van der Maas et al., 1992, p. 139).

The figures for general practitioners from both countries are compared in Table 16, below. In the Dutch study Q.3a /3b and Q.5a/5b were combined when reporting these figures (van der Maas et al., 1992, p. 139). New Zealand results have been combined for purposes of comparison and are based on $n = 1100$, which was the total number respondents who said they had attended a death in the last 12 months. Dutch figures were based on usable questionnaires returned including stratum = 0 which comprised physicians who had attended a death but did not have the opportunity to make an MDEL (van der Maas et al., 1992, p. 121), a similar group to the 1100 respondents included in this study.

³⁹ There are some notable exceptions – see comments on the case of Mr L in Section One and (Auckland Area Health Board vs Attorney-General, 1992)

Table 12.1: Table showing comparison between Dutch and New Zealand general practitioners of last mentioned MDEL (withdrawing/withholding combined for analysis)

	Last-mentioned MDEL ¹						MDEL action	No MDEL action	Total %
	3a/3b %	3c %	4 %	5a/5b %	6 %				
New Zealand general practitioners <i>n</i> = 1100	5.0	33.8	8.6	12.0	3.5	63.0	37.0	100.0	
Dutch general practitioners <i>n</i> = 2356*	6.9	13.4	4.2	5.7	3.7	33.9	66.1	100.0	

¹Taking into account the probability that the end of life was hastened by:

3a withholding treatment

3b withdrawing treatment

3c intensifying alleviation of pain and/or symptoms

In part with the purpose of hastening the end of life by:

4 intensifying alleviation of pain and/or symptoms

With the explicit purpose of hastening the end of life by:

5a withholding treatment

5b withdrawing treatment

6 prescribing, supplying or administering a drug

* (van der Maas et al., 1992, p. 139).

Data were collected in Holland for the death certificate study during the period August to November, 1990 (van der Maas et al., 1992). Data for the New Zealand study were collected in the period August to December, 2000. New Zealand figures are meant to represent the current situation in that country. Any interpretation of comparative results should take the decade difference into consideration.

There is a higher incidence of MDEL-actions performed by GPs in the New Zealand sample (63.0%) than in Holland (33.9%) (see Table 12.1, above). This may reflect differently perceived roles of general practitioners in either country. A higher incidence of MDEL-actions from specialists and nursing home physicians reported in the Dutch research suggests that end of life care may be more likely to be under specialised care rather than the general practitioner. While residents in homes for the elderly (1400 homes in 1997) are under the care of their own general practitioner, those who become too debilitated to go into such a home or have a serious chronic condition are more likely to be in a nursing home (verpleeghuis) (325 in 1997) where specialist geriatricians become responsible for care (Francke & Kerkstra, 2000). Patients who have more serious and debilitating problems may be more likely to require a MDEL.

Access to palliative care and decision-making

One reason for the high incidence of MDEL-actions by general practitioners in New Zealand may be the availability and accessibility of palliative care and pain management teams to assist with specialist advice for the GP while allowing primary care to be retained in that practice. The present study indicates that nearly 90% of GPs in New Zealand may have access to such specialist advice and virtually all of them consult such a team (see Table 11.15, p. 180). Access to palliative care advice for GPs in Holland was not as wide-spread when data for the Dutch study were collected. The impact of palliative care expertise on decision-making will be discussed further in Section Four.

When the benefits to the patient of further treatment are outweighed by the burden, withdrawal is generally seen as the appropriate medical action. Actions involving withholding/withdrawing treatment, nutrition and hydration and therapies are the premise of care that wishes to relieve a dying patient of burdensome interventions. Inherent in the concept of palliative care is an understanding that patient comfort is the main aim and it would be inappropriate to prolong life by such interventions (Doyle, Hanks & MacDonald, 1998). Similarly, effective palliative care addresses pain or symptoms that are distressing to the patient. Increasing medications to sufficient quantities to relieve distress may result in life being shortened. Thus actions that require an affirmative answer to Questions 3a/3b and 5a/5b are arguably appropriate to good medical care in situations that require such actions (Ashby, 1997).

While affirmative answers to Questions 5a/5b suggest that the intent of the physician is to hasten the end of life or not prolong life, this can be argued as a reasonable decision, taken in conjunction with the wishes of the patient and/or family.

Question 4, which covers increasing medication “partly” with the intention to hasten death can also be covered by the umbrella term of “palliative care”. As has already been discussed in Section Two (Chapter 7), intractable pain or intractable distressing symptoms may require an extreme action of sedating the patient until death occurs – terminal sedation. The death may occur days later, and the intervening time may prove distressing for the family. The suffering in this instance comes from the time it is taking to die. The humanity of the physician involved, does not preclude a desire “partly” to hasten the death and thus save the family, and the patient, further suffering. While it is a professional obligation to address patient suffering as has been stated, the accounts presented by doctors in the present study suggested that compassion played a role in many, if not most, actions described. Similarly withdrawing treatment that has maintained a quality of life for the patient, such as dialysis for example, would result in a period of time when

physical and/or mental deterioration may be distressing. Increasing medication to address this “partly” to hasten the inevitable death would be regarded as palliative. Half of the physicians who increased medication “partly” with the intention of hastening death as the last-mentioned MDEL (13.6%) did so after withdrawing or withholding antibiotics, food and fluids or “normal medications” (see Table 11.3, p. 167).

One outstanding comparative result is the 33.8% ($n = 1100$) of New Zealand physicians who increased medication as the last-mentioned medical action to alleviate pain and/or symptoms taking into account the probability that this would hasten death. This compares with only 13.4% of Dutch GPs (see Table 12.1, p. 185). This action is perhaps the cornerstone of palliative care to address symptoms in the dying patient and requires further discussion. Although there are ten years between the times the data were collected in the two countries, New Zealand has consistently appeared in the top ten countries in the world for (licit) morphine consumption (Doyle, 1991; International Narcotics Control Board, 1998). Consumption in The Netherlands is consistently much lower.

In 1987 New Zealand had approximately 1200 daily defined doses (30mg) per million inhabitants per day and was one of only ten countries worldwide where morphine consumption had increased in the previous decade (Doyle, 1991). In contrast, in 1990 The Netherlands had 371 daily defined doses (30mg) per million inhabitants per day (Zenz, 1991). Figures from 1996 indicated that New Zealand remained in the top five countries in the world for morphine consumption (33.86mg/capita) while The Netherlands consumption was still much lower at seventeenth position (11.39mg/capita) (International Narcotics Control Board, 1998). Attitudes towards morphine use in terminal care may have changed little in Holland. Elsewhere in a follow-up to the original Rimmelin study, research indicated that the proportion of physicians who reported on the administration of opioids with possible life-shortening effects did not change between 1990 and 1995 (van der Maas et al., 1996). It is also interesting that the difference between the two countries of roughly 1:3 for Q.3c is similarly mirrored in the differences in morphine consumption figures, strengthening the argument that international morphine consumption figures is reflective of morphine use to palliate symptoms. The difference in morphine consumption, a crucial and necessary part of any palliative armamentarium, supports the notion that palliative care in Holland may not have developed as far as palliative care in New Zealand. An alternative explanation may be that Holland may not use so much morphine because those cases requiring increased doses opt for euthanasia instead (and something other than morphine is used as the euthanatic).

It was claimed in 1991 that many health professionals were under the impression that “spinal opioids via catheter, reservoir and other means, should be attempted *before* resorting to oral or subcutaneous morphine” (italics in original). While the value of such interventions were acknowledged, the benefits of “simple oral regimens which will control the great majority of cancer pains” were emphasised (Doyle, 1991, p. S72). General practitioners in Holland in 1990-91 may have been under the impression that effective pain control may best be achieved by such specialist interventions as spinal catheter. They may have been largely unaware of the benefits of oral/subcutaneous morphine, which may have affected their willingness to deliver morphine in sufficient quantities via these routes to control intractable pain. Such attitudes may not have changed. Recently a doctor in Holland commenting on palliative care in Holland to this researcher, stated

The second dimension is symptoms and symptom treatment. And many people in this country think that palliative care is pain control, and pain control is anaesthesiology and anaesthesiology is pricking, injecting, cutting nerves, and that's all. And if you define palliative care like this, we have beautiful palliative care in this country - we have specialists at the top level in the world. But that's not all palliative care (is). (Dutch palliative care specialist/Interview 1998)

The development of the Rummelink questionnaire took place at a time when the side effects of morphine may have been less understood than they are now. Recent empirical research indicated that “the appropriate use of opioids for symptom control does not shorten life and there is little if any need to invoke” the principle of double effect (Thorns & Sykes, 2000, p. 398). These authors acknowledge that the invocation of the principle of double effect offers reassurance to physicians facing difficult decisions. However they suggest that if a physician feels the “need” to invoke the principle of double effect when an action is being considered they should involve a specialist palliative care team (Thorns & Sykes, 2000).

Another point that supports the argument that palliative care may not be disseminated in The Netherlands as well as it is in New Zealand even today is that palliative care expertise has been developed and disseminated from hospices, internationally. Hospices have a particular mandate to develop and disseminate specialised palliative care knowledge (Saunders, 2000). In 1997 there were six hospices in Holland with a population of 15.8 million (Francke & Kerkstra, 2000). Developing and disseminating knowledge gained in these few units, particularly among institutions that do not have a palliative care culture, would be difficult (to be discussed further in Section Four).

Currently there are over thirty hospices in New Zealand, with a population of 3.5 million, and this research indicates 90% of general practitioners in New Zealand have access to such specialist care for their patients. Additionally, New Zealand along with the United Kingdom, Canada and

Australia, are now integrating palliative care as a specialty incorporated into main-stream medicine (Doyle, 1998c). This is in addition to, not instead of, a dedicated hospice institution. Data collected in 1997 indicate that specialised palliative care services in Holland may often be regional with “almost no palliative care units in elderly homes” in the south and north of the country (Francke & Kerkstra, 2000, p. 32). While there is a recent government commitment to developing palliative care this will be within existing institutions and systems with even the few existing privatised palliative care services predicted to integrate to access government funding (Francke & Kerkstra, 2000).

There does not appear to be research available to indicate how many general practitioners in Holland have access to a specialist palliative care team. However such access would be crucial given that over 40% of deaths in Holland occur in the home and almost all of these would be under the care of a general practitioner (van der Maas et al., 1996). Although the difficulty of comparing palliative services cross-culturally renders conclusions tentative (considerations must also be given to quality of such services), it does seem that New Zealand general practitioners may have wider access to dedicated palliative care collaborators.

Affirmative answers to Question 6.

Affirmative answers to Question 6 indicated that of the respondents who had attended a death in the last twelve months 3.5%, prescribed, supplied or administered a drug with the explicit purpose of hastening the end of life (or of enabling the patient to end his or her own life) (see Table 12.1, p. 185).

There was a significant difference in ethnicity, religion and age between doctors who had answered Question 6 affirmatively and those who had not but had performed another MDEL-action. Māori physicians were more likely to have answered affirmatively (33.3%) however the difference in ethnicity should be viewed with extreme caution given there were only 6 Māori physicians who had made an MDEL and several cells in the chi analysis had less than 5. Physicians over 45 were more likely to have answered Question 6 affirmatively than younger physicians and those less religious than more religious (see Table 11.4, p. 170). Numbers in the sub-sample are small. Question 6 will be discussed further in more detail later.

Decision-making in MDELS

Respondents who answered any of Questions 3-6 affirmatively were invited to complete the next section related to decision-making. Questions 7 to 21 were to address the action last referred to affirmatively in Questions 3-6. Results discussed in these following sections are based on figures

in Table 3 ($n = 693$). Because separate figures for Dutch general practitioners are not available for this section of the questionnaire comparisons are with the whole Dutch sample.

Extent of shortening life

The high non-response to Question 7 (13.5%) (see Table 11.5, p. 170) suggests that respondents may have chosen not to answer because they did not believe that their actions had shortened the life of the patient. The original authors suggest that such information should be viewed with extreme caution given the difficulty of assessment. However, if the act/omission was estimated to shorten life by hours or days it could be assumed that the patient was dying. If life was shortened by weeks or months, the patient, although undoubtedly seriously ill, was clearly not dying at that point (van der Maas et al., 1992, p. 24). Even the last option “life was probably not shortened at all” is not an absolute statement that life was not shortened. Those who had responded with Questions 3a, 3b or 3c⁴⁰ as their last-mentioned MDEL-action may have considered that there was no effect of action on length of life and preferred not to infer that there may have been by ticking “probably not shortened”. Examples of such concern are clearly articulated

I am disturbed about Q3c. In my opinion this could be taken to mean different things as the wording is not clear. I administered morphine to this patient in an attempt to secure pain relief and I still don't know whether I should have answered yes or no. I am sure others were similarly confused. (NZ GP/302)

She was given frequent doses of short acting morphine on day of death to relieve respiratory distress caused by ca lung, but not considered “probable” that this would shorten her life. (NZ GP 504)

I know this (questionnaire) seems detailed but it is too simplistic. My patient died in a hospice and there is always a compromise of making her exit as comfortable as possible and yet allowing her to stay alive. The decisions you make in treatment will often have an unknown outcome in the level of improvement of quality of life or shortening of life. (NZ GP/679)

A very difficult questionnaire to complete – complex issues that I do not believe are able to be determined by yes/no answers. Hence my revisiting some of the questions. NB My response to the questions may have been quite different if Q3 had stated possibility rather than probability. (NZ GP/292)

As the decision becomes more serious, respondents were more likely to respond, even if it was only to indicate that life was “probably not shortened”. However when the decision was more serious respondents, not surprisingly, were less likely to judge that the life had not been shortened. A similar effect was noted in the Dutch study (van der Maas et al., 1992, p. 129). The majority of respondents in this study estimated that the action taken had shortened life (see Table 11.5, p. 170).

⁴⁰ ¹Taking into account the probability that the end of life was hastened by:

3a	withholding treatment
3b	withdrawing treatment
3c	intensifying alleviation of pain and/or symptoms

The length of time by which life is shortened by the MDEL-action increased as the action became more serious (see Table 11.5, p. 170). A similar result was found in the Dutch study (van der Maas et al., 1992, p. 130) and supports the argument that decisions made to withdraw or withhold treatment can be as consequentially serious as prescribing, supplying or administering a drug with the explicit purpose of hastening death (this will be discussed further in Section Four).

Decision-making – discussion took place

In the original research conducted in Holland the authors stated that to “do justice to the many aspects involved the questionnaire also allows for a situation in which someone was partially able to assess the situation and on this basis adequately take a decision” (van der Maas et al., 1992, p. 23). When discussing results they report that patients for whom a consultation took place “were completely capable of assessing their situation” (van der Maas et al., 1992, pp. 132-133). It is unclear if they included in the data the “partially able to make a decision” group as being able. Given the seriousness of the decisions being made, it should be noted that for the purposes of analysis in this present study, assessments on competency (Questions 10, 12, 14) were based on judgments that the patient was fully capable of discussing or requesting an action.

There was a high non-response rate for Question 8, which asked if a (possible) hastening of the end of life that could result from the last-mentioned act or omission was discussed with the patient. Several respondents stated that the reason they did not respond was because the actions were judged to be part of good medical treatment. As implied by NZ GP/302 (previously quoted see p. 190) and others, the wording in Question 3, may have been seen as unnecessarily suggestive of intent to harm. This suggests that these doctors may not see discussion about the life-shortening effects of these procedures as necessary. This mirrors findings in Study One when more than one third of respondents (GPs) considered increasing medication at the risk of hastening death, without consent, to be justified and legal. As the decision becomes more serious and the intent to hasten death becomes more explicit, non-response decreases and a discussion is more likely to have taken place (see Table 11.6, p. 172). This parallels findings from the Dutch study (van der Maas et al., 1992, p.131).

No discussion took place with the patient before the MDEL-action in more than half the cases (54.8%) (see Table 11.6, p. 172). If the missing cases indicate (as is plausible) no discussion, this would increase to 67% of MDELS actioned with no discussion with the patient about the potential hastening of death.

Of the 33% of patients with whom a discussion took place at some time beforehand or at the time of the action, the discussion was more likely to have occurred when the action became more

serious (see Table 11.6, p. 172). However in 43.6% of cases ($n = 39$) no discussion took place when Question 6 was answered affirmatively (see Table 11.6, p. 172). This compares to only 17% ($n = 204$) of respondents in the Dutch study who did not discuss the possible hastening of death of the ingestion of a drug for that purpose (van der Maas et al., 1992, p. 131). In each of the cases in this present study, a doctor and/or nurse introduced the drug into the patient. Curiously in one of the instances where there was no discussion and no previous wish or request, the doctor indicated that doctor and patient had introduced the drug into the patient. It seems difficult to understand how the patient could have been implicated if no discussion had taken place beforehand. “No discussion” responses will be discussed more later.

Competency

Three-quarters of the patients with whom a discussion took place were considered to be competent to do so (see Table 11.7, p. 173). Responses indicating “not fully capable”/“not capable at all” of assessing situation/making a decision are combined for Question 10. The rationale for combining these figures for analysis/discussion is that for informed consent to be valid, the patient must be fully capable of understanding what is happening/proposed and fully capable of making a rational decision. This means that when a MDEL-action occurred, the physician had a “discussion” with the patient despite knowing that the patient was not capable of meeting the legal requirement for informed consent in 21.5% of cases (see Table 11.7, p. 173).

Cases where a discussion took place but the patient was not fully/not competent of assessing the situation mainly clustered around Q.3a/b and Q.5a/b or 6, when one of these were the last-mentioned MDEL-action (see Table 11.7, p. 173). It is clear from those cases where details of the illness are recorded that most of these cases were imminently terminal and the effects of illness and approaching death was the cause of incompetency. However many other doctors in such cases did not have a discussion, citing that “it would have done more harm than good” or that this was “clearly the best action for the patient” (see Table 11.9, p. 176).

Although elderly and accepting of her diagnosis, she was not able to talk about death and dying to myself or her family. (NZ GP/550)

This suggests that the doctors who had such a discussion with patients who were not fully/not competent may have been doing so to fulfil legal/institutional requirements only – the benefit to the patient would appear to be minimal.

Alternatively, the doctor may have had the “discussion” in order to discharge what was perceived as a moral consideration given the potential consequences of hastening death from the action to be taken. It is clear from the length of time that life may be shortened by actions to withdraw or withhold treatments (see Table 11.5, p. 170) that such decisions are weighty and important. The

seriousness of actions that have the potential to hasten death may invoke a perceived need for the practitioner to self-protect by following some formatted guidelines or protocols. Certainly “informed” consent is a legal requirement.

I support a more liberal attitude with the correct legal/ethical oversight being provided. Perhaps some “guidelines” (dare I use the word) are in order. (NZ GP/48)

Discussion initiation

Where a discussion took place ($n = 228$) the doctor or the patient initiated the discussion in a large majority of cases (see Table 11.7, p. 173). There was a clustering around Q.3a-3c indicating the doctor initiating the discussion, but as the action became more serious the picture changed and the patient was more likely to initiate the discussion, indicated by clustering around Q. 4-5c (see Table 11.7, p. 173). There was little difference indicated between patient or doctor initiating the discussion when Question 6 was answered affirmatively. Generally, as the action proposed became more serious the patient was more likely to initiate the discussion. This may be indicative of the physician being reluctant to propose a course of action that could be seen as intentionally hastening death, discussions about more weighty decisions having to be initiated by the patient. Authors of the Australian study commented on the cases where Australian doctors chose intentionally to end the lives of some patients without patient consent. They concluded that present laws in Australia prohibiting the intentional taking of life prohibited doctors from discussing end of life decisions, physicians fearing that their involvement in such discussions could be construed as collaborating in the intentional termination of life (Kuhse et al., 1997). One doctor in this study articulated this fear

It is such an emotional and value-dependent issue. I will do anything to protect myself medico-legally, some of the actions taken are futile and wasteful and not of any “benefit” to the patient. (NZ GP/307)

Similarly, the patient/relative was more likely to initiate the discussion as the action became more serious with this more likely to occur when withholding/withdrawing treatment with the explicit intention of not prolonging life or hastening the end of life (see Table 11.7, p. 173). The need for these more serious decisions may be more likely to occur when the patient was debilitated and compromised, suggesting the importance of a health care proxy to advocate on behalf of the patient in such situations.

In approximately one third of cases where a MDEL was discussed and actioned the patient made an explicit request for the action to be taken. In virtually all cases the patient was judged competent to assess the situation (see Table 11.7, p. 173). Requests tended to cluster around withholding or withdrawing treatment particularly with the purpose of not prolonging life (see

Table 11.7, p. 173). Although a discussion took place for 22 of the 39 cases when Question 6 was answered affirmatively, an explicit request was made in only 11 of these (see Table 11.7, p. 173).

Written directives

Written directives were only available in 13 cases where a MDEL was actioned and in 9 of these cases, the directive was influential in making a decision. The small numbers make it difficult to draw conclusions about the role of advance directives in end of life decision-making however those that were recorded tend to have been made/invoked in the more serious decisions (see Table 11.7, p. 173). This strengthens the comment above that the availability of an advance directive or a proxy previously nominated by the patient may be helpful in assisting doctors to make decisions. This supports a tentative conclusion from Section Two (Chapter 8) and suggests that work to increase the availability of advance directives in New Zealand could be beneficial for both patient and doctor.

Decision-making – no discussion took place

A discussion did not take place with the patient in the majority of cases where an MDEL-action occurred (54.8%, see Table 11.6, p. 172). A similar result was found in the Rummelink survey (van der Maas et al., 1992) and was strongly criticised as evidence of the “slippery slope” down which the Dutch were sliding towards involuntary and non-voluntary euthanasia (Keown, 1995). Presumably Keown would have a similar comment for these New Zealand results given that treatments were withheld or withdrawn, and medication increased without discussing these with the patient. However Griffiths counters this criticism by pointing out that

Keown’s argument, which he apparently thinks condemns the Dutch approach by demonstrating a high level of non-voluntary shortening of life, is actually a boomerang. It is precisely the idea that abstinence and pain relief are *fundamentally and unproblematically different* from euthanasia and intentional termination of life with an explicit request that underlies legal policy in all other countries. If, as Keown argues, such a distinction cannot be made, then he ought to be looking closer to home for the horrors he claims to have found in the Netherlands. (Griffiths et al., 1998, p. 27).
(emphasis in original)

The wording in Question 8 asked if the (possible) hastening of the end of life as a result of the action was discussed with the patient. If the physician did not believe that the end of life was hastened by the action taken (as discussed above), they may have answered “No” to this question.

Conversely, all of the actions described were potentially life-shortening, even if not “probably” life shortening (Question 3) or “explicitly” life shortening (Question 5). Informed consent to treatment decisions is predicated on an understanding that risks are made known to the patient. It is interesting that results from Study One indicate that lack of discussion of the action described here in Q.3c had a significant effect ($p < .001$) on all respondents judging the action as not

justified. This may reflect the difficulty of using vignettes to demonstrate scenarios. Only 36% of doctors in Study One judged it justified to increase medication to alleviate pain, at the risk of hastening death, without discussing it with the patient first (see Section Two, Table 9.3, p. 138).

Inherent in a commitment to informed consent is the understanding that the patient is competent to assess the situation. In nearly three-quarters of the cases where a discussion did not take place, the patient was not/not fully capable of having the discussion (see Table 11.8, p. 174). In cases where the patient is not capable of having a discussion it can be argued that a written directive would be helpful in making the patient's wishes known. There was only one case where a written directive was used for this purpose and it was invoked in a case where Question 6 was answered affirmatively.

A request for hastened death from others

When no discussion had taken place, a wish to have death hastened was known by the physician in 16.9% of cases, (see Table 11.8, p. 174). Such a wish occurred relatively more often in conjunction with a MDEL-action involving increasing medication "partly" or "explicitly" to hasten death (see Table 11.8, p. 174). In response to the patient conveying the wish for death to be hastened, the physician was relatively more likely to have increased medication partly or explicitly to hasten death, but also to have withheld or withdrawn treatment explicitly to hasten death (see Table 11.8, p. 174). When the patient's partner or relative conveyed the wish, similar serious actions were taken (see Table 11.8, p. 174). Similarly, an explicit request to have death hastened by the partner/relative was more likely to be associated with more serious MDEL-actions (see Table 11.8, p. 174) which suggests that the physician acted to hasten death possibly partly in response to this request. Explicit requests to hasten death were also made by nurses.

Presumably requests to have death hastened from someone other than the patient would be in response to patient suffering. This raises again the issue of vicarious suffering of those who are involved with the patient on a day to day basis. This suffering needs to be addressed within the caring team by rotating staff who are caring for the dying, and/or providing debriefing on an ongoing basis and after the death. Similarly, giving the family the opportunity to vent their feelings privately around the death in the caring environment and post-death bereavement support would assist with residual feelings of uncertainty or concern about care given and the type of death experienced by their loved one.

It is clear from the MDEL-actions that were recorded in conjunction with an expressed wish or explicit request to have death hastened that physician response to requests for hastened death do not restrict themselves to increasing medication/opioids. As previously argued, withdrawing or withholding treatment (including food and fluids) with the explicit intention of hastening death,

are also significant methods by which a physician may respond to a request for assistance to die. Such actions may arguably be seen as a method whereby the physician may intentionally hasten death on request by passive, and apparently lawful, means.

Reasons for no discussion with the patient

Reasons were given for no discussion with the patient. This mostly occurred because the patient was unconscious (38.6%) or the patient was demented (19.9%). Other reasons given for no discussion mainly related to apparently paternalistic judgments that such a discussion “would have done more harm than good” or that no discussion was required because the action was “clearly the best for the patient” (see Table 11.9, p. 176). Although paternalism within the doctor/patient relationship may be judged in perjorative terms, some respondents suggested (and it is acknowledged that these statements came from the doctor) that patients may sometimes be willing participants in such an arrangement. Patients may in fact demand this relationship from the general practitioner (Emanuel & Emanuel, 1992) (see Table 11.10, p. 176). Patients, particularly older patients, may prefer the “doctor knows best approach” as one practitioner claimed.

Patient explicitly had a No Resus order and was ready to die. The likelihood of the treatment for pain relief shortening his life was low, the need for pain relief was high. The patient did not like detailed information and I therefore considered it unnecessary to discuss the information with the patient. (NZ GP/241)

Perhaps not surprisingly, this respondent indicated that life had probably not been shortened at all.

When Question 6 was answered affirmatively and there was no discussion with the patient (17 cases), there was a range of reasons given for non-discussion and these follow the reasons given for the wider “no discussion” sample (see Table 12.2, below).

Table 12.2: Table showing reasons given for non-discussion when Question 6 was answered affirmatively (*n* = 17).

Reason given for no discussion on the possible hastening of the end of life by prescribing/supplying or administering a drug with the explicit purpose of hastening the end of life*	No of cases
Patient was too young	1
Patient emotionally unstable	1
This action was clearly the best one for the patient	5
Discussion would have done more harm than good	2
Patient was mentally handicapped	1
Patient was unconscious	7
Patient was demented	6
Patient was suffering from psychiatric disorder	1
Other	1

* More than one reason could be given

There was no information collected on the patients for whom the MDEL-action occurred (to assist anonymity) however responses to Question 15 give some indication of the cases where dementia was involved. In 76 cases where a MDEL was actioned and no discussion occurred, the patient was demented. In 25 of these cases (see Table 11.9, p. 176), an action was taken with the explicit purpose of hastening the end of life. This again strengthens the argument for the usefulness of advance directives, particularly when more serious MDELs are being considered, notwithstanding arguments (discussed elsewhere) that raise the issue of the altered personhood of the patient with dementia and whether or not the advance directive should morally be applied (Singer, 1994a).

Statements under the “Other” option of why a discussion did not take place also centred around the discussion not being necessary because hastening the end of life was not the intention, this was the most appropriate treatment for the patient, and in the case of withdrawing tube feeding, the inappropriateness of continuing the treatment in terminally ill patients. When the patient is in end stage disease and withdrawing or withholding treatment is considered, a discussion around the hastening of the end of life by such actions may justifiably be seen as unnecessarily intrusive and inappropriate.

Other discussants when an MDEL was actioned

In half of the cases where a MDEL was actioned where no discussion took place and there was no known wish expressed to have death hastened ($n = 299$), the physician discussed the decision with someone else (see Table 11.11, p. 177). The main non-professional discussant was a relative (30.1%) and the main professional discussant was the nurse (22.4%). Discussions with the relative were least likely to occur when increasing medication (3c), but relatively equally likely to occur when withdrawing/withholding treatment either with the probability or explicitly to hasten death or when medication was increased “partly” or “explicitly” to hasten death (see Table 11.11, p. 177). This lends weight to the idea that the action covered in 3c, is not regarded as death hastening, but appropriate and normal medical practice.

Discussions with the nurse were more likely to occur as the decision becomes more serious (see Table 11.11, p. 177). The main reason given for a professional consultation (colleague, professional caregiver/nursing staff) was to make it a joint decision and this is more likely to occur as the decision becomes more serious (see Table 11.11, p. 177). This may be in part to share the responsibility for the decision-making, which may lessen any negative psychological effects from acting alone, particularly when the action involves the explicit hastening of death. However, in one case where a drug was administered with the explicit intention of hastening death and death ensued, there was no discussion with the nurse, who administered the drug alone (on doctor’s prescription orders, as formulated in the wording of the question).

It is interesting to speculate the reasons for the physician acting alone without any discussion with others. If a discussion had been attempted and met with disapproval from a professional colleague it may not have been pursued and the physician may have considered it wiser to act alone. If the physician believed that this was clearly the best action for the patient and feared censure and even investigation, non-disclosure of action may have seemed the best option. Cases where their colleagues have threatened doctors with legal action when a particular course of action that hastened death was considered/actioned have received wide publicity⁴¹.

Do-Not-Resuscitate Orders

In two thirds of the cases where the doctor had prior contact with the patient, a DNR decision was made. This was four times the number of DNR orders recorded by Dutch general practitioners. Although 35% of Dutch doctors (all disciplines) recorded a DNR order, Dutch general practitioners “rarely” made DNR decisions in advance of death (van der Maas et al., 1992, p. 146). This ties in with Dutch general practitioners being less likely than specialists or nursing home physicians to make any MDEL-action (van der Maas et al., 1992).

In this study, the DNR decision was frequently made in consultation with more than one person but there were no cases reported where the decision was in consultation with someone other than the patient without the patient being consulted, even when the decision was implicitly based on institutional protocols. In other words, when a patient came into an institution where there were implicit orders that in the event of cardiac arrest resuscitation would not be attempted, the patient was informed of this. This suggests that there are end of life decision-making conversations routinely held in institutions involved in terminal care, probably on admission. How often discussions occur and whether they could incorporate a discussion about advance directives is something that could be explored further. Recommendations along these lines were endorsed by the influential SUPPORT study from the USA (SUPPORT Principal Investigators, 1995). However, there was no DNR order in 28.6% cases and non-response to the question was 6.7%.

Explicit request to terminate life

In cases where there was a potential for an MDEL-action or an MDEL-action occurred ($n = 971$) 41 patients (4.2%) who explicitly made a request were refused (see Table 11.13, p. 178). This compares with 1.4% in the Dutch study (van der Maas et al., 1992, p. 146). These authors stress the seriousness of this result given that an explicit request was made, emphasising the importance

⁴¹ Doctors at Auckland Hospital sought legal advice after nurses threatened to report them when they proposed turning off life support on Mr L (discussed in Section One).

of this decision-making circumstance. Requests that were not actioned were also received from others. In total, there was a request that was not actioned in 57 cases (5.9%) (see Table 11.13, p. 178). (Requests could have come from more than one source in each case). These results indicate that explicit requests for life to be terminated occur relatively often.

It has already been discussed that a request for life to be terminated can and is met by physicians in ways that stand within the law. However some physicians may be constrained by their understanding that the *intent* of terminating life when performing these actions makes this ethically problematical for them. Or it may be that in these cases, intentionally ending the patient's life was not considered the most appropriate action to take.

The discussion process when a request for hastened death is received was discussed in Section Two (Chapter 7).

Legislation

Of the doctors who performed an MDEL-action, 8.7% stated that New Zealand law “inhibited or interfered” with the preferred management of the patient in this action (see Table 11.14, p. 179). Seven of these had answered affirmatively to Question 6 suggesting that there were aspects of care in this extreme decision that would have been different if the law had permitted it. This suggestion is given weight because all seven recorded that a change in law would have enabled the patient to receive better care. The actions described may have had to be delivered clandestinely given the prohibition on the intentional ending of life in New Zealand. The psychological effect of acting in such secrecy could be uncomfortable for all those involved and “secrets” surrounding the death could complicate grieving for those who knew the actions taken.

Results from Holland indicate that death-hastening actions can have negative psychological effects on the physician involved. A significantly high number seek support after the event. Interestingly support is more likely to be sought from friends and family (83% for euthanasia and 72% for “life ending without explicit request”) than colleagues (60% and 44% respectively) (Haverkate et al., 2001).

Not all doctors who stated that the law interfered with preferred patient management supported that a change in the law would have enabled the patient to receive better care (see Table 11.14, p. 179). This suggests that administering a drug to hasten death may be tolerated differently by doctors involved. Some may have acted outside of the law to deliver the care they deemed appropriate, possibly feeling comfortable in such decision-making without a change in law being necessary. Others may have experienced problems with the action.

Several doctors noted in their comments that they offered assisted death to patients on request, if not in the case under discussion, then in others. One strongly emphasised that this was between the patient and the doctor and no-one else should be involved in the decision.

Very dangerous territory. Only the doctor and patient, don't include anyone else. (NZ GP/41)

Another prioritised the wishes of the patient and family over the law

I was more concerned about what the relatives (wife, adult daughter) thought rather than legislation. Indeed when the patient pleaded with me for him not to have another night of extreme respiratory distress he cautioned me to “protect myself” (against the relatives) however they had previously introduced the idea! (NZ GP/63)

Another raised the issue of interventions at the end of life that are “futile” and of no benefit to the patient, implying that these were initiated in order to meet legal requirements rather than because they were deemed the best medical decision for the patient

It is such an emotional and value-dependent issue. I will do anything to protect myself medico-legally, some of the actions taken are futile and wasteful and not of any “benefit” to the patient. (NZ GP/307)

Concern over physician vulnerability to those who examine actions related to end of life care was expressed by another doctor.

I feel legislation, if done well, could help but all attempts re euthanasia, abortion etc seem frustrating. I yearn for the days when patients, relatives and GPs had much mutual trust and things went generally well. In recent years this has been lost. We now have to think about whether we may act quite properly but be potted by an activist or a department or a “do-gooder”. Regarding Q24, I act as I feel, properly, so don't worry too much about the law. (NZ GP/1129)

The issue of the illegality of assisted death inhibiting the initiation of such discussions in the doctor/patient relationship (Kuhse et al., 1997) was discussed in Section Two (Chapter 7).

Findings in Study One suggested that some GPs may be unaware that supplying information (if it is acted upon) could implicate the physician in assisted death (New Zealand Crimes Act, 1961). For others, the illegality of the proposed action may be seen as a barrier to exploring the issue of assisted death with a patient when it was considered appropriate.

Often patients don't ask about choosing the time and mode of death in a terminal illness and I do not initiate discussion as this is not yet a clearly legally available option. So in my opinion, I am not yet obligated to offer this option (but I would prefer to be able to either offer and/or respond better to the occasional request for euthanasia). (NZ GP/447)

Those who are unaware (or uncaring) of legal constraints upon giving information to patients to allow them to commit suicide may be more comfortable in having such discussions. One respondent appeared to differentiate between giving information on how to hasten death (as being legal) and assisting in hastening death (as being illegal).

My patient died of ca secondaries all of her own accord without my intervention. However I had discussed with her (a) how to shorten the process herself if she so desired it and (b) that I am unable to help with this as it's illegal for me to do so. (NZ GP/774).

Another doctor suggested that the availability of euthanasia restricted the development of palliative care. However this doctor also stated that the law as it stands would not inhibit (his) preferred treatment of the patient.

I would not be inhibited by the law if I felt an action was in the patients best interests. However I feel VERY strongly that a doctor should bring life not death. I will withhold meds and willingly give alleviation. I will not give meds for the sole purpose of causing death, not because it is illegal but because it is not right. I believe those countries with euthanasia have not pursued the option of palliative care and are very poor at it. (NZ GP/573)

It appears that some general practitioners in New Zealand may deliver the care the patient requires, regardless of how this relates to the law in some cases. Others may feel threatened that their actions may be construed as breaking the law and believe that this inhibits the care they offer.

Palliative Care

Nearly 90% of all respondents ($n = 1255$) have access to a multi-disciplinary palliative care or pain management team and virtually all of them consult with the team when caring for dying patients, the majority consulting the team “frequently” or “always” (see Table 11.15, p. 180). The majority (80.5%) of those who do not have access to a team would consult with one if available. However, not all general practitioners consult with a team, or would consult with a team. Reasons for not doing so were primarily because the physician had sufficient palliative care knowledge. However a number of other reasons were cited including:

Antagonism between hospice and district nursing due to contract for terminal care provision (NZ GP/417)

This has been noted elsewhere in research into the positioning of palliative care programmes within the health care environment (Vachon, 1998).

Communication difficulties

It is difficult at times working with hospice, conflicting advice. (NZ GP/506)

Team taking over the patient

Usually sideline GP and overmedicate patients in terminal stages (NZ GP/510)

Lose track of patient – unsatisfactory. Outpatient service – nurse makes decisions then expects GP/on call GP to action stat. (NZ GP/785)

It is vital as GP that terminal case decision-making is not usurped by outsiders (NZ GP/1113)

The implication from the last quote is that the palliative care team may interfere in the doctor/patient relationship. The intimacy of the doctor/patient relationship which may be built up over many years is cited as a prerequisite to granting the euthanasia request in Holland (Griffiths et al., 1998).

Conflict and communication difficulties within the caring team are likely to impact negatively on the dying experience for the patient and the family. Although respondents recorded few comments regarding this aspect of care (15 cases), the management of team dynamics would seem to indicate a need for a primary healthcare provider who coordinates end of life care. Given the relationship between the general practitioner and the patient, one option would be for the GP to remain as the coordinator of care unless/until care is signed over to another provider either through the GP requesting assistance or the patient indicating dissatisfaction with the level of care received.

One respondent who had consulted a palliative care team “frequently” suggested that in some instances it was more appropriate for the general practitioner to retain care of dying patients because of palliative resource constraints.

They do not want to know about every old person they would be overloaded with work. (NZ GP/932)

Of those who answered affirmatively to Question 6, 34 (87%) said they had access to a palliative care team (see Table 11.4, p. 170). It seems that in these cases, adequate palliative care provision has not been sufficient to prevent a perceived need to prescribe, supply or administer a drug with the explicit intention of hastening death. The problem of intractable suffering was addressed in Section Two.

Alternatively, those who answered affirmatively to Q.6 may have acted according to palliative care advice as it was relayed and interpreted this in terms outlined in Q.6.

The special case of children

Although there were only two children for whom a MDEL-action was made, the special nature of paediatric terminal care demands that these cases be considered. Physician responses to suffering in both cases were couched in terms of compassion and accounts give some indication of the extreme trauma for everyone involved in such cases.

In one case, the doctor and nurse are reported to have administered drugs to the child with the explicit intention of hastening the end of life. This was in response to the suffering of both the child and family. The decision was enacted after consultation with the family, caregivers and professional attendants.

Child dying of cancer. Discussed with family possibility of hastening terminal event when the whole family distraught and exhausted. Joint decision among all caregivers and professional attendants. (NZ GP/910)

It was noted that a palliative care or pain team was not available.

In the second case, the doctor did not register the actions as “explicitly” to hasten death but rather “partly” taken to hasten death (Q.4). In this case the suffering of others is also implicated in the actions taken.

Terminal illness in a child for 10/52. Towards the end extremely restless, agitated despite high doses s/c morphine. The use of midazolam in good doses and morphine I knew would depress respiration. However in my opinion it was needed. All had had enough of the suffering. (NZ GP/1109)

Access to a palliative care team was available and the doctor described use of the service as “frequent”.

In an article on the management of refractory symptoms and terminal sedation in children it is acknowledged that the suffering of the parents may be implicated in the treatment of the child’s symptoms (Kenny & Frager, 1996). These authors clearly differentiate between terminal sedation and euthanasia and emphasise the importance of differentiating between the two actions to the parents

“The fact that a child is unresponsive when intentionally sedated in the terminal phase must not convey a sense of ending the child’s life. Euthanasia ends life to end suffering; palliative care responds to pain and suffering so that life is lived as fully and comfortably as possible until death” (Kenny & Frager, 1996, p. 41).

It is of interest that the treatment of the two cases was similar, but were classified differently as to intent. It may have been that the second was subjectively classified as terminal sedation (intention “partly” to hasten death) particularly given that the physician had access to a palliative care team and would presumably have known that terminal sedation is the strongest palliative “alternative” to euthanasia.

In the first case the doctor was more explicit that the intention of the action taken was to hasten death and may have been unaware of terminal sedation as a legal alternative to euthanasia. In Study One, 19% of GPs were unsure of the legality or judged it illegal to terminally sedate a dying patient in response to intractable pain.

Alternatively, the first doctor may have sedated the child with the explicit intention of hastening death and preferred not to classify this in “palliative” terms, but rather in terms structured in Question 6, which would more correctly be classed as euthanasia (given the discussion/consent of the family). On the other hand, the doctor may have been aware that terminal sedation was a palliative alternative that could be presented in “double effect” terms as provided for in Q4, but did not do so because he did not see a moral difference between the two actions. (Billings & Block, 1996)

It may have been that the subjective classification of the actions taken was the only difference between the two cases. Whether this indicates that such actions should register as palliative care or euthanasia is open for discussion (Douglas et al., 2001).

Question 6 – Was death caused by a drug prescribed, supplied or administered with the explicit purpose of hastening the end of life (or of enabling the patient to end his or her own life)?

Taken in the context of follow-up questions related to discussion, request and competency, this question is asking the doctor if euthanasia (administering a drug with the intention of causing death at the request of the patient) or physician-assisted suicide (prescribing and/or supplying a drug to allow the patient to end his/her own life), occurred.

Who administered the drug

A breakdown of drug administration is demonstrated in Table 19 and includes:

1. Drug administered by physician alone in 13 case, in six cases with a nurse (one case also with Other and one case also with Other/Patient) and two cases with the patient.
2. Drug administered by nurse alone in 15 cases and in six cases with a doctor (one case also with Other and one case also with Other/Patient)
3. In two cases the patient self-administered the drug, acting alone.
4. In the two cases where Other was involved, a doctor and nurse were also involved in administering the drug and in one of these the patient was also indicated.
5. In one case it was not reported who administered the drug.

Following research elsewhere indicating a strong presence of nurses in medical decisions that hasten death (Asch, 1996a; Kuhse & Singer, 1993; Stevens & Hassan, 1994), this research shows a consistent presence of nurses involved in MDEL-actions either as a discussant (see Table 11.7, p. 173), advocate (see Table 11.8, p. 174 & 11.13, p. 178) or consultant (see Table 11.11, p. 177 & 11.12, p. 178). However it is the strong presence of nurses involved in administering a drug with the explicit intention of causing death that is one of the most interesting findings of this research, reflective of findings in Australia which were discussed in Chapter 2 (Stevens & Hassan, 1994). There was no discussion with the patient in 11 of the 15 cases where the drug was administered by the nurse alone (although it is acknowledged that the nurse presumably would have been following physician orders). In 7 of these 11 cases there was no expressed wish or request. This compares to only 2 of 13 cases where there was no discussion with the patient,

and the physician administered the drug alone (in one of these there was no expressed wish) (see Table 12.3, below).

Table 12.3: Table showing details of cases answered affirmatively in Question 6.

Case No	Discussed at same time or sometime before	Request/Wish expressed by Patient	Drug given by Patient	Drug given by Dr	Drug given by Nurse	Drug given by Other	Life Shortened by*
1	X	X		X			D
2	X			X	X		E
3	X	X		X			E
4	X	X		X			D
5	X	X		X			E
6					X		E
7	X	X		X			E
8	X			X			D
9	X				X		D
10	X			X			E
11**		X					F
12					X		F
13	X	X	X	X			D
14			X	X			E
15		X		X			D
16					X		C
17	X			X			D
18		X			X		D
19		X			X		D
20	X			X			E
21					X		D
22	X	X		X	X	X	D
23	X		X	X	X	X	F
24	X	X	X				C
25				X			D
26				X	X		E
27	X			X	X		D
28	X	X	X				D
29					X		E
30				X	X		D
31		X			X		E
32	X				X		D
33	X	X		X			E
34					X		E
35		X			X		D
36	X	X		X			A
37	X	X			X		E
38	X				X		D
39					X		D

* A = >6 months B = 1-6 months C = one to four weeks D = one day to one week E = <24 hours

F = Probably not shortened at all

** Did not state who administered drug

Discussion/no discussion with patient

In the 39 cases where Question 6 was answered affirmatively, there was a discussion in 22 cases and in 2 of those cases the patient was not considered capable of assessing the situation. There was no discussion with the patient in 17 cases and in 16 of these cases this was because the patient was judged not capable. In the remaining case there was a written directive available

which was influential in the decision-making. In six cases where there was no discussion, a wish to have death hastened had previously been expressed by the patient. There was no known wish expressed in 10 cases with one case missing. This means that in at least 10 cases the drug was given with the explicit purpose of hastening death and death ensued with no discussion with the patient, no request from the patient at any time (necessary for euthanasia) and no expressed wish from the patient at any time to have death hastened (see Table 12.3, p. 205). This is 25.6% of cases where Question 6 was answered affirmatively. In the Dutch study, there was no discussion with the patient in 17% of the cases where Question 7 (Q.6, here) was answered affirmatively (van der Maas et al., 1992, p. 133).

Cases where the action was taken without a discussion could not be classified as “euthanasia” as that term is understood in the international literature and outlined in the Dutch research (van der Maas et al., 1992). This is predicated (among other things) on an informed, consistent request preceding the action. However the classification is moot as New Zealand law does not even allow for euthanasia and states that

If a person actually kills another, the latter’s consent is no defence to a charge of murder (s 63), although the offence is manslaughter only if done pursuant to a suicide pact: s180 (a new provision). Aiding or abetting suicide, or inciting, counselling or procuring suicide or attempted suicide, is a crime punishable by up to 14 years’ imprisonment (s179) (New Zealand Crimes Act, 1961, CA167.18)

With no actual legal guidelines about how to assist death, it does not seem sensible to invoke the “rules” for euthanasia when discussing cases of assisted death in countries where this is not a legal option, something that has been done by others (Emanuel et al., 1998).

The authors of the Dutch study stressed that answers to Question 7 (Question 6 here) often elicited a comment from the respondent that although they had acted according to the question, they did not judge the action to be euthanasia or physician-assisted suicide. They stated that respondents had replied affirmatively to Question 7 (6) but stated that they thought their actions were more in line with “partly” not “explicitly” with the intention of hastening death (van der Maas et al., 1992, p 119). It seems difficult to understand why these physicians, who had been given the “partly” to hasten death option (see our Question 4) would then answer affirmatively to Question 7 (6) “explicitly” to hasten death.

Physician interpretation of questions implicated in responses

Physician interpretation of Questions 3-6 is crucial. As has already been suggested, the interpretation of what constituted “probability” of death being hastened, or physician “intent” in action taken may differ between physicians. Dutch results also indicate that this could differ for individual physicians over time. All respondents in the interview study of the Rummelink research were asked to complete the questionnaire used in the death certificate and prospective studies.

Over the time between filling the questionnaire and being interviewed, there was a change in how some physicians interpreted their actions. Several physicians “downgraded” their interpretation of the action taken (a very few others, “upgraded” to a more severe interpretation). Most notably, of the 34 ($n = 370$) who had originally answered Question 7 affirmatively (Question 6 in the New Zealand study), 8 changed their minds and said that action was partly to hasten death and 2 said the action was taken with the probability that death was hastened. One respondent, upon reflection, increased the severity of the action taken to that represented in Question 7 (6, in the New Zealand study) (van der Maas et al., 1992, pp. 238-239).

It may be that some physicians in this study may also, upon reflection, have wished to “downgrade” the severity of their answers. Rather than this being a reflection of an actual lessening in the severity of the decision made, it may sometimes reflect the effectiveness of any defence mechanisms employed by the doctor to allow the comfortable recollection of an action that could have serious legal consequences, apart from the moral issues. It may be that the intense recollection necessary to complete the questionnaire triggers a mental process that over time, causes (or allows, if the deployment of defence mechanisms is seen as a positive effect) a change of interpretation of events. Elsewhere research indicates that physicians may struggle with how they would classify their MDEL-action with some reporting that they have performed euthanasia when their actions were better described as palliative care (Emanuel et al., 1998). Affirmative answers to Q.6 must therefore be viewed with caution.

Older doctors and less religious doctors were significantly more likely to have responded affirmatively to Question 6 (see Table 11.4, p. 170) and doctors who identified themselves as Māori were significantly more likely to have taken this action. However the figures related to ethnicity are of little use here given that 32 of the 39 doctors in this sub-group identified as Pakeha and only 2 as Māori. One respondent objected strongly to the ethnicity question on the questionnaire, challenging the usefulness and appropriateness of the information

Object! Data useless and politically hot. (NZ GP/543)

This text unit demonstrates again the attitudes of many doctors that the information in the questionnaire was sensitive.

When life was shortened by the actions in Question 6, this was by less than a week in 85% of cases. Clearly these patients were in end-stage disease and a strong assumption can be made that physician response was to address the suffering that can be associated with such disease. In the three cases where life was shortened by one to four weeks or more than six months (see Table 11.5, p. 170), there were no further details given about why the action was taken. A discussion took place with the patient in two of these cases but there was no discussion and no wish or

request expressed at any time by the patient in one case where life was shortened by one to four weeks (see Table 12.3, p. 205).

SUMMARY AND CONCLUSION

A MDEL-action that had the probability or explicit purpose of hastening the end of life was taken in 63% ($n = 1100$) of deaths attended. In 3.5% of deaths attended a drug was prescribed, supplied or administered by the doctor with the explicit purpose of hastening the end of life (or enabling the patient to end their own life). This figure indicates that the number of cases where medication is prescribed/supplied or administered for the explicit purpose of hastening death and death ensues is similar for patients in the care of general practitioners in New Zealand and Holland. If this figure is applied to the 3000 practicing general practitioners in New Zealand, at least 1.3% of general practitioners have performed this action in the last twelve months. The methodological rigor of asking respondents to report on the last death attended in the last twelve months suggests that this figure is probably conservative. Not all respondents were happy to restrict their answers to the last case in the last twelve months.

Because I have answered regarding the most recent death which was sudden and “unexpected” in a 90 year old unfortunately I have been denied the opportunity to answer Q3-21 and this frustrates me! I would have liked to participate more fully in your questionnaire. (NZ GP/804)

To get accurate picture of attitudes you need to ask about more than one episode of death. (NZ GP/352).

General practitioners also withhold and withdraw treatment with the explicit purpose of not prolonging life or hastening the end of life, the intent of the action clearly being to hasten the death of the patient. Such actions may arguably be seen as a method whereby the physician may intentionally hasten death on request by passive, and apparently lawful, means.

When any of the three actions explicitly taken to hasten the end of life were reported, a discussion occurred in less than half the cases, the majority (71.3%) of times because the patient was not considered competent. Previous requests or expressed wishes from the patient and the requests of others on behalf of the patient were reported most of the time in conjunction with the action taken when the patient was not judged competent to have a discussion.

When a discussion took place, this was more likely to be initiated by the physician when actions were proposed that had the probability of hastening death. When the action became more serious and had the partial or explicit intention of hastening death, the patient was more likely to initiate the discussion.

When an advance directive was available, this was influential in physician decision-making. Given the number of times actions were requested by those other than the patient (see Table 11.8, p. 174) when no discussion had occurred with the patient, an advance directive could be a positive presence in making patient wishes known when these can no longer be determined in real time.

Given the large majority of cases (85%) where life was shortened by less than 7 days (see Table 11.5, p. 170), the MDEL-actions taken were in response to distress experienced in the last few days of expected life and may therefore be seen as a compassionate response to need. The issue of vicarious suffering which has been raised suggests that the distress/response may not always have been, or not exclusively have been, on behalf of the patient (Goodwin, 1991).

The more serious the action considered, the more likely the physician was to include other professionals in the decision-making with “joint decision-making” given as the main reason for such consultation. As the decision became more serious, there is an increase in “exchanging information” as the reason for collegial discussion. Nurses were identified as primary consultants in decision-making.

A high proportion of physicians (148) made a death hastening decision without discussing it with the patient and without professional consultation. This may be related to avoiding consultation through fear of consequences when the action to be taken is judged to be the best medical decision but ethically or legally questionable.

Nurses were also identified as principal agents when drugs were administered with the explicit purpose of hastening the end of life and death ensued. In 13 of the 39 cases the doctor administered the drug alone, and in 15 cases the drug was administered by the nurse alone. In total, nurses administered the drug that ended the life of 21 patients (see Table 11.3, p. 167 & 12.3, p. 205).

There were only two cases of physician-assisted suicide reported (drug prescribed or supplied but not administered by the physician) (see Table 12.3, p. 205) although in three other cases the physician-assisted the patient to commit suicide. This suggests that in the majority of the 39 cases where there was an explicit intention to hasten death with a drug, the intervention of the physician or another professional was required to assist with drug administration either because this was physically necessary or because the patient preferred it. Physician intervention in the form of administering a lethal injection has been noted in previous research where complications have followed the self-administration of lethal drugs (Groenewoud et al., 2000).

There were 15 cases of euthanasia reported (drug administered by physician in response to a request or expressed wish by the patient for death to be hastened) and two cases of physician-assisted suicide (see Table 12.3, p. 205). The remaining 22 cases where a drug was prescribed, supplied or administered for the explicit purpose of hastening death and death ensued contravened the internationally agreed guidelines for euthanasia and physician-assisted suicide (Griffiths et al., 1998). Specifically, there was no request or someone other than the physician (euthanasia) or patient (physician-assisted suicide) administered the drug, i.e. a nurse.

Palliative care or pain management services are available and accessible for a large majority (88.9%) of New Zealand general practitioners. The very small minority of cases who expressed reservations about shared care seemed to reflect concerns related to the disruption in the general practitioner/patient relationship.

End of life decision-making has a high profile in the care given by New Zealand general practitioners with at least 63% of respondents having made such a decision in the previous twelve months. Given the stringent parameters of the research question, which related to the last death in the last twelve months, this number would certainly have been much higher if doctors were asked to report on any case in the previous twelve months where a medical decision at the end of life had been made.

To get accurate picture of attitudes you need to ask about more than one episode of death (NZ GP 325).

Bit frustrating as the last patient I was involved with was an acute MI in an 88 year old. I would have opinions on management in terminal care that are not canvassed here (NZ GP 499)

You ask for deaths in the last 12 months but there are ones in which I have assisted death which lie outside this time-frame (NZ GP 1038)

Issues surrounding end of life decision-making to do with communication about dying with patients/relatives, responding to requests for hastened death, advance directives, team dynamics and wellbeing, addressing suffering of patient and caregivers, palliative care and legal requirements should therefore have a high profile in education and the ongoing education of doctors. Moreover, the active involvement of nurses in serious decision-making suggests that this section of the care team should receive education specific to such decision-making and a clear directive as to their moral and legal obligations when following physician orders.

Physician attitude to a law change in New Zealand to accommodate elective assisted death seems to be related more to subjective attitudes towards experiences with hastening death than with the perceived need to hasten death, per se. In other words, some doctors feel comfortable with taking

actions explicitly to hasten death even when this may not be lawful, while others would prefer the protection of the law when such actions are considered.

Limitations of the study

- (i) As has been previously pointed out, the wording of the questionnaire may have “forced” respondents to indicate an action performed that did not correctly reflect the actual action performed. Several respondents objected to the word “probability” in Q.3 at least one indicating this should more correctly have read, “possibility”. This argument seems plausible in the case of increasing morphine to address pain (Q.3c) however “probability” may be more reflective of the potential outcome with the cessation of other treatments such as food and fluids, cardiac medications, dialysis etc (reflected in Q.3a and Q.3b).
- (ii) Physician interpretation of the questions and the actions taken in the case under consideration may have led to misrepresenting the action taken.
- (iii) By asking physicians to complete the questionnaire relating to a death which occurred at some time previous, the intervening period may have created a confound. Firstly if a death-hastening decision was made and the physician was uncomfortable with it, rationalisations may have been raised in the time since the death to allow the doctor to live with the action. Thus the responses may have reflected this defence mechanism rather than the action per se. However, no death occurred more than 12 months previously and it is plausible that many were within weeks of the questionnaire being filled out.
- (iv) The words included together in the questionnaire related to “not prolonging life” or “hastening the end of life?” and could arguably reflect to two different intentions for the doctor. The former is reflective of omission and the latter of commission. However in much philosophical argument, acts of omission and commission are considered to be ethically and morally similar. Legally in New Zealand these would also be considered similar relating to providing the necessities of life.
- (v) The structure and language of the questionnaire was criticised
 - A very difficult questionnaire to complete – complex issues that I do not believe are able to be determined by yes/no answers (NZ GP 292)
 - I am disturbed about Q.3c. In my opinion this could be taken to mean different things as the wording is not clear. ... I am sure others were similarly confused” (NZ GP 302).
 - This is obviously written by a Dutch person who has not concept of care of the terminally ill!!! (NZ GP 1169)
 - Shocking question (Q.5) – need a degree in English to translate (NZ GP 816).

- (vi) Further, it was suggested that the questions were not reflective of the different experiences of general practitioners in rural locations

Offering her tube feeding was not an option given remoteness and resources available. I do not think this questionnaire is well designed so will not give a reliable answer regarding end of life decision-making. A lot of things available in city practice are not available rurally (NZ GP 1107).

- (vii) Response rates may have been affected by the workload of the respondents and the number of questionnaires sent to general practitioners

You need to be aware that as a GP I have been sent about 6 different surveys in the last few months! May affect your return rate (NZ GP 979).

Those who felt most strongly about the issue may have been more likely to respond although asking about the last death in the last twelve months may have controlled somewhat for those respondents who may have wanted to express personal opinions on issues (apart from comments which have been reported and have been useful in illustrating points).

SECTION IV

CHAPTER 13

STUDY THREE: THE DUTCH EXPERIENCE – PHYSICIANS' CARING FOR THE DYING PATIENT

INTRODUCTION & METHODOLOGY

The Rummelink research is generally agreed to be rigorous and reliable (Emanuel, 1994a) however the interpretation of the data presented in the report has been criticised as being politically biased in an attempt to "remove any anxieties about the practice of euthanasia" (ten Have & Welie, 1992, p. 36). In part these authors argue that such bias is evidenced by the non-inclusion of 7,000 patients per annum who have treatment withdrawn or withheld even when this action has the aim of hastening death. The implication here is that withdrawing or withholding treatment, so called passive actions, should be reported as acts of euthanasia. Elsewhere it is argued that there is a difference between withdrawing or withholding treatment and euthanasia, not the least for the legal implications (Buchanan, 1995; Quill et al., 1997b). This raises the question of exactly where the line can be drawn between MDELs that are considered to be euthanasia and those that are normal medical practice, and it is argued that this distinction rests on the intent of the doctor performing the action (Gillett, 1991).

Differentiating between "motive" and "intent" Gillett (1991) endorses the motivation shown by Dutch doctors to relieve suffering but questions the use of euthanasia as a medium to achieve that

end, disputing the need to include "the intent to kill as part of our medical ethos" (Gillett, 1991, p. 121). Gillett argues that palliative care and the engagement of the physician on a "human" level with the patient will address the suffering of dying patients (Gillett, 1991). However, this may not be enough to address intractable suffering which can be a very real problem for patient and practitioner alike (Mount & Hamilton, 1994). It is suggested that a lack of palliative care expertise may be implicated in Holland and the Northern Territory developing legal structures to accommodate the practice of euthanasia as a way of addressing the suffering of patients (Buchanan, 1995).

Billings and Block (1996) criticize the "fine ethical distinctions" that discriminate among "voluntary active euthanasia, physician-assisted suicide, the principle of double effect, and withholding or withdrawing life-sustaining treatment" (p. 26). These authors appear impatient with what they call "subtle and often meaningless moral distinctions between intended and unintended consequences of actions or between slow and fast euthanasia" (p. 28). They suggest that "slow euthanasia", as in terminal sedation without hydrating the patient, is euthanasia presented in a way that is morally and legally acceptable. Further, the use of the term by these authors of "double-effect euthanasia" (Billings & Block, 1996, p. 25) rather than the more usual "double-effect" or "principle of double-effect" implies some impatience with what could be seen as euphemisms or a semantic 'dressing up' of a practice that clearly has the intention of hastening death. Elsewhere we are warned of "the insidious role of language in shaping the euthanasia debate" (Mount, 1996).

Some doctors appear confused over bioethical categorisation of the assistance they provide to the terminally ill. In a study of 355 oncologists in the United States, 56 indicated that they had acted intentionally to end a patient's life. Researchers found that 12 (21.4%) of these cases were not consistent with generally accepted definitions of euthanasia or physician-assisted suicide (Emanuel et al., 1998). However these doctors would have been living with their understanding of their actions as euthanasia.

In Australia, 5.3% of surgeons ($n = 683$) indicated they had given a patient a lethal bolus and 36.2% indicated they had given drugs with the intention of hastening death (Douglas et al., 2001). It is argued that whether the actions taken are "good palliative care" or "non-voluntary euthanasia" depends on subjective perceptions including perceptions of "intent" (Douglas et al., 2001; Gillon, 1999).

Concerns are expressed that MDELs that hasten death through one of the accepted mediums, i.e. withdrawing/withholding treatment, double effect, terminal sedation may go unscrutinized

(Billings & Block, 1996). Further, it is suggested that it may be in the best interests of the doctors not to endorse transparency of practice in making these decisions in order to preserve "maximal wiggle room" (Brody, 1996, p. 40). This will allow doctors who engage in such MDELs to present to themselves and others an account of these actions in a manner that preserves the ethical and moral assumptions that underpin acceptable medical practice within their society. Similarly, the doctors will be able to present accounts of these actions in ways that preserve personal philosophy and belief systems related to end of life care.

This study examines the accounts of two groups of Dutch doctors engaged in the care of the dying, to identify any differences in the approach to this care that may account for one group performing euthanasia and one group not. Conclusions drawn from the study may contribute to the debate that arises in New Zealand from time to time on whether euthanasia should be available in this country.

AIM

- To examine the accounts of Dutch doctors engaged in the care of the dying
- To identify similarities and differences in the approaches to care of Dutch doctors who have performed euthanasia and doctors who have not performed euthanasia

PROCEDURE

Semi-structured interviews were conducted with ten doctors in Holland, five who had performed euthanasia and five who had not. All doctors were involved in end of life care as a normal part of their practice.

Dutch doctors were interviewed for this study because they were able to speak openly and frankly about end of life care that hastens the death of the patient when this is intentional. Interviews conducted in New Zealand would not encourage such a breadth of inquiry given the legal implications for doctors of disclosing such actions.

Recruitment

Medical decisions at the end of life can occur in many locations so doctors in the community, hospice, nursing home and hospital were interviewed. Purposeful sampling was carried out. An introduction to the medical director of a nursing home led to interviews with several doctors. A personal approach was made initially by phone to medical directors in two other institutions who cared for the dying, resulting in more doctors agreeing to be interviewed. Further interviews with nurses and ancillary personnel were conducted as background to this work. Introductions to physicians also arose from some of these interviews. When contact was made with a potential

interviewee, an initial screening question ascertained whether or not they cared for dying patients as part of their practice. Those who had performed euthanasia consisted of four nursing home doctors and one general practitioner. Those who reported they had not performed euthanasia consisted of one nursing home doctor (palliative unit), three oncologists and one palliative care specialist. The even split between those who had performed euthanasia and those who had not was fortuitous (see Table 13.1, below).

Table 13.1: Table showing position, age and religious affiliation of ten Dutch doctors interviewed.

Identifier	Position	Age Years	Gender	Religious Affiliation
(EU1)	Nursing Home Physician	46	Male	No religion
(EU2)	Medical Chief, Nursing Home	53	Male	No religion
(EU3)	Nursing Home Physician	46	Male	Catholic
(EU4)	GP (retired)/Lecturer on Euthanasia	68	Male	No religion
(EU5)	Nursing Home Physician	42	Male	No religion
(NEU6)	Oncologist, University Hospital	45	Male	Catholic
(NEU7)	Palliative Care Specialist, Hospice	42	Male	Catholic
(NEU8)	Oncologist, University Hospital	61	Male	Catholic
(NEU9)	Nursing Home Physician (palliative care unit)	39	Female	Protestant
(NEU10)	Medical Oncologist, Hospital	46	Female	No religion

Key: EU = Doctor who has performed euthanasia. NEU - Doctor who has not performed euthanasia.

INTERVIEW PROCESS

When contact with a participant was achieved, telephone discussions explained the nature of the study and the participant information sheet, demographic sheet and consent form were sent to the respondent (see Appendix E). An appointment for the interview was made at this stage.

Interviews were conducted in English, the second language for all respondents. Interviews lasted for approximately one hour and were audiotaped. Respondents understood that the tape could be stopped at any time. Open questions were used initially to encourage disclosure on perspectives on end of life care, and later more direct questions related to disclosed personal experience with medical decisions that hasten death, guided by the discourse. If the doctor did not mention

euthanasia it was introduced by the question, "Have you had any experience with euthanasia?" If the doctor did not mention palliative care it was introduced by the question, "Could you tell me what palliative care is?"

Transcriptions

Interviews were transcribed and when a word required negotiation during the interview because of language difficulties respondents were advised that this was bracketed in the transcript.

Transcripts were sent to respondents within one week of the interview with instructions to add to, delete from or alter as they wanted to and return within one month of receipt. If they were not returned it was to be taken that the transcript was accepted as it read. All transcripts were returned. When the altered transcripts were returned, the final draft was corrected as per respondent instructions and imported into Nud*ist (Non numerical Unstructured Data Indexing Searching and Theory-building). Nud*ist is a computer program that allows for the systematic analysis of large amounts of qualitative data.

ANALYSIS

The level of analysis was restricted to broad themes and issues arising rather than an analysis of discourse occupied by the process by which these themes and issues came to be exposed. English was not the first language for any of the respondents. Concentrating on the "fine-grain examination of discourse" (Wetherell, Stiven, & Potter, 1987, p. 60) may have led to assumptions arising from the accounts that would not have been supported if the cultural language differential between researcher and researched did not exist. In this context, "cultural" is taken to mean the difference between Dutch and English as first language. Rather, in this study, the methodology of Wetherell et al. in their study of discourses concerning gender and employment opportunities was adopted. This focuses on

"the broad *types* of versions accessible to our respondents, the themes and theories they use to structure and formulate a world view for these interview topics or the set of inter-subjectively shared resources available to them in this case." (Wetherell et al., 1987)

Although the "versions, themes and theories" that are accessible to Dutch doctors in the context of this study may in many ways be "foreign" to this researcher and as such could be inaccessible, a shared culture between respondents and researcher in end of life care assisted in locating and naming these themes (see Reflexive Account).

A general inductive approach was taken to analysing interviews. Potter is critical of "hypothetico-deductivism" in psychological research that is occupied with studying social phenomena (Potter, 1997, p. 130). While not advocating "naïve, assumption-free inductivism", he endorses an approach that gives the researcher freedom to move within the data for a fuller

exploration of the subject matter (Potter, 1997, p. 130). The underlying assumptions of a general inductive approach begin with a deductive determination of research objectives followed by "multiple readings and interpretations of the raw data (inductive)" (Thomas, 2000). Analysis consists of developing categories and identifying themes and the research findings result from the interpretations of these themes by the researcher. The "trustworthiness" of the findings is to be found in comparisons with related findings through replication, previous research, triangulation (within the project) and feedback from participants and consumers of findings (Thomas, 2000). Trustworthiness in this study was addressed by

- (a) allowing respondents access to the interview before analysis for correction
- (b) an independent assessment of topic categories related to the interviews. This was achieved by supplying the rater with categories and a comprehensive explanation of what the category name signified. Text units in four or five randomly picked pages per interview were read and coded into categories. Some confusion occurred over the "Palliative Care" and "Autonomy" distinctions as these tended to be blurred in the interviews with doctors who had not performed euthanasia given that Autonomy was linked strongly to palliative care knowledge for this group. This is addressed by (d).
- (c) linking findings to current research (outside of this project)
- (d) transparency of process. This has been attempted by including sufficient representative text units to illustrate fully the themes under each topic. Analyses of the text under each theme form the basis of Issues Arising under each theme.

The specific objective of analysis was to identify the accounts doctors gave of their experiences directly related to medical decisions at the end of life and to explore these accounts for emergent themes. The transcripts were divided into the two groups (doctors who had performed euthanasia and doctors who had not) and group-wise analyses proceeded. Transcripts were read several times to develop an overall feeling for the content. There were two dominant categories evident in the interviews from each group to do with Palliative Care and Euthanasia. There were also two bisecting categories that were placed between the main categories as linking agents, called "Euthanasia-Palliative Care Continuum vs Dichotomy" and "Autonomy". Units of text were assigned to these four categories. Further reading exposed themes emergent under each of these categories, some parallel between the groups, others not. By that I mean that some of the themes were "mirrored" in the groups and others were found in one group only (see Table 14.1, p. 222).

"Issues Arising" under these themes were compared and contrasted between the groups and form the bulk of the comparative analysis. Themes and Issues Arising from those themes are summarised in tables throughout the comparison chapters. Each category is summarised and those categories that contained several themes contain more than one summary. These summaries form the basis of the Discussion section.

Instructions for reading data

- All reported text units are numbered.
- Although all Dutch respondents spoke excellent English, where a word or phrase was negotiated between the interviewer and the interviewee this was bracketed in the transcript to ensure the respondent was reminded of the negotiation to allow for re-thinking if necessary. These have been left in situ.
- Square brackets around researcher additions or precis of data
- Unreported data between two reported sections of data in one text unit is represented by ...
- One or more unreported text units between two reported sections of data from single respondent is represented by (gap)
- Numbers in brackets denote pause : (.1)= short (.9)= long
- /- denotes word cut off or not completed by speaker

REFLEXIVE ACCOUNT

I found that my self-perceived status as a white, middle-class, middle-aged female familiar with the medical field through my work as a palliative care nurse, provided some security (comfort-wise) when the interviews were carried out - all in the clinical setting, bar one. Moreover, I discovered that the period of time I spent in Holland (3 months) was perceived by the doctors as being quite a long time. I sensed that they took this as a sign of my commitment to the project and that they approved of this. Because of the unique approach of the Dutch to end of life care, they seemed used to people coming from overseas to do research, but the length of stay tended to be days rather than weeks (Crook, 1997). I found myself somewhat overwhelmed by their hospitality at times which in turn brought some degree of discomfort, as I did not want to present their accounts in anything other than the best light. That is to say, I was concerned that I did not contravene what could be perceived as the duty one would expect of a well-treated guest to speak well of the host.

My professional background as a palliative care nurse influenced my approach to the interviews. I could identify with much of the difficulties and experiences that were expressed about caring for the dying. However interviews were carried out at the beginning of my PhD work and I was aware of feeling some embarrassment when asking doctors in Holland to talk about their euthanasia experiences. I was aware of my cultural viewpoint which says that euthanasia is regarded as murder, and unethical and I found myself wanting to avoid using the word "euthanasia" in the interview. I was aware of *feeling* that discussions about euthanasia, and the doctors' involvement in euthanasia, were discussions about an illegal act, despite knowing that the practice was legally sanctioned in Holland, and this contributed to my discomfort. I was aware of being impressed with the depth of compassion of the doctors interviewed, and the apparent willingness to explore with me the perceived need to perform euthanasia, whether or not this had been done. I perceived a need by the doctors who had performed euthanasia for me to understand why they felt that they had had to do this (whether or not this "need" actually existed). Because of this I felt that I had permission to do this research with them.

There were many more interviews conducted in the course of this research of families, nurses and ancillary health workers. Interviews with doctors were chosen for this thesis but the wide exposure to the subject of euthanasia during the course of my activities facilitated a change in my feelings about the subject. I am aware that I can now discuss the subject and ask more direct questions of others about intentions and attitudes related to euthanasia without feeling the same initial awkwardness. Because of the complexity of motivations that have been exposed in this research pertaining to the euthanasia decision, I now find it difficult to separate euthanasia fully from some other palliative care actions that hasten death. This may have impacted on the way I have organised the data and the conclusions I have drawn.

I am an ex-hospice nurse and a strong advocate of palliative care. I have a Christian background although I no longer attend church. I do believe in a higher power, I do pray and I do believe that life is sacred. Before attempting this research, I believed strongly that euthanasia or physician-assisted suicide was "wrong" and I believed that effective palliative care should make the need for this redundant. However my hospice experiences made me question the seemingly arbitrary division between euthanasia and some palliative actions I had been involved with. The research undertaken for this section of the thesis has changed my views on euthanasia. I would have difficulty supporting a national and formalised euthanasia policy given the possible negative implications for some sections of society and I do not feel confident that all interests could effectively be safeguarded in New Zealand as health care now stands. However I now believe that there is a place for euthanasia or assisted suicide (not necessarily physician-assisted but not excluding physician-assisted) in New Zealand. I believe such options should only be available

in a palliative-rich environment, but equally I wonder if a lack of palliative care may make such actions more necessary. I do not feel wholly comfortable with this change in my views, aware of the loss of security of a certainty of position.

CHAPTER 14

RESULTS

Four similar categories were identified in the accounts of doctors who had performed euthanasia and those who had not. There were two main categories evident to do with Palliative Care and Euthanasia. There were two smaller bisecting categories evident to do with Palliative Care/Euthanasia Continuum vs Dichotomy and Autonomy. Some themes emergent under these categories were similar, others differed (see Table 14.1, below).

Table 14.1: Table showing categories and themes represented in discursive accounts of Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not².

EUTHANASIA ¹	NO EUTHANASIA ²
CATEGORY 1: PALLIATIVE CARE	
<ul style="list-style-type: none"> • Characteristics of Palliative Care • Treatment withdrawal • Terminal Crises precipitate hastening death actions • Palliative care requires a multi-disciplinary team approach • Delivery of palliative care to the consumer (institutionalisation and education) 	<ul style="list-style-type: none"> • Characteristics of Palliative Care • Commitment to the patient part of palliative care • Effective palliative care solutions can be relatively simple • Treatment withdrawal • Terminal Crises precipitates hastening death actions • Palliative care requires a multi-disciplinary team approach • Palliative care involves a facilitative function that requires a team approach • Delivery of palliative care to the consumer (institutionalisation and education)
CATEGORY 2: EUTHANASIA/PALLIATIVE CARE CONTINUUM VS DICHOTOMY	
<ul style="list-style-type: none"> • Palliative care that hastens death is judged analogous to euthanasia 	<ul style="list-style-type: none"> • Terminal sedation is the hardest "palliative" option and different from euthanasia. • Terminal sedation is not always a viable "solution"
CATEGORY 3: AUTONOMY	
<ul style="list-style-type: none"> • Autonomy in euthanasia decision-making • Effect on consumer of euthanasia availability in society 	<ul style="list-style-type: none"> • Empowerment in practice – increasing autonomy by providing care alternatives • A lack of palliative care knowledge limits the autonomy of the doctor by limiting treatment options • Effect on consumer of euthanasia availability in society
CATEGORY 4: EUTHANASIA	
<ul style="list-style-type: none"> • The euthanasia request • Protocols and processes – facilitative function • Difficulties with protocols and processes • Effect before euthanasia is performed • Effect after euthanasia is performed • Relieving the dissonance associated with performing euthanasia 	<ul style="list-style-type: none"> • The euthanasia request • Considering the euthanasia request part of commitment to patient • Implications of performing euthanasia for the practitioner • Effect on doctor of performing euthanasia

CATEGORY 1: PALLIATIVE CARE

Characteristics of Palliative Care

All doctors appeared to have a good understanding of palliative care in the care of the dying (see Table 14.2, p. 224). That is, to address physical and psychological symptoms related to the dying process with "care" not "cure" as the primary focus. The most common definition of palliative care was comfort care at the end of life and this is exemplified by one EU doctor who stated that palliative care included a multidisciplinary approach (L13-18, L20-22) to patient focused care (L6-8, L20-22) concentrating on quality of life issues (L2-4, 11-15, L20-22). This included spending time with the patient (L12-13) and working with loved ones facilitating leave taking (L13-14). It could also involve aggressive "curative" care (L9-11, L23-27). Others from both groups cited similar points. Doctors from each group raised the issue of palliative care being given at all stages of illness, not just in the dying phase. This is a liberal interpretation of a method of care that has largely been appropriated as applying to the care of the dying patient (Doyle, Hanks, & MacDonald, 1998). In these respects, when the accounts of palliative care characteristics for the two groups of doctors are compared, they are similar.

1 *EU5 I think it's the point where you as a physician accept that you cannot, or will not*
2 *(take measures) to prolong life. It's the sort of care that starts after that point ... I think*
3 *the primary role to prolong life fades away, and the other role, the quality of life, not to*
4 *prolong life, making the life a richer quality, that is the field of palliative care. So it's*
5 *very broad, it has a lot of aspects which the physician has a role as physician, but it is far*
6 *broader. You want to give someone comfort, and your attention is directed not on curing*
7 *all kinds of diseases which probably aren't curable anyhow, but you ask yourself, what*
8 *does this symptom, or this disease, mean [emphasis] for the person. Does he suffer, is*
9 *there any need to change (treatment). When the person who has metastatic disease in the*
10 *bone and breaks a bone, and has a life expectancy of more than a few weeks, it could be a*
11 *good idea for the bone to be operated on if that can take away the pain. So it is another*
12 *way of looking at things. It means also that you need time in the room for people to*
13 *express themselves on how they want to look back on their life, or how they want to part*
14 *from relatives, or people they know. It's so much more - in a psychological way you have*
15 *to look at so many more aspects than just cure. Because things like pain killers, and*
16 *things like wheelchairs and things like that are a technical part, but they have no other*
17 *intention than to give more comfort. So I think most - the one thing in palliative care is*
18 *giving attention to people. (Dutch nursing home doctor)*

19 *K Okay. Um, can you tell me what you think palliative care is?*
20 *NEU6 Yes, I think I can. Um, first of all, palliative care means that all the sorrow*
21 *of the people, psychological, as well physical, as well emotional, as well spiritual, as well*
22 *in the social context, should be (addressed). And there is no special moment that you can*
23 *say "Now it starts, and before it shouldn't". It is at any time. ... And some people think*
24 *you only address people who are terminally ill and will only live a few hours a few days a*
25 *few weeks, but it starts at the beginning of the diagnosis of cancer, and if you are treating*
26 *people not for cancer but for any other disease, acute or chronic, it doesn't matter, you*
27 *should have an eye for the palliative side. Somebody breaks his leg, and you just start*
28 *treating it, you do wrong. At least you must give a pain killer before you do anything. Of*
29 *course the pain killers do nothing for the survival of the patient (Dutch Medical*
30 *Oncologist).*

Table 14.2: Table showing issues arising around characteristics of palliative care for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not².

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Characteristics of Palliative Care</u></p> <p><u>Issues Arising</u></p> <p>There was good understanding of doctors in this group as to the function and characteristics of palliative care. Explanations included</p> <ul style="list-style-type: none"> (i) wholistic care at the end of life that focuses on quality of life (ii) multidisciplinary approach (iii) patient focused (iv) requires time with the patient (v) aggressive "curative" care at times (vi) includes relatives and loved ones (vii) facilitates leave taking (viii) care at any stage of illness that works to minimise unpleasant symptoms for the patient that cannot be controlled by medicine (ix) Psychological interventions to address the patient's fear of dying. 	<p><u>Characteristics of Palliative Care</u></p> <p><u>Issues Arising</u></p> <ul style="list-style-type: none"> • These doctors had an understanding of palliative care that included all the characteristics identified by the EU doctors. • There was a strong differentiation made between palliative care that addresses physical pain and palliative care that addresses suffering on another level. • Deeply disturbing issues surface at the end of life and may present palliative care challenges when the attendant suffering impacts on symptoms. • A hospice approach was seen as best suited to meet the challenge of addressing these symptoms and to facilitate leave-taking. • Palliative care to address such suffering required unconditional commitment. <p><u>Commitment to the patient part of palliative care</u></p> <p><u>Issues Arising.</u></p> <ul style="list-style-type: none"> • Verbal assurance that the doctor was committed to the patient increased patient confidence that the doctor would always be there • Unconditional acceptance of the patient, despite personal feelings is part of practitioner commitment. • Unconditional acceptance and professional support of patient's care decisions, regardless of personal feelings about these. <p><u>Effective palliative care solutions can be relatively simple</u></p> <p><u>Issues Arising</u></p> <ul style="list-style-type: none"> • Effective palliative interventions can be relatively simple. • Simple interventions involved the practitioner in <ul style="list-style-type: none"> - Developing an intimate relationship with the patient to increase patient confidence in practitioner commitment - Encouraging patient disclosure on fears related to dying and addressing those fears - Normalising the dying experience to develop patient confidence in the dying process - Providing information on what may happen in the dying process - Including the family by providing information and support

EU3 goes further to suggest that the care of the dying would be better termed "terminal care" and that the use of the word "palliative" when applied to the dying is euphemistic and "hiding" from the reality of what is happening.

31 (EU3) *We call it terminal care in Holland, not palliative care. ... We think that's*
32 *quite a good word but there's a taboo because terminal is terminal and palliative is you*
33 *may say, a little bit hiding from it. Me myself, I am talking about palliative care in the*
34 *terminal phase, palliative care in the chronic phase, palliative care in the curative phase.*
35 *"Palliative" just means wholistic (Medical Director, Dutch nursing home)*

It was suggested by one NEU doctor that palliative care was seen by "many people" in terms of pain control only, in Holland (L36-38). This doctor suggested that pain control was extremely well done in Holland (L38-39) but that more than "just" pain control was involved in palliative care (L39-40). Each symptom resulted in "spiritual" changes that the practitioner must be aware of because they may be extremely important in terminal care (L42-44). In Holland in the past, pain control equated to palliative care without recognition of the need to address psychological suffering to achieve the balance required in palliative care (L46-50).

36 NEU7 *And many people in this country think that palliative care is pain control, and*
37 *pain control is anaesthesiology and anaesthesiology is pricking, injecting, cutting nerves,*
38 *and that's all. And if you define palliative care like this, we have beautiful palliative care*
39 *in this country - we have specialists at the top level in the world. But that's not all*
40 *palliative care is.*
41 (gap)
42 *Every pain, and every symptom is also resulting in some spiritual changes and you must*
43 *be very aware of [these]. ... And for terminal patients, they may be extremely important,*
44 *extremely important.*
45 (gap)
46 *We have the feeling in this country, for many years, well, pain is the most important, if*
47 *you take away the pain other problems will be solved automatically, you don't need to care*
48 *for these feelings. But that is wrong. ... We need to integrate (the whole care), and weigh*
49 *up what is being done, what are the results of it, to make it good, to make it balance. And*
50 *balance, that is palliative care.*
51 (Dutch hospice doctor)

However doctors from both groups did differentiate between physical symptoms and psychological symptoms stating that the psychological suffering experienced by the dying patient could be more distressing than physical symptoms. Further, the psychological distress some dying patients experienced was deeper than that experienced with some psychological illnesses such as depression.

52 EU2) *Palliative care. For me it means looking to the whole person, seeing his*
53 *suffering, and trying not to cure because that's almost impossible, ja? to cure? but to help*
54 *as much as possible. With all kinds.*
55 K *What do you mean by all kinds?*
56 (EU2) *Well, it's not only physical, but also psychological. It has more aspects.*
57 K *Okay. And are you thinking of psychological illness like, um, like perhaps depression,*
58 *or is it more than that?*
59 (EU2) *Oh, it's more than that, it's sure more than that.*
60 K *Can you put it into words - what do you mean?*
61 (EU2) *Oh, it's a bit difficult (wry laugh). Okay. It's the fear for what's coming for*
62 *them, but also very - you understand me? ... Ah, when there is someone with lung cancer*
63 *and it goes very bad with them, the dyspnoea is progressing, his pain is progressing, you*
64 *tried all kinds of medicine - morphine, neuroleptics, etc, ja? and it's not possible to help*
65 *him, ja? He is also fearing for the next moment to be more distressed, ja? Well all parts*
66 *of that are (involved) in palliative (care) in my opinion (Medical Director, Dutch nursing*
67 *home).*

There is a sense that there may be two levels of psychological distress that the dying patient may experience. The first involves the "normal" psychological issues one might expect during the dying experience related to grief, fear, anxiety etc (which is not to say that all persons may experience these). The second involves suffering at a deeper level. While the EU doctors acknowledged the wholistic nature of palliative care and the depth of psychological suffering that it may need to address, NEU doctors were more specific about the nature of this deep suffering.

One NEU doctor gave a graphically descriptive example of this suffering. He suggested that the patient operated on three levels. The "first level" was health. The "second level" was ill health, physical or psychological, which required symptom control. The "third level" addressed deeper suffering that could manifest itself in intractable physical symptoms. Such suffering was deemed to be "spiritual" in nature, but not restricted to religion. The cause of such suffering was attributed to unresolved issues in the past. The approach of death allowed/encouraged such issues to surface. Much of the intractable suffering that may be experienced in the dying phase was attributed to the failure of medicine to address such suffering.

68 *NEU 7* *Then there is a third level which is more abstract. ... What I call*
69 *spiritual pain - they are soul wounds. People who are damaged in the past, had multiple*
70 *losses or very significant losses which they couldn't work through, and this hurts. And*
71 *wounds tend to open at the end of life, especially when the wounds were never healed,*
72 *never well worked through. People are not aware of them any more, or they have denied*
73 *this for many years They tend to open at the end of life, and hurt a lot. And that's a kind*
74 *of spiritual pain people experience which is adding suffering to the physical pain. It*
75 *can be manifested as a physical pain, sometimes intractable pain*
76 *(gap)*
77 *Spiritual care, I do not see as religious care - it's something completely different.*
78 *(gap)*
79 *I don't think there is the need to (suggest) that everybody, every patient has spiritual pain*
80 *and these kinds of needs, but in the very complicated cases, it is really one of the most*
81 *common reasons of failure of technological medicine. (Dutch hospice doctor)*

Two of the case studies reported by NEU doctors suggest that it may be necessary to assess whether the surfacing issues require caregivers to facilitate disclosure, or to facilitate continued repression, possibly using drugs. The first concerns a patient who clearly needed and wanted to unburden himself at the end of life, and the second a patient who may have preferred not to. Both of these patients were suffering unbearably, and both had requested euthanasia to address this suffering.

The patient discussed by NEU7 had kept his secret for fifty years. The doctor stated that he believed the patient wanted to disclose (L114-115). When he was provided with the opportunity and environment in which to do so, he benefited from doing this through a reduction in physical pain prior to death (L124). The particular approach possible in the hospice environment was described as "*special*" (L137-140) and successfully addressed the suffering being experienced on this level by this patient. This approach required (a) a skilled practitioner who recognised the

patient's need to disclose (L115-116) (b) time to spend with the patient (L116-117), (c) privacy, possibly without the patient's family (L129-130), (d) unconditional acceptance of the patient's story (L136-138), (e) empathy (L138), (f) the trust of the patient (L138-140). The patient described died peacefully after a period of protracted and unrelieved anguish and pain, once he had unburdened himself to a nurse.

82 *NEU7* *What I call spiritual pain - they are soul wounds. People who are damaged in*
83 *the past, had multiple losses or very significant losses which they couldn't work through,*
84 *and this hurts. And wounds tend to open at the end of life, especially when the wounds*
85 *were never healed, never well worked through. People are not aware of them any more,*
86 *or they have denied this for many years They tend to open at the end of life, and hurt a*
87 *lot. And that's a kind of spiritual pain people experience which is adding suffering to the*
88 *physical pain. It can be manifested as a physical pain, sometimes intractable pain. We*
89 *have plenty of this kind of person in hospice, because this is (something) our very*
90 *pragmatic medicine cannot deal with and the patient is looking for other opportunities,*
91 *other possibilities, and they find hospice. Well, with some spiritual care, looking at the*
92 *patient from a different angle, you can do a lot for them, if you understand where they are*
93 *coming from. I can give you an example of a (very recent) patient. This was a patient*
94 *without cancer, but with obliterated blood vessels in both his legs from smoking a lot. At*
95 *a certain moment he went to the hospital because one of his legs became necrotic and*
96 *started to smell and his toes were falling off. He went to the hospital and the doctor said*
97 *that his leg must be amputated - this was the only way to treat the pain. (The patient)*
98 *started to have horrible pain and said "No, no, no amputation - never. Never in my life,*
99 *amputation". So this patient - the doctor said "Okay" and put as many as possible*
100 *fentanyl patches on his back, and he will be (pain free). They increased the dose, and*
101 *nothing worked, really nothing worked. The man was horribly in pain. They came to*
102 *something like 600 - 6 large patches of 100mcg. The man was asleep, was waking up and*
103 *still in pain and crying from pain. At a certain moment he asked for euthanasia and his*
104 *GP responded to this and said, "Okay, I feel (that this is justified) but I need to have a*
105 *second opinion from another doctor". Another doctor came and he said "No, no*
106 *euthanasia, because this is a reversible pain. You can amputate his leg. If he doesn't*
107 *want to amputate his leg, (that's his decision). No euthanasia for him". And they turned*
108 *their back on the patient, and he was suffering horribly. At a certain moment, the district*
109 *nurse said "You can phone hospice, he can go to hospice". And the GP asked me for*
110 *consultation. I came to see (the patient). We started to treat his pain at home, it was a*
111 *little bit successful, but I couldn't do miracles at home and I said the next day that he*
112 *should come to hospice and we could take care of him there much better. I needed to have*
113 *intensive control on what I was doing from one hour to another. And he came to hospice,*
114 *and we started to treat his pain, and it (lessened) In the evening he had less pain, not*
115 *without pain, but he had less, and he started to tell the story of his life. And the nurse*
116 *from hospice knew something would happen now and she called another nurse to come to*
117 *take over the whole house, and she went to sit with this patient. And he told the story of*
118 *the war time when he was in a Japanese camp in Indonesia. And there he was forced by*
119 *Japanese to do things so horrible that he could not even talk with his wife. He never*
120 *talked with his wife about it. It was something about leg amputation, and and, well*
121 *something about corpses. And when they proposed to him, leg amputation, he said, "No*
122 *never. It is the last thing that I will do to myself". So it was very much a spiritual pain -*
123 *he couldn't tell anybody about this - even his wife - what he was suffering, because he*
124 *tried to protect her. And the next day he died, without pain. That's a story of enormous*
125 *suffering that everybody tried to approach with a more physical approach, (that came*
126 *from) so much suffering from far far ago. And I think that with the proper attention to*
127 *these kinds of things, also proper treatment of pain, this man would have had an earlier*
128 *opportunity to open (up), to tell his story, and to reconcile with his wife and to discuss this*
129 *with his wife, and to, well, this was a horrible problem. He wanted to do this with the*
130 *nurse - to talk with the nurse, and not with his wife. And that's spiritual pain we*
131 *experience very often. And these are things that modern medicine has no idea about, and*
132 *no advice and no hope to discover this.*
133 *K* *So do you think that spiritual pain is on the third level, or part of the third level, or is*
134 *the third level?*
135 *NEU7* *Ja. Ja They are old wounds, sometimes fresh, sometimes old, but*
136 *some of these wounds tend to open and they are all on the third level. And that's, for the*

137 *patient, not so easy to talk about. And you must have the special approach, you must have*
138 *the empathy, you must have the trust too. How is it possible if somebody is coming from*
139 *outside, a doctor, and he knew him for 24 hours? And yet he had enough trust in us, and*
140 *he told the story - he wanted to get rid of it. But, it must be a special approach. (Dutch*
141 *hospice doctor)*

Another doctor supported the view that deep-seated issues surface at the end of life and can cause difficulties for the patient. In this case the patient was extremely distressed by physical symptoms and the emotional expression of issues around a difficult marriage (L145-146). He begged for relief from his suffering (L146-147). The doctor increased morphine to address the suffering, thereby preventing further communication between the patient and his wife (147-149). The wife was very angry that communication had stopped (L149-150). The doctor expressed some surprise that the communications had not been carried out at some previous time. There is a sense in this account that the issues were addressed (facilitated by a psychiatrist) more to meet the needs of the wife than the husband.

142 *NEU8 About a half a year ago a person was going to die. He was extremely ill,*
143 *he had asked for dying some months before and every time, (he asked) again. Three days*
144 *before the patient really died, a psychiatrist came to discuss with him and his wife, the*
145 *problems he had. And they had difficulty in their marriage in the past, and there was*
146 *much emotion (expressed). And on Friday, because that person [was physically*
147 *distressed] he said "Help me, I can't live like this". I gave him the morphine, and the*
148 *patient slept because he was so sick and he was dyspnoeic because the problems were in*
149 *the lung... and the day the patient died, the wife of the person came to me and was very*
150 *angry that I had given the patient morphine, because she had so much to tell him about*
151 *the problems in the past. ... Yes. She was very angry that the dialogue was stopped. ...*
152 *It was strange that it was just such a talk at the end of life. It should be done months*
153 *before of course. (Dutch Medical Oncologist).*

Another NEU doctor mentioned that the inability of the patient to live with their situation, and the inability to talk their feelings through was a source of deep psychological suffering which negatively affected the dying experience.

154 *NEU9 More often, there are psychological things which you can't help. ...*
155 *sometimes people can't live with their past, can't live with their illness and the loss of so*
156 *many things. Sometimes also because they can't talk at all. Sometimes you meet people*
157 *where you know there are great problems, but they can't talk ... and you see them getting*
158 *um, and then you don't finish the way you would like. (Dutch nursing home doctor)*

Commitment to the patient part of palliative care

The commitment to the patient evident in the accounts of both groups of doctors when discussing the characteristics of palliative care appeared to deepen and be translated on another level in the accounts by the NEU doctors (see Table 14.2, p. 224). One suggested that verbalising commitment statements to the patient was a way of increasing the patient's trust and confidence. She had underscored "commitment" statements in the transcript when she had the opportunity of editing this.

159 *NEU9 Um, but I think it's our task, um, you have an English saying, to*
160 *cure sometimes, to um, and the last thing is to comfort always. And I think I have to*
161 *comfort always, otherwise I can't say to this patient when he comes it, "We will be there*
162 *[underscored in transcript], whatever happens [underscored three times], we will be*

163 *there". And I can't say that when we might get into circumstances that there is nothing*
 164 *more (to be done) and then I say "Sorry, this is it". Then I can't say when they come in*
 165 *"We will be there".*
 166 *K Do you say that to them when they come in? We will be with you? Do you actually*
 167 *verbalise that to the patient so they have that assurance that you will be there.*
 168 *NEU9 Ja, ja. And it works. People get to know that you will always be there.*
 169 *(Dutch nursing home doctor)*

When a patient refuses help to address psychological or physical suffering it was seen as important to stay with the patient until death, and to accept the patient's decision and way of dying. It was stated by two doctors that this may be difficult to do. NEU7 raised the issue of overcoming personal negative feelings for the patient in order to maintain unconditional commitment.

170 *K Okay, so if you have patients that are experiencing this and they can't or won't open*
 171 *up, and they are dying terribly, what would your response be to a patient like that?*
 172 *NEU7 Well, you can't do much. You can't make this possible, (if) the patient*
 173 *refuses, and a lot of people refuse this, or are afraid of or do not trust. Very important is*
 174 *to be with the patient to the very end. Not to be frustrated or to turn with the back to the*
 175 *patient. "You don't like me, I don't like you". It is hard to stay with such a patient and to*
 176 *accept him like he is. And this acceptance is also very important. (Dutch hospice doctor)*

NEU9 stated that she felt she had failed as a doctor (L183) because there was no acceptable way (to the patient) of relieving the patient's pain (L181-184). She found it difficult to see the patient every day knowing that the pain was unrelieved. There is a sense here that this doctor understood her function was to support the patient's decision despite the negative psychological effect on herself. This ties in with the level of commitment previously mentioned (L161-163).

177 *NEU9 I remember especially one 85 year old woman who had quite a lot of pain.*
 178 *She stayed in our home for a very long time. 6 - 9 months. And for her it was clear that*
 179 *life was given by God and he would take it. That's the Dutch way of saying it, "God gives*
 180 *life and God will take it". Well there it was clear that I just had to be there, but that was*
 181 *it. And I had to keep thinking of course, to try to comfort her, but my role would never be*
 182 *to do whatever that could shorten her life. It was very clear. So in that sense I had a*
 183 *problem because I felt myself more or less failing as a doctor, in the sense I wanted her to*
 184 *have no pain and I couldn't, and she didn't want to do anything. And I think that was*
 185 *more distressing for me than for her. It sounds a bit strange, but I think that was the*
 186 *(case). Because I had to (see) her every day, and I saw her suffering and I think it was*
 187 *my problem that for me it was hard to see her suffering and to see her choosing this fate.*
 188 *But of course we did. ... She chose this way to die, and she was of course, she was*
 189 *allowed to choose this way to die. (Dutch nursing home doctor)*

Effective palliative care solutions can be relatively simple

Palliative interventions can be relatively simple and yet effective. NEU9 stated that spending time developing a relationship with the patient helped the patient to feel "known" which was depicted positively (L211). Addressing patient concerns was normalising (L196-201). Sharing information with the patient was empowering (L203-207). For this doctor the "important" information about the patient was not necessarily in the patient notes and required time and the provision of a supportive environment to encourage the patient to disclose (L190-196). This mirrors the account of NEU7 who spoke of the nurse making time for the patient to disclose

(L115-117) and the importance of "empathy" and a "special approach" to encourage patient trust (L135-140). (see also L354-358)

190 NEU9 *You know, people come in, and take half an hour at least just for*
191 *these people to tell their story. I let them tell what they like to tell me so I don't, as a*
192 *doctor often does, ask when were you operated (on), how was this, how was that, I just let*
193 *them talk for half an hour. ... And after half an hour, I know what is important for*
194 *them. That's what I want to know. I mean their history, their medical history is written*
195 *down somewhere. What's important to them usually is not written down, and I like to*
196 *know about it. And then often for example, people tell me, "I don't eat very well". And*
197 *they don't complain about it, they just tell me. And then I think it's my task to talk about*
198 *that, and to talk, maybe just to tell them that it's very normal that they don't eat. ... And I*
199 *try then to help them to feel more comfortable and more (looking for word) this word will*
200 *come up later, it is an important word, but to find a place where they can be safe, a safe*
201 *place.*

202 K *Confident?*

203 NEU9 *Confident! And where they know I can be 'who I am', and 'where*
204 *people understand me', and 'they will try to help me in the way I like'. And often you can*
205 *achieve this within this first talk, just by picking up some of those things, and also (if) they*
206 *don't complain, I think it's my task to tell them when I think it's appropriate, to talk about*
207 *that. And then you see them "Oh, it's normal" (relieved) "Why didn't anybody tell me?"*
208 *Because "my wife wants me to eat I think I should eat", and you know, they are*
209 *comfortable because of this information (and) they just start to eat everything they like*
210 *now. They are very simple things to help them feel comfortable um which are not*
211 *complicated or expensive. You know, they have to feel "known" to the person. (Dutch*
212 *nursing home doctor)*

As well as empowerment, sharing information with the patient was seen as a preventative in reducing the potential for end of life crises. When the patient understood the psychological processes involved at the end of life, it appeared to decrease anxiety. Prevention was seen as an important component of palliative care for the patient and the family.

213 NEU 7 *But also, people are very afraid that they will lose their mind. They*
214 *will get comatose or they will get crazy. And you can prevent it. You can warn them, you*
215 *can prepare them for this (feeling like they will lose their mind) and that. In prevention,*
216 *giving information is most important. You are preventing a lot by informing patients of*
217 *what can happen. And it is not increasing patient's anxiety, but decreasing it.*
218 *(gap)*
219 *Preventing critical situations which may lead to crisis ... And I think three quarters of*
220 *what I am doing is preventing - a very important dimension of palliative care.*
221 *(gap)*
222 *It (giving information) prevents also breakdown among the carers. If you do this*
223 *properly, you will get a lot of satisfaction, and people, especially families, are very grateful*
224 *for this. (Dutch hospice doctor)*

NEU9 concurred with this notion of the preventative function of palliative care. It was postulated that anxiety experienced was associated with the unfamiliarity of the dying process through lack of exposure in modern society to dying (L229-231). This anxiety was related to (a) how death would occur (L225), (b) experiencing pain (L226), (c) experiencing anxiety (L226), (d) altered body image/social role (L226-227), (e) dependency (L227), (f) family not coping (L227-228). This doctor stated that the patient gained confidence from knowing that dying was "normal" for staff in the hospice facility (L231-234). Doyle argues that the increasing institutionalisation of dying is due partly to increased health care funding to hospitals over community; patient/family preference for hospital care to relieve carer stress and increased access

to medical and nursing personnel and medications in institutions over the community (Doyle, 1998a). The result of this is that people are increasingly not involved in caring for their dying loved ones and are unfamiliar with what can be expected.

225 NEU9 *But people are afraid of what will come. How will they die, they don't*
226 *know. Will they have to suffer pain? Will they be anxious? How will they look now for*
227 *those around them? Will the family be able to take care of them at home, or are they too*
228 *tired? There are many things they think about. I think the word "anxiety" is the central*
229 *word in all this. And "anxiety" and "insecurity", I think these are the central words,*
230 *because this is a way you have to go which you never went (before). The unknown way.*
231 *And nowadays people don't see so many people dying in their surroundings. So I think*
232 *it's very important for people, they have to know this is normal here, we know about it, we*
233 *know how these things will happen. I don't know of course, exactly how this patient will*
234 *die, but I know how people die. Of course we have to preview possible problems,*
235 *and sometimes we'll talk about those with the patients. (Dutch nursing home doctor)*

To summarise, both groups of doctors spoke of palliative care as a discipline that addresses the physical and psychological suffering associated with disease processes for which there is no cure. Doctors from both groups recognised that work to normalise the dying experience for the patient and the family requires time and commitment from the practitioners. A commitment to this approach is thought to reduce patient/family anxiety, increases confidence and acts to prevent crises in end of life care management.

Doctors who had not performed euthanasia elaborated on the nature of suffering in the dying phase and suggested that it may have an underlying etiology in unresolved issues from the past that surface at the end of life. The patient may require assistance and support to disclose and resolve issues prior to death or may prefer assistance and support to continue repressing issues. There is a need for clinical staff to assess the patient's preferred option. Palliative care knowledge may increase practitioner comfort in exploring the nature of suffering with patients, the physician feeling confident in an ability to address this suffering effectively. If the palliative care knowledge of the NEU doctors was superior to that of the EU doctors (and this might be expected in the case of NEU7 given his hospice experience) this may explain their greater emphasis on this aspect of care noted in the interviews.

Treatment Withdrawal

Doctors in both groups expressed concern that the treatment given to patients, including artificial nutrition and hydration was often inappropriate in the terminal stage of an illness (see Table 14.3, p. 232).

Table 14.3: Table showing issues arising around palliative care, treatment withdrawal and terminal crises for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not².

<u>EUTHANASIA</u>	<u>NO EUTHANASIA</u>
<p><u>Treatment withdrawal</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Artificial nutrition and hydration in the terminal phase of illness is inappropriate and interferes with natural death. • Life saving treatment should not be administered to terminally ill patients <u>unless</u> the threat is unlikely to cause death i.e. urinary tract infection which would make the patient uncomfortable but would not necessarily lead to death. • Administering treatment inappropriately at the end of life results in a prolonged death which is a modern form of medical torture. <p><u>Terminal Crises precipitate hastening death actions</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • When a terminal crisis occurs and there is no time to meet correct procedures for euthanasia the doctor may take palliative action to control pain that results in hastened death. • Foreseeing death from palliative actions may be the same as euthanasia. • Doctors for whom euthanasia is not an option may increase morphine as a response to intractable pain without thinking through the consequences of subsequently hastening death. • Terminal sedation is given when there is not the time or opportunity to meet the correct procedures for euthanasia. 	<p><u>Treatment withdrawal</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • If treatment including the artificial administration of food and fluids is withdrawn at the appropriate time the dying patient is less likely to require euthanasia to achieve a peaceful death. • Withdrawing treatment may be more difficult in a hospital setting that is committed to cure. <p><u>Terminal Crises precipitate hastening death actions</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Euthanasia is not possible to meet terminal crises. Such crises require immediate action and euthanasia cannot be performed without going through the necessary legal protocols. • Palliative alternatives may be introduced in such crises, even if the action hastens death. • The practitioner should be aware of the role of "intent" when administering large doses of opioids in a terminal crises. • Life threatening doses of medication should not be administered without discussing the possible consequences with the patient.

NEU9 acknowledged that withdrawing treatment may be difficult in institutions that are committed to curing the patient. The staff may find it hard to change from a "cure" mentality to a "care" mentality that embraces the concept of the life ending. However she stated that if medical staff did not make the decision to withdraw or withhold treatment they may be faced with a decision further down the line about whether to actively terminate the life of the patient. Euthanasia in intensive care where the emphasis is on life-sustaining treatment was considered to be an oxymoron by this doctor. She considered such a concept "stupid", while acknowledging the difficulty for the staff involved.

236 *NEU9 I think in many cases people get euthanasia where the treatment goes on*
 237 *until the moment of euthanasia and then I think "Please stop your treatment, so the*
 238 *patient will die". The people get the fluid and feeding and not in the normal way but they*
 239 *get a central line for feeding, they get everything (incredulous) because they can't eat any*
 240 *more and then I say, why don't you stop this feeding, why don't you help this patient, not*
 241 *to suffer any more or why did you at all start this feeding? Didn't you know then what*
 242 *you were getting into? Because then you don't need euthanasia. Euthanasia often is*

243 *necessary, seems to be necessary where your medical treatment in fact was (going on) too*
 244 *long. It was (inappropriate). Stupid.*
 245 *(gap)*
 246 *In a hospital they are to cure people, this is also their way of thinking. And you often see*
 247 *that it is difficult for them to change their mind and to say "Well, it's over, that we cure, it*
 248 *is also over that we try to lengthen his or her life in an active way, so we should start to*
 249 *talk about the end". That's difficult for the doctor, and for the nurses. And then they get*
 250 *into those problems. And then people are in intensive care and get euthanasia on*
 251 *intensive care. Think about it, what is intensive care for? And then they get euthanasia.*
 252 *Stupid [annoyed]. But that's hard. I mean for me it is easy to say, but for a doctor (in*
 253 *these situations), it is very hard. (Dutch nursing home doctor)*

EU3 concurred, suggesting that intravenous feeding in the terminal phase of an illness was inappropriate and that such feeding interfered with the "traditional" way of dying. A traditional way of dying was defined as a "quick death". Similarly, treatment should only be given for life-threatening conditions in the terminal phase if the condition would not lead to the patient's death. A quick death was associated with palliation for symptoms secondary to withholding treatment and was seen as acceptable by this doctor.

254 *(EU3) We have to learn the possibilities of the medical society, "When will we do*
 255 *something?" "When will we leave something?" "When will we stop this thing?" ... too*
 256 *many people are coming also to our unit for palliative care in the terminal phase with*
 257 *intravenous feeding and so on and so on. I wonder if this is a good thing. I don't agree*
 258 *that it's a good thing, there are a lot of complications with those feeding processes and so*
 259 *on. So in nursing homes you may say that we have tried to bring back the traditional way*
 260 *of dying, if possible, a quick death. We have to (bring) back the quick death. Why such a*
 261 *prolonged death? If a patient gets pneumonia, I will give only antibiotics if I think he*
 262 *will not die by the pneumonia. If I think this is his chance, leave him, give him comfort by*
 263 *relieving the symptoms of dyspnoea and pain and so on and so on and if he is dying*
 264 *sooner just by complications of the medicine, it's okay, why not? (Medical Director, Dutch*
 265 *nursing home)*

This doctor suggested that many modern nursing home residents received inappropriate medical treatment at the end of life that "prolonged death", defining this as one of the "tortures of our society".

266 *(EU3) And in the nursing homes, you may say that one of the problems of our time, all*
 267 *of the people living in the nursing home would have died, wouldn't have lived any more if*
 268 *they had lived 60 years before because all of our people in the nursing homes you may say*
 269 *are the, how do you say it in English, they had bad luck because they were in the hands of*
 270 *doctors who prolonged life and ... that's one of the tortures of our society, our culture*
 271 *you may say. That people are suffering a prolonged death (Medical Director, Dutch*
 272 *nursing home)*

This statement seems reminiscent of observations from a past time when pneumonia was regarded as "the old man's [sic] friend", a way for those who reached the end of life to quietly die without intervention.

Terminal crises precipitate hastening death actions

When a crisis of suffering occurred in the terminal phase it was agreed by doctors in both groups that aggressive palliative treatment to address this was appropriate even if such actions hastened the death of the patient. EU1 describes the hastened death of the patient in such circumstances as a "side effect". This doctor includes the patient and family in such decision-making.

273 (EU1) *I think if the primary goal is to relieve the pain, then in some (crisis) situations I*
274 *am willing to turn up the morphine, um, but to relieve the pain. Then I discuss it with the*
275 *patient and the family as part of some of the side effects, sometimes you see that someone*
276 *dies more quickly. But the primary goal in that situation is palliative care to relieve pain*
277 *(Dutch nursing home doctor)*

NEU6 concurs that such actions are appropriate emphasising that euthanasia in a crisis situation would not be legally possible because the necessary protocols cannot be met. This doctor suggested that one patient was already dying from unrelieved pain, and moves to reduce the pain by introducing a "massive dose" of IV morphine were appropriate palliation. (There may be an element of rationalisation here because this doctor had previously stated that palliation did not "do anything for the survival of the patient" see L28-29). However to be fair, there is some empirical support for the pain-mortality link even given the difficulty of measuring this (Staats, 1998).

278 NEU6 *If somebody is dying, then euthanasia is not important. I mean, if*
279 *somebody is dying with a few hours, what are you going to do with euthanasia. By the*
280 *time you got everything there, the patient is dead ...What is the most important item then;*
281 *it's to relieve the patient. But that's different, that's not euthanasia. And relieving the*
282 *patient, it doesn't matter, it doesn't matter that he may live less than three hours, less than*
283 *two hours because I have seen a patient who almost died from pain. And then at last I*
284 *give him a massive dose of morphine IV slowly, and he almost choked, he almost stopped*
285 *breathing, but then he went to sleep and after four hours he slowly awoke, and then he*
286 *said "Now I have no pain". And before that time, he was dying just by pain, not by*
287 *morphine, because he didn't have morphine, he had low blood pressure, he was gasping*
288 *from the pain, shouting to die. But after he got the right amount of pain killers, his*
289 *blood pressure became normal, he (got) out of his bed and he (went) home. I think he*
290 *died three weeks later at his own time. But the point is, if you do not give the care*
291 *someone needs, he can even die just by complications of his disease. And I don't (worry) if*
292 *I give the right palliation and people should die, that's (not an issue). (Dutch Oncologist)*

However this doctor did address the issue of increasing morphine, **intending** that the drug would kill the patient. He stated that this was "going over the edge" and such an action should not be taken without the patient's permission. This mirrors the statement by EU1 (L274-276) that he includes the patient and family in such decision-making.

293 NEU6 *But if you think to yourself, I'm giving a little bit more, hopefully he will die,*
294 *then you are going over the edge. Because that's an item you should discuss with each*
295 *other. The patient should choose that. (Dutch Oncologist)*

The beginning of potential differences between the views of the two groups may be evident at this point. One EU doctor who suggests that terminal sedation is "the way" to euthanasia (L298) questions aggressive palliative treatment of symptoms. However the difficulty of making decisions to address patient suffering in a crisis situation are acknowledged.

296 (EU2) *Yes, but what's curing the problem for a lung cancer patient with very heavy*
297 *dyspnoea. Huh? Morphine until he's unconscious? What are you doing. I think with*
298 *morphine until unconscious, I believe that is the way to euthanasia. But those are very*
299 *difficult situations because you have to do so much in a very short time.*
300 (Dutch nursing home doctor)

Similarly, EU2 suggested that doctors in New Zealand, faced with intractable symptoms in a dying patient may increase morphine to "free" the patient from suffering by intentionally hastening death. In such circumstances the doctor may respond to a need to relieve the patient without thinking through the possible consequences. He likened this situation to the one that existed in Holland prior to the sanctioning of euthanasia.

301 (EU2) *I think that a practitioner in New Zealand in a village, under the same*
302 *circumstances that I have in my [nursing] home, then I think that he would try to free*
303 *them perhaps with morphine or something when the pain and the fear and the prognosis*
304 *is so very very bad. I think he doesn't realise it but he gives a higher dose. I think also*
305 *that in the past in the Netherlands, the same.*
306 (Dutch nursing home doctor).

Given the severity of the action proposed it is unlikely that "not thinking" would be due to inattention or casual attitude. Rather this doctor may be implying that the doctor would "not think" as a way of avoiding confronting the real intentions of the action if the intent is to hasten death.

However the issue of "intent" of action was explicitly addressed by the NEU doctor who stated his patient was dying from the pain. If the physician increased morphine with the intention of hastening death he was "going over the edge" (L293-294). Implicit in this statement is that it is the lack of consultation that put the action "over the edge" not the action itself (L294-295). This may indicate that this doctor may be open to euthanasia as an option although he has not already done this.

To summarise, the two groups had similar views in this section. Both felt that life-sustaining treatment in the terminal phase can continue for too long. It was expressed that practitioners need to balance the needs of the patient to receive curative care or comfort care that has a curative purpose, with the need of the patient to die. An appropriate balance may be psychologically difficult for staff to achieve in medical units dedicated to cure and/or sustaining life. When terminal crises arise, palliation to address suffering is seen as justified, even if the patient's life is shortened as a result of the treatment. Doctors from both groups acknowledge that such decisions should be made with care, recognising the role of physician intent and patient consent. There appears to be some evidence of a difference developing in the views of the two groups with two EU doctors questioning that aggressive palliative care that hastens death may be the same as euthanasia while the NEU doctors strongly maintain that such actions are different from euthanasia.

A multi-disciplinary approach to palliative care

Doctors from both groups emphasized the importance of a multi-disciplinary team approach to the care of the dying patient from the perspectives of (a) the professional team and (b) the patient (see Table 14.4, p. 237).

(a) The team

It was suggested that the team provided confidence and support to staff, particularly when dealing with difficult cases, and also provided the opportunity for debriefing after the death. When the decision-making was questioned after the death, the team provided a forum in which it was helpful to be able to recall the reasons for the decisions and the context in which they were made. This function of the team was identified as particularly helpful when there were aspects to the death that were considered negatively by those involved.

307 *NEU7* *But you need to remember that these are very difficult cases, and you*
308 *must never do this alone, one person. I am never doing it alone, I do not trust myself*
309 *enough, I need to have the whole team, and to share with the team these kinds of feelings.*
310 *Also to have feedback from the team, even if things do go wrong, so we can recall this,*
311 *and "We made this decision on this or that ground, this was the right decision at that*
312 *moment, even if it turned out to be wrong".*
313 *(Dutch hospice doctor)*

The doctor had control of medications and was seen as necessarily involved because of that. Ultimately however, the patient could choose whom to talk to about their dying experience (Gregory & English, 1994) and it was the responsibility of the whole team to support that person as they provided comfort to the patient. Receiving the confidences of the patient was identified by EU5 as a source of job satisfaction (L325-326).

314 *(EU5)* *So I think most - the one thing in palliative care is giving attention to people.*
315 *And it's not very important who gives the attention. People tend to ask for the physician*
316 *when they experience pain, but they can talk to a priest or someone (else) when they want*
317 *to talk about (the fact) that they are going to leave this life - "What does it mean for me".*
318 *Sometimes they go to a physician with questions like that and as a team I think you have*
319 *to take care that the one person the patient chooses to (speak with confidentially) has to be*
320 *supported, to be able to give a good form of attention.*
321 *K* *Okay, so you're saying that the person that the patient goes to to talk about these*
322 *things with, you have to ensure in a team that that person gets support from the rest of the*
323 *team?*
324 *(EU5)* *Yes, and that's a responsibility of every member of the team. A lot of times*
325 *you are asked for symptom (control) (but) there is more than just symptoms (at issue). I*
326 *like that part of my job, but I can't describe it very well, because it's very much a team effort*
327 *(Dutch nursing home doctor)*

Inherent in this approach is a commitment to team equality - that the professional team members are equal in status and can be open in their communication. NEU9 identified that being able to be open and honest within the team when questioning personal competency, was useful in reducing her stress related to decision-making. Such equality appeared to be premised on the team members each developing their individual professional skills to a level where they could be regarded as professional equals.

Table 14.4: Table showing issues arising around team approach to palliative care for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not².

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Palliative care requires a multi-disciplinary team approach</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • Palliative care requires a multidisciplinary team approach. The power dynamics in the team are equal. • The doctor has particular responsibilities related to medicating the patient but there is increased satisfaction for the doctor in meeting other patient needs than symptom control. • Some team members may find the demands of the patient difficult to cope with. It is the responsibility of the palliative care team to support each other when delivering effective care to the patient. • It is necessary to spend time with the patient in order to deliver effective palliative care. • Some members of the team may have more opportunity to spend time with the patient than others. 	<p><u>Palliative care requires a multi-disciplinary team approach</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • Difficult cases require a team approach to care and decision-making. • The palliative care team provides support through debriefing and feedback after the death. • Debriefing and feedback is identified as helpful in rationalising negative outcomes. • Low power distance between team disciplines is identified as helpful for the doctor when reviewing practice decisions. • Communication between team members required management, particularly between disciplines or institutions. <p><u>Palliative care involves a facilitative function that requires a team approach.</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • Palliative care has a facilitative function that encourages patients to manage their situation in the preferred way. • Practitioners are responsible for controlling symptoms and ensuring comfort and the patient has a responsibility to make their treatment wishes known. • Successful facilitation of the dying process is instrumental in achieving a peaceful death for the patient and may nullify a requirement for euthanasia.

328 NEU9 *I think one of the great things is that we have a very good team so*
329 *you could talk about it you know, without thinking that you should be shamed. Also*
330 *when I did something wrong. I remember once calling the nurse, "Oh, I (must be) mad, I*
331 *think I did this wrong", and just in that moment I didn't know what to do, and you can get*
332 *so very insecure about what is going on and she just said "Well, why don't you go to this*
333 *patient and see if it is okay". Of course, that's a normal question. Well, and of course*
334 *then I just went there and had a look, and it was okay [laughing]. But I think it was very*
335 *very good that this was possible. That's something else that happens that is very*
336 *important, ... for our terminal care, it was very important that the nurses came to a level*
337 *of knowledge, of doing their thing of how they felt, that in our team, we were equal. Of*
338 *course, we are (different), we have different professions, but we are equal. And often of*
339 *course, you know, there is the doctor, the priest, and there are some nurses around, and*
340 *that also makes such things possible.*
341 K *So you are a real team?*
342 NEU9 *A real team, and in this team you all have your role but you are equal in*
343 *how you talk to each other. So it was possible to just go to her and say, "Help me, I am*
344 *in trouble, help me". (Dutch nursing home doctor)*

The issue of communication difficulties within the caring team was raised. One institution was implementing an approach whereby the team would be managed by one "leader" for each patient, responsible for integrating and disseminating information on patient progress to the appropriate person. This form of information gathering was identified as being different from the usual reports completed each shift.

345 *NEU10* *At the moment we are starting a project to make a map on which everyone*
346 *can write their problems with (each) patient. So if it is a doctor or a nurse, everyone can*
347 *write, so that one person, the Oncologist perhaps, can make the overall plan. ... every*
348 *time they get more people around the patient, and it is very hard to translate everything,*
349 *and also to give the right information to that person at that moment.. So when you write*
350 *your problems, or something like that on the paper everyone can read it and also make his*
351 *own.*

352 *K* *Okay. So this is slightly different from the normal report we do?*

353 *NEU10* *Yes, yes. (Dutch Oncologist)*

(b) The patient.

A multi-disciplinary team was seen as important from a patient perspective to address patient need on every level. While pain control and physical symptoms were addressed by medical and nursing staff other therapists were also involved. Psychological, spiritual or existential issues were addressed by the psychologist (L357, L378), priest/chaplain (L316) and physiotherapists (L378-379).

Spending time with the patient was seen as a necessary component to relieve suffering (see also L190-191). Nurses were seen as having greater opportunity than the doctor to address suffering in the nursing home situation because they spend more time with the patient.

354 *(EUI)* *I think, most times medical interventions, for example medicines, are just a very*
355 *small part of the relief, and most of the relief has to come from talking. Ja*

356 *K* *So, spending time with patients?*

357 *(EUI)* *Ja. Spending time for the doctor, spending time for the psychologist or even the*
358 *family (to relieve suffering).*

359 *K* *Do the nurses have a role in this?*

360 *(EUI)* *Ja. A very important role. I see the patients let's see, about 10 minutes a day.*

361 *And the nurses see them 24 hours a day. (Dutch nursing home doctor)*

Palliative care involves a facilitative function that requires a team approach

While doctors from both groups recognised the advantage of a multi-disciplinary team approach for staff and patients, the doctors who had not performed euthanasia explicitly identified that assisting a patient through the dying processes involves the team in a facilitative function. The practitioners were seen as responsible for controlling symptoms and providing a supportive environment but more than this they were responsible for "*facilitating*" the dying process. It was stated that an empathetic professional approach that supported the patient's physical and psychological needs enabled the patient to control the process, in the preferred way.

362 *NEU7* *You know what we think we are doing in hospice is not pain control,*
363 *that's one of the things maybe you can use more as a tool, but what you are doing in*
364 *hospice is facilitating processes. And we let the patient say what kind of process and in*

365 *what direction the process will go, but by controlling pain, controlling nausea and other*
366 *symptoms, by approaching the patient empathically you are facilitating a lot of processes.*
367 *(Dutch hospice doctor)*

368 *NEU9* *It was my responsibility that the patient would not be distressed*
369 *because of the many somatic problems you can have, and it was the task of the nurses to*
370 *take care that the patient was comfortable in his chair, and when he was walking, and in*
371 *his bath, and, well, whatever he liked. And the responsibility of the team had more to do*
372 *with the overall idea. "How was this patient doing". So it was about the patient, and not*
373 *about my more or less heroic things I was doing, or the nurses more or less heroic things*
374 *that's their problem and they solve it.*
375 *(Dutch nursing home doctor)*

NEU10 suggested that this multi-disciplinary approach to patient problems allowed the patients to manage the dying process so successfully that euthanasia ceased to be an issue (L377).

376 *NEU10* *But I think most of the time, it is possible to give the patient that treatment he*
377 *needs so that the question for euthanasia is also not done any more ... We have in our*
378 *department also a psychologist. We also have a person who will give treatment of the*
379 *respiration and also a little bit of psychosis. So to give the patients an easier way to um*
380 *perhaps to manage their disease. (Dutch Oncologist)*

Successful facilitation of the dying process decreased anxiety and allowed people to die as they would wish. One doctor recalled patients who found a renewed enjoyment of life in the inpatient unit. This renewal contributed to a successful dying (implied by "*finish their lives in their way*") (L384).

381 *NEU9* *... but I also know people who came in (to the palliative unit) very*
382 *unquiet, and every day they (would) tell me "Oh, I'm so bad today", and then within a*
383 *week or two weeks, suddenly they say "You know, I did that and that yesterday". And*
384 *then people sometimes find the strength to finish their lives in their way. And to talk to*
385 *the people they have to talk to. To see the children who they didn't see for many years.*
386 *Well, ah, to do lots of things. I think that's your one great task as a unit, to help people*
387 *to get the opportunity to do it their way. (Dutch nursing home doctor)*

Given that finishing their life "*in their way*" could conceivably include euthanasia, this suggests that this NEU doctor had found palliative interventions had been sufficient to meet patient need. This suggests that symptoms for all the patients for the five NEU doctors had not proven intractable, either because symptoms were not particularly severe or more likely because these doctors had sufficient palliative skill to address patient need without resorting to considering euthanasia.

In summary, a multi-disciplinary approach to the care of the dying patient was emphasized by both groups of doctors. Such an approach was instrumental in addressing staff stress by providing a supportive environment that fostered, and was reliant on, equality within the professional team. A multi-disciplinary approach provided the patient with available resources to address needs on every level. There was a requirement noted for communication within the team to be managed to ensure effective patient care through the appropriate dissemination of patient requirements.

While doctors from both groups emphasized that the responsibility of the team was to meet patient need, doctors who had not performed euthanasia elaborated on this as a requirement to facilitate a good death following the preferred options of the patient. It was suggested an appropriately managed and effectively facilitated dying process could make euthanasia redundant.

Delivery of palliative care to the consumer (institutionalisation and education)

There were no clear group-wise differences between the two groups in statements on the dissemination of palliative care to the consumer. However there were differences in individual views (see Table 14.5, below). It was noted that the Dutch government was committed to developing palliative care education and knowledge within the existing health care structure and was not encouraging the establishment of a separate hospice system.

Table 14.5: Table showing issues arising around delivery of palliative care to the consumer for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not²

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Delivery of palliative care to the consumer (institutionalisation and education)</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • The Dutch Government encourages work in palliative care in Holland but does not want to establish a separate hospice system. • Verpleeghuizen are regarded by the Dutch Government as appropriate vehicles for the delivery of palliative care to the dying patient. • A criticism of the Government's position is made on the basis that the development and dissemination of palliative care knowledge will develop further and faster in units dedicated to the care of the dying where practitioners have constant exposure to the dying patient and associated problems. • Patients who die on busy hospital wards may be isolated in their dying when there are no particular problems that require the input of staff. Staff may be more likely to be occupied with acute problems. 	<p><u>Delivery of palliative care to the consumer (institutionalisation and education)</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Palliative care in the community is becoming an increasing requirement with the aging population. • General practitioners need to develop palliative care skills to meet consumer demand. • Palliative care should be concentrated in specialised units or hospices to potentiate the assimilation and dissemination of knowledge. • Dying patients should have a choice of places to die, hospital, hospice or home. • The development of palliative care is at a pioneering stage in Holland and has not become fully integrated into the health care system. • The culture of existing institutions may have to change to accommodate positive dying practices for the consumer.

388 (EU4) *There are also hospices, not many, and the Government is not encouraging them,*
389 *not because they are not in favour of palliative care. The Government is encouraging*
390 *education of pain control and palliative care, but has the policy that these institutes and*
391 *establishments should be able to provide palliative care, terminal care.*
392 (gap)
393 *The Government encourages the hospice principle, but not as a separate institution. But*
394 *still We have about 6 or 8 hospices (Retired Dutch GP).*

The Minister of Health was quoted as implying that hospices and verpleeghuizen are analogous.

395 (EU3) *So in 1989 there was another discussion in Government in the second chamber,*
396 *and people from the Anti-Euthanasia Debate asked the Minister of Health "Why don't*
397 *you establish hospices?". And she answered, "We have our nursing homes" (Medical*
398 *Director, Dutch nursing home) **

* in the context of the interview, "nursing homes" here were meant to denote verpleeghuizen.

NEU8 (a hospital oncologist) agreed with this view, stating that the optimal care of the dying patient was achieved when the patient was cared for in the hospital facility that had been involved in the curative phase of the illness because this was familiar to the patient. A separate hospice facility for the dying patient was a less desirable but more cost effective choice.

399 NEU8 *I think the best of course is where you have a department with beds for*
400 *patients who get palliative treatment, who get curative treatment, alongside patients who*
401 *are in the terminal phase and who are going to die. Because the patients who have been*
402 *treated before know the (unit) well and would like to be in the same department. So I*
403 *think the optimal situation is to have the possibility to care for such patients in the end*
404 *phase of their disease. That is the best, but it is sometimes not possible. [Hospital beds are*
405 *expensive].*

406 K *Okay, so you see hospice, or a hospice-type facility even if it's not called hospice, as*
407 *um desirable from the point of view of funding, more than because you think it is the best*
408 *thing for the patient? Is that right?*

409 NEU8 *That's right, yes. (Dutch Oncologist)*

However others from both groups, disagreed. Concern was expressed that in a busy hospital ward the dying patient could be ignored, particularly if they were uncomplaining and did not demand attention.

410 EU5 *But when you spend your last days in the hospital - it is so busy ... people run*
411 *from one acute problem to another ... When you ... don't give real problems you don't cry*
412 *out loud, they tend to put you to one side. (Dutch nursing home doctor)*

413 NEU9 *...in many houses they said "Well when someone is dying, we (put them) in a*
414 *separate room at the end of the corridor, not too near by" and they talk about who had*
415 *[emphasis] to go there that day. (Dutch nursing home palliative unit doctor)*

EU5 elaborated on why he disagreed with the restriction of incorporating palliative care into existing institutions without developing separate palliative care units. He maintained that the use of a multi disciplinary team in palliative care and the concentration of terminal care in separate facilities increased the development and dissemination of palliative care knowledge. He argued that palliative care knowledge would not develop so far and so fast if it relied on nursing homes alone, where difficult cases would be seen infrequently, restricting the necessary experience for the gathering of knowledge. This doctor also maintained that the 3-5 cancer patients he had at any one time, while they received adequate care, were not receiving care of the quality that a more concentrated exposure by him to such patients would engender.

416 (EU5) *When care has to be very intensive, I would like it to be concentrated so that we*
417 *can (investigate) all the possibilities. When you have a good organised team,*
418 *physiotherapists, nurses, who know as a group more than each of them separately, you*
419 *have to have a certain (structure) ... It seems to be very difficult to spread knowledge - to*
420 *spread the things you learn in the houses [nursing homes] - how do you prevent people*
421 *from getting pain, ... there's a certain knowledge about it. You can spread the*
422 *knowledge so that when (others) don't see things like that happen every day in (their)*

423 *environment, I can explain them or educate other places. I think it would be good to keep*
424 *concentrated people who have to have much care, and to use that knowledge, to bring that*
425 *knowledge on a consultancy base to places where people need a little bit less care, but*
426 *need your attention too.*
427 *(gap)*
428 *And because I've got maybe three, four, five people with metastatic carcinomas, I read*
429 *about it, consult people and I think we give reasonably good care, but that knowledge is*
430 *not of the quality of when you see people like that three or four times a day, week in week*
431 *out. You tend to sharpen your senses (Dutch nursing home doctor)*

Some NEU doctors concurred with this view stating that dedicated palliative care units also had an educational component, with knowledge gained about palliative care of the terminally ill being disseminated to the wider caring community.

432 *NEU6 The problem is of course, that um, if you do not have any specific group,*
433 *hospice or centre, that is only looking at possibilities of palliative care, you may know a lot*
434 *of items but you may also not know all the possible items and that is a pity. So I think it is*
435 *very important that some groups give special attention to palliative care in its pure form.*
436 *(Dutch Oncologist)*

437 *NEU9 But of course such a unit (as the hospice) is a place where you find out a lot*
438 *of things together, and you use them in the other wards as well. And this is one of the*
439 *good things (about) making such a special ward on one subject, is that you together learn*
440 *a lot and that you give yourself time to learn and you can use that in your home. Many*
441 *things that we did over there are now done at our house. It is good.*
442 *K And do you disseminate this knowledge more widely to other places, to other houses.*
443 *NEU9 Well, we did write a book with our ideas of what kinds of things you should*
444 *have to have a good terminal care department in your verpleeghuis, which was edited by*
445 *the a national organisation where all verpleeghuizen are (represented). So all Dutch*
446 *verpleeghuizen can buy those there and see what we think they should do. (Dutch nursing*
447 *home palliative unit doctor)*

EU5 referred to the "enormous knowledge" derived from concentrating palliative care in dedicated centres

448 *(EU5) I am very pleased that Rotterdam University (is giving) lectures on palliative care.*
449 *And the Regional Cancer Society also organises courses in palliative care. And because*
450 *of the very different strategy of concentrating and consulting, there is an enormous*
451 *knowledge in the hospice field about symptom control (Dutch nursing home doctor)*

and NEU7 suggested there was a perceived need for the dissemination of such knowledge given the aging population and overcrowding of institutions and an increasing requirement for general practitioners to care for patients requiring palliative care in the community, including in homes for the elderly⁴². He claimed increased consumer demand had raised the interest of GPs in palliative care. It was suggested that the aging population may prefer access to palliation options and home dying rather than some of the care options presently, and possibly inappropriately, available. (see also Treatment Withdrawal L236-272). Dying at home is expressed in traditional terms.

452 *NEU7 And all these people need to go home, because there is no place in*
453 *the institutions. The institutions are very crowded. The nursing homes and hospitals are*
454 *very crowded so most of the people need to go home and the GPs are getting more and*

⁴² There are 1400 homes for the elderly in Holland (to be differentiated from nursing homes known as verpleeghuizen). "Admission is only possible if the patient's general practitioner will be responsible for the necessary medical care" (Francke & Kerkstra, 2000).

455 *more loaded with (cases that require palliative care) and they do not know much about it.*
456 *So now they are desperate to get some courses, and training in palliative care. It is*
457 *changing dramatically...I mean, the aging of society is a problem in all the world, and we*
458 *will be confronted with a situation in 10 years where we cannot pay any more for this kind*
459 *of medicine, for we need to pay for the care of old and dying people and we don't know*
460 *anything about this. And we are spending much money on things which may be*
461 *unimportant. ... most of the people would like to die at home. So that's a kind of tradition,*
462 *cultural tradition, to die at home. (Dutch hospice doctor)*

NEU9 suggested that developing and disseminating palliative care information was a recent development in terminal care in Holland that cast palliative care practitioners in a pioneering role. It was expected that it would take a long time for the concept of terminal care as a proactive discipline to be assimilated because the culture of some organisations was such that dying patients were "side-lined" within the institution and within the caring team. This doctor testified to representatives from such institutions about the role of palliative care in terminal care. She stated that there was a lot to do before progress could be made in establishing effective palliative care within such a culture.

463 *NEU9 So that is in fact part of our pioneer role because we have a pioneer role and*
464 *I think we will have that for a long long time.*
465 *K Why do you think that you will have a pioneer role for a long time?*
466 *NEU9 Because a culture has to be ready for it, from the top to the auxiliaries ... it*
467 *has to do with the awareness not only of the nurses but also of the Director, what terminal*
468 *care is, that you have to do something with terminal care, to give good terminal care. And*
469 *I know now it may be about seven or eight years ago, but there was a national meeting of*
470 *this organisation and we were ... talking about terminal care and in many houses they*
471 *said "Well when someone is dying, we (put them) in a separate room at the end of the*
472 *corridor, not too near by" and they talk about who has [emphasis] to go there that day,*
473 *and I said, "I don't share those feelings at all. The nurses like the terminal care because*
474 *then they can do what they like to do. They can care, and they are allowed to take time to*
475 *care, to comfort". But when you are thinking like that in your home, there is quite a lot to*
476 *do before you start a terminal care unit. It takes time, and we started 20 years ago, so it is*
477 *something that goes on and on and on. (Dutch nursing home palliative unit doctor)*

To summarise, the Dutch government recognises the importance of palliative care and is committed to increasing the availability of palliative care for consumers. This is driven by the needs of an aging population and an increasing requirement for dying patients to be cared for in the community or homes for the elderly. Initiatives are to develop the discipline within the existing health care institutions. The advantage of this is that the dying patient can be cared for in their known caring environment. The disadvantage is that the development and dissemination of palliative care knowledge may be compromised.

There is support from both groups of doctors that concentrating palliative care in dedicated units enhances and deepens the development of knowledge. It is maintained that palliative care is in a "pioneering" stage in Holland and there will need to be a change in the caring culture of many existing institutions before optimal and effective palliative care is available.

CHAPTER 15

Two bisecting categories, “Euthanasia-Palliative Care Continuum vs Dichotomy” and “Autonomy”, stand between the larger categories of Palliative Care and Euthanasia.

CATEGORY 2: EUTHANASIA-PALLIATIVE CARE: CONTINUUM VS DICHOTOMY

Differences in the accounts of the two groups become more evident in the analysis at this bisecting point between the main categories of Palliative Care and Euthanasia (see Table 15.1, below). The five doctors who had not performed euthanasia described euthanasia and palliative care that hastens death in dichotomous terms and as distinctly different. Three doctors who had performed euthanasia described the two as occurring on the same continuum and as similar acts.

Table 15.1: Table showing issues arising around palliative care that hastens death for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not²

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Palliative care that hastens death is judged analogous to euthanasia</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Terminal sedation is analogous to euthanasia. • Voluntarily stopping eating and drinking is analogous to euthanasia. • Withdrawing nutrition and hydration is analogous to euthanasia because death is the only possible outcome from the action. For this reason withdrawing nutrition and hydration should be subject to the same rigorous controls as euthanasia. • Euthanasia is placed on a continuum with palliative care but should only be considered if all palliative alternatives have failed. • Euthanasia and physician-assisted suicide are analogous. • Euthanasia is seen as the last alternative after palliative care fails. Not having effective palliative alternatives to offer results in avoidance of the patient with the patient suffering isolation in their dying as a consequence. Euthanasia in this situation is seen as more humane than the patient suffering isolation. 	<p><u>Terminal sedation is the "hardest" palliative option</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • The patient decides when the suffering is too great to bear. • Terminal sedation is a palliative solution to meet intractable suffering. • Terminal sedation is not the same as euthanasia. • Terminal sedation is an acceptable alternative to euthanasia when the patient requests an elective death but the family is opposed. <p><u>Terminal sedation not always a viable "solution"</u></p> <ul style="list-style-type: none"> • Terminal sedation may not always be a compassionate alternative for the patient who requests an elective death. • Terminal sedation may be difficult to implement and sustain for some patients. • Supporting the patient through the prolonged dying that can accompany terminal sedation may be difficult for families to bear.

Terminal sedation is the "hardest" palliative option

NEU doctors described the option of terminal sedation as a "solution" (L479, L499) to intractable somatic or psychological suffering when all other palliative options had failed (L480-482). It is the patient's call as to how much suffering is bearable, not the doctor's (L488-490). Sedating the patient until death is depicted as the "one choice" available to the doctor for intractable suffering (L490-91). Although death is foreseen from the action, this is depicted as being an option different from euthanasia (L491-492). Although this doctor states here that she is comfortable with this option (L491), elsewhere she has described shortening the patient's life as a "price" to pay for meeting need, (see L967).

478 NEU9 *It is more difficult when people ask you "Please do something for me". For*
479 *myself, I found a good solution where I feel ah, ah, which makes me feel okay. Ahh,*
480 *because I think when you really know [emphasis] you did everything, and then you have*
481 *to know that you did, and that you have to know that you know what you are talking*
482 *about. Then I think the last possibility is to help people not to know it any more. And I*
483 *think that's of course a kind of palliative care which may (have the result of shortening*
484 *life). But I think when people really can't, can't, are not able to live any more in this way,*
485 *somatic or psychological, for them it's equal, they just can't live like this any more. And*
486 *the last thing I can do is help them not to know any more. And of course the result is that*
487 *they will die soon, but I think they are allowed to choose. And my experience is that*
488 *nearly all people would like to live as long as possible. Nearly all. But in a way that they*
489 *are able to bear their suffering, how much or how little that (may be) in my eyes. But*
490 *they have to be able to have this life. And when they really can't any more, I think then*
491 *you have only one choice. And the reason I can live with this very well, is that in my*
492 *opinion it has nothing to do with euthanasia, although the result of course is that the*
493 *patient will die within a week, or a few days, or longer than that but of course the patient*
494 *will die and the patient knows he will die.*
495 *(Dutch nursing home doctor)*

The emphasis in this text unit on "people really can't, can't ... can't live like this any more" (L484) gives an indication of the desperation this doctor perceives in some patients when they experience intractable suffering, and the potential tension the doctor is exposed to when the desire to address patient suffering may only be gained at the risk of hastening the patient's death.

NEU6 also posits terminal sedation as a "solution" to the problem of intractable pain. He elevates the importance of terminal sedation as a palliative act by stating it is the "last thing" he can do to address such suffering, citing this option as the reason why he has never had a patient he could not help (to die peacefully, implied). Elsewhere this doctor speaks negatively of euthanasia as interfering with the dying process (L641-643).

496 NEU6 *I don't know any patient that I have not been able to help. Although I*
497 *know that there are patients that you can't get pain free and that will be still suffering the*
498 *feeling of dyspnoea. But the last thing I can do is to give them a very strong anaesthetic*
499 *that makes them sleep more so that they don't feel the dyspnoea, and they don't feel the*
500 *pain. So there is always [emphasis] a solution for any problem*
501 *(Dutch Oncologist).*

NEU10 stated that on the basis of intent, terminal sedation was not euthanasia as the intent was to relieve pain. Foreseeing the hastened death of the patient as a result of the action taken is judged

as different from giving an infusion with the purpose of killing the patient. Again, the knowledge of the patient is emphasised as a component of this action (L504).

502 *NEU10* When, when, when they have a lot of pain and it is not possible to relieve the
503 pain with a patch, we ask about the possibility of giving an infusion with morphine or
504 sedation, and then the patient knows that it is possible to die sooner. But I don't think
505 that is euthanasia. It is a way of relieving the pain of the patient, and you know that the
506 patient will die a little bit sooner, but that is not the same as giving an infusion from which
507 you know 30 minutes or one hour later, the patient is dead. (Dutch Oncologist)

Terminal sedation was also proposed as an alternative to euthanasia when the patient was requesting this but the family did not agree. NEU10 had been involved with three cases where the patient had requested euthanasia but opted for terminal sedation when the family did not support their decision. Providing an acceptable alternative to the family is deemed important and may assist with grieving. The implication here is that terminal sedation is not euthanasia.

508 *NEU8* Another experience you don't hear often about when speaking about
509 euthanasia is the fact we have encountered three times that I know of, is that the patient
510 says "I want euthanasia", but the children and the husband say "No, we don't want her to
511 have euthanasia". Then you get a discussion, and the patients who have that request, we
512 could arrange it and communicate it that she agreed with the husband and the children
513 that she didn't get euthanasia. We (explained) "When you have so much pain, and it is
514 perhaps a kind of euthanasia, we will (ensure) that you don't (suffer). We will give you so
515 much morphine you will (probably) fall asleep but you won't have more pain". She
516 agreed to do this. That is also important for the family afterwards, (if they have a
517 problem) that their mother has permitted euthanasia. She should live (longer) and when
518 they don't have a good feeling about the dying, I think it is important also to listen to
519 them. (Dutch Oncologist)

In contrast, doctors who had performed euthanasia judged some palliative options that hasten death as analogous to euthanasia. These doctors had the opportunity to fully explore their subjective conclusions that euthanasia and for instance, terminal sedation were similar acts, given their experiential exposure to both.

Palliative care that hastens death is judged analogous to euthanasia

Although EU1 and EU3 had stipulated that palliative actions that hasten death are different from euthanasia (L263-264, L273-276) three EU doctors clearly stated that there was no difference between some palliative actions that hastened death and euthanasia. Terminal sedation given to a patient on request, was described as "*essentially the same thing*" as euthanasia (L531-533). This doctor described a patient who had requested euthanasia and could not be given it because time constraints and the patient's condition precluded following legal guidelines (L527-529). At the patient's request terminal sedation was given (L529-530). The doctor describes how this action "*felt the same*" (L530-531) as a previous time when he had given euthanasia to a patient by infusion. (This suggests that if euthanasia has been requested and the doctor agrees that it is justified but is unable to comply, giving terminal sedation may have the same effect on the doctor as euthanasia. It may be difficult for the doctor to psychologically differentiate "intent" from "outcome" in such a situation.)

520 (EU5) *But a couple of years before I ah, (had) a patient who was so ill and so sick and*
 521 *so terminal she couldn't follow the book in the sense that there was no time to ask a*
 522 *second opinion, there was no time to talk things thoroughly through because she had*
 523 *brain metastases and had (fluctuating) consciousness. And at a certain point when she*
 524 *had a lot of pain, we talked about the possibility of ending her life, because her mood was*
 525 *changing - one day she was all bright and clear and wanted to visit her home for a couple*
 526 *of hours, and the next day she would be crying, "I want to die, I want to die, I want to*
 527 *die". So both physicians in the house couldn't decide whether it was a consistent*
 528 *(attitude). But she got so ill that she, asked to be given symptom control in the sense that*
 529 *she didn't want to be conscious and at that time, I promised her, "I will keep you*
 530 *sleeping". She was almost dying, maybe a couple of days, three. And in a way that felt*
 531 *the same [referring to euthanasia this doctor had given to another patient]. And I think*
 532 *that when your pain-killing medication and your sedative medication go so high that you*
 533 *know that the person sleeps until death, it is essentially the same thing (Dutch nursing*
 534 *home doctor)*

Differences in the representation of voluntary cessation of eating and drinking for doctors from each group may be evident in the following quotation. EU4 recalled a case where he had asked a hospice doctor to admit a woman who was dying electively by refusing food and drink. The hospice doctor agreed and the following statement implies that EU4 sees supporting a patient to die through voluntary cessation of eating and drinking as euthanasia, given that he judges the hospice doctor as "very fair" to grant the patient admission to the unit. Conversely, it could be argued that the hospice doctor did not regard voluntary cessation of eating and drinking as euthanasia and was therefore following normal admission procedure for a dying patient.

535 (EU4) *It's [euthanasia] against his [Hospice doctor] belief. A short time ago I*
 536 *phoned him and said, "I want your (facility) for a patient who wants to die by starvation.*
 537 *And he said, "Alright, let her come". So he was very fair. (Retired Dutch GP)*

EU2 did not differentiate between "euthanasia" and withdrawing nutrition and hydration from a patient. This patient had been comatose for three years following an accident, suffered contractures, may have been in pain and his wife wanted the feeding discontinued. Wider opinions on prognosis were sought. Despite the doctor recognising that the official Dutch recommendations covering withdrawing nasogastric feeding in such a case is not euthanasia, it is clear that EU2 considers it so when he includes this case as a time when he has performed euthanasia (L540) and his explicit statements about his personal feelings that the action is euthanasia (L549-551).

538 K ... *So have you been involved in euthanasia in the last - how many years that you have*
 539 *been working here?*

540 (EU2) *13 years. Two times, personally, ja, ja.*

541 (gap)

542 (EU2) *The second patient, I couldn't speak with, it was a coma patient. He was*
 543 *three years in a coma, he was ah, each month you could see the contractures, you know?*
 544 *He had unspoken wishes before his accident, his wife also had the same wishes, the team*
 545 *might think that he was suffering, but I don't think so, he was comatose. We have asked a*
 546 *third opinion from --- University ... and they give us the prognosis for the suffering,*
 547 *incurable, ja. All that, all that, all that. He had artificial feeding and we made the*
 548 *decision to stop it and I took out his nasogastric tube, the artificial feeding tube? Ja. ja.*
 549 *Officially in the Netherlands it is not euthanasia, but in my feeling it is euthanasia.*

550 K *So you don't see a difference?*

551 (EU2) *I don't see a difference, no. You terminate his feeding. (Dutch nursing home*
 552 *doctor)*

However EU2 did differentiate between withdrawing food and fluids and withdrawing antibiotic treatment for pneumonia. Withdrawing antibiotics did not have a clearly foreseeable outcome - the patient may fight off the infection without the aid of the drugs. Because death was the only foreseeable outcome to withdrawing food and fluids, EU2 suggested that this action should be subject to the same procedural rigor as euthanasia.

553 *K Do you see a difference between terminating feeding and terminating antibiotic*
554 *therapy with pneumonia?*
555 *(EU2) Yes, I see (a difference) ... because with feeding, you are sure what he will*
556 *do, with antibiotics, it is not sure. You can give it to him and have no result, that's*
557 *possible, it's not sure. But terminating the feeding you are sure someone will die.*
558 *K So, the end result of what you are doing is known to you so therefore it's euthanasia.*
559 *(EU 2) Ja, in my view. So you have to be as careful with that as euthanasia. So*
560 *you have to speak with the people, with the team etc. Ja ja. (Dutch nursing home doctor)*

EU4 represented euthanasia and physician-assisted suicide as actions to be considered after palliative care options had been exhausted. He makes a point of equating "euthanasia" with "physician-assisted suicide". Although his statement that euthanasia exists on the same continuum as palliative care is in response to a leading question (L567-568), he does expand the statement (L569-570).

561 *(EU4) Euthanasia is only to be considered after all the other possibilities have been*
562 *exhausted, after the best possible terminal (care) including palliative care. Euthanasia is*
563 *certainly not something to choose as another choice opposed (emphasis) to palliative care.*
564 *No, it is after palliative care. It is to be considered in those circumstances where*
565 *palliative care does not satisfy this patient in these circumstances. If I say "euthanasia" I*
566 *also mean every time "assisted suicide".*
567 *K I understand. So, do you think that euthanasia is on the extreme end of palliative*
568 *care, do you see it on the same continuum?*
569 *(EU4) I see it on the same continuum. Not parallel, not one or the other, but one after the*
570 *other. (Retired Dutch GP)*

EU2 concurs that euthanasia and palliative care are on a continuum. Euthanasia was portrayed as being the last option after palliative care failed. Not having palliative alternatives to meet patient need was seen as isolating for the patient, with medical and nursing staff and "other people" avoiding the suffering patient (L577-578). EU2 expressed distress at this and sees the availability of euthanasia as an option in such circumstances as positive.

571 *(EU2) ... Euthanasia is the end of the line. There can be moments when palliative care*
572 *is not enough. Ja*
573 *(gap)*
574 *(EU2) Oh, you can't imagine ... what it means to someone to have pain or dyspnoea or*
575 *other things that are unbearable. Then you see, I don't know exactly the situation in your*
576 *country, a very very small part of it. But I see sometimes in my home where I am, ja? that*
577 *when the people are in the room on those circumstances, the nurses, sometimes the doctor*
578 *and other people, they are avoiding to enter the room, because they are asking for things,*
579 *and they cannot give them. And that's awful, that's really awful. Ja*
580 *K Yeah. The same thing happens in New Zealand.*
581 *(EU2) Ja? So I am very glad that in this country, there is the possibility that when you*
582 *are with your back to the wall, that you can do something. Ja, that's my opinion. (Dutch*
583 *Nursing home doctor)*

This text unit also exposes the potential role of physician distress in physician attitude towards euthanasia. When palliative options were unsuccessful, the suffering of the patient is described

as "awful". The opportunity to address the suffering with euthanasia is welcomed by the doctor, possibly also to relieve his own distress (implied). NEU doctors are also exposed to the stress of intractable pain, but consider terminal sedation a "solution" short of euthanasia. However two of the NEU doctors suggested that terminal sedation was not necessarily an unqualified solution to managing the patient with intractable suffering.

Terminal sedation not always a compassionate "solution"

NEU9 described a case where the patient could not tolerate the option of being unconscious and having others in control of her body because of previous extenuating and terrible life experiences. Euthanasia was judged to be the preferable option to terminal sedation by those consulted and the correct procedures were carried out. This doctor stated that in this case there was no other choice. Because of this experience she would not commit to saying that euthanasia should never be an option. She was present at the euthanasia and found the experience "frightening" (L597). She felt obliged to attend after having made a commitment to always be there for the patient (L598). (see also L161-163)

584 NEU9 *But sometimes it happens - I know of a young woman of not so long ago,*
585 *she was a very young woman, she had had a very very difficult life, and things in reality*
586 *are really more severe than you read in the books. We often think when you read in a*
587 *book that it can't really be that bad, but sometimes life is really worse than you could ever*
588 *think of. She had had a very very bad life, incredible, it was really incredible what had*
589 *happened to her. She was 22, and was dying of cancer. And for her, with her history, the*
590 *idea of being asleep and of not being able to control her life which had been such an*
591 *anxious and insecure life, she could not bear the idea. And so my colleagues could*
592 *understand that this was impossible for her in this specific situation. The only possibility*
593 *was euthanasia because that would be a way she could die quickly. So it all happened as*
594 *it should happen, you know, telling the police. So that's why I say, "never say never",*
595 *because in this special circumstance, there was no choice. For me it was uncomfortable,*
596 *but for her with her history, it was not. And then, well I had promised her to be there,*
597 *and I saw it happen. It was frightening, but that was a consequence of the choice I made,*
598 *it was a free choice. (I had promised I would be there! Always! Whatever happens!)*
599 *[handwritten on transcript] (Dutch nursing home palliative unit doctor)*

This doctor also spoke of the technical difficulty of implementing and sustaining terminal sedation for some patients. The inference here is that the longer the patient is sedated, the greater the risk of sedation being unsuccessful.

600 NEU9 *When you talk about it, (you say) the last thing you can do is help them not to*
601 *know.*
602 K *So are you talking about sedation?*
603 NEU9 *Yes, or even sometimes anaesthesia.*
604 K *And you keep them asleep until they die?*
605 NEU9 *Ja. It's hard. It's hard I can tell you [laughing]. It's very hard. It's hard*
606 *because they get accustomed to those drugs. (Dutch nursing home palliative unit doctor)*

NEU10 spoke of the potential difficulty for relatives when the patient had terminal sedation. When dying was prolonged, relatives could find this distressing. Such distress may result in requests by them for a faster death. This doctor empathised with the difficulty for the family.

607 NEU10 *Sometimes there are problems with the family, the relatives because they*
608 *think it's taking too long, everything has to go sooner. Yes? Because most of the time we*

NEU doctors who question whether terminal sedation, or other palliative actions that hasten death are compassionate options for some patients may experience stress related to the implementation of such actions. This strengthens the assertions of those doctors who stressed the supportive function of the caring team when decision-making was questioned, post death (L310-315, L330-343).

To summarise, doctors from the two groups have differing viewpoints on the status of terminal sedation and other palliative decisions that hasten death. The five doctors who had not performed euthanasia stated that terminal sedation is different from euthanasia and a "*solution*" to the difficulty of (a) the patient who experiences intractable suffering and (b) the patient who requests and is eligible for euthanasia but whose family is distressed at this decision. However two NEU doctors stated that terminal sedation may not always be a viable option. It can be technically difficult to implement and sustain and it may not be the most compassionate option for patients who find it psychologically difficult to surrender themselves to an unconscious state with others in control of their bodies.

Three doctors who had performed euthanasia stated that medical decisions that hastened the death of the patient were analogous to euthanasia when the physician knew that death was the expected outcome. Given that the physician could foresee the death, it was argued that such actions should be placed on the same continuum as euthanasia and should be subjected to the same scrutiny as euthanasia decisions. Doctors who had practiced euthanasia expressed relief that this option was available as a way of addressing intractable symptoms but it was stressed that palliative alternatives should be exhausted before euthanasia was considered.

CATEGORY 3: AUTONOMY

There were differences in the way "autonomy" was represented in the accounts of the two groups of doctors. NEU doctors represented autonomy in terms of empowerment for both doctors and patients through practitioner knowledge and experience. EU doctors represented autonomy in more direct terms related to self-determination for patients and doctors (see Table 15.2, p. 251).

Empowerment in practice - increasing autonomy by providing alternatives

Doctors who had not performed euthanasia appeared to represent palliative care knowledge as a mechanism for enhancing the autonomy of the patient (by providing choices other than euthanasia). It was argued that palliative care knowledge increased the doctor's autonomy by

offering end of life care alternatives to euthanasia to present to the patient and increased the patient's autonomy by giving choices of interventions.

Table 15.2: Table showing issues arising around autonomy in end of life decision-making for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not²

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Autonomy in euthanasia decision-making</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • Euthanasia is a "dangerous liberty" that requires strict societal control. • To restrict abuse, euthanasia requires an egalitarian society where the power differential between patient and practitioner and practitioner disciplines is equal. • How far and for how long curative or palliative treatment should continue is up to the patient to decide. • Although there are limits to the autonomy of the patient when choosing euthanasia, these limits should be considered within an emancipatory framework that acknowledges the sovereignty of the patient over his or her life. • A request for euthanasia marks a point of limitation to patient autonomy. The autonomy of the doctor who is to give euthanasia is equal to that of the patient and the relationship enters a period of negotiation. • The warrant for the autonomy of the doctor being equal to that of the patient is based on the enormity of the doctor being asked to kill and the need for the doctor to find a way to live with that. • Those who argue for patient autonomy in having euthanasia may have little understanding of the effect on the doctor of giving euthanasia. 	<p><u>Empowerment in practice - increasing autonomy by providing care alternatives</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • The autonomy of the doctor is increased when palliative alternatives are known. This knowledge allows the doctor to offer choices other than euthanasia to the patient. • The autonomy of the patient is increased when palliative alternatives are made available by offering a sense of control by exercising choice in treatment options. • Administering euthanasia may limit the dying experience for the patient by cutting short the dying process. • Not knowing palliative alternatives may impact on the support the dying patient receives. <p><u>A lack of palliative care knowledge limits the autonomy of the doctor by limiting treatment options</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • A lack of palliative care knowledge was implicated in decisions to agree to euthanasia. • General practitioners may not have sufficient palliative care knowledge to successfully meet the needs of dying patients. • GPs have high status in Holland and enjoy the confidence of families. • Palliative care and hospice practitioners should provide advisory services to GPs rather than act directly with patients in the community to protect the GP/patient relationship.
<p><u>Effect on consumer of euthanasia availability in society</u> <u>Issues Arising.</u> Having euthanasia available in a society</p> <ul style="list-style-type: none"> • may encourage "consumer" perception that this option is easily obtained • may create a perception that it is a preferred option compared to the sometimes time consuming and complicated alternatives in palliative care • may influence doctors to accommodate elective death • Dutch doctors are not required to give euthanasia on request, even if all requirements have been met. However, they are obliged to refer on to someone who will. • Giving euthanasia runs counter to the doctor's role which is perceived to be that of caring and saving life. However when palliative care fails, euthanasia is perceived to be part of the caring role and is described as the "ultimate care". 	<p><u>Effect on consumer of euthanasia availability in society</u> <u>Issues Arising.</u></p> <ul style="list-style-type: none"> • Having euthanasia available and freely discussed in society may influence patients to make a request. • Media representations may have an influence on increasing euthanasia requests. • Prominent members of society who decide to have euthanasia may influence others in the community. • Informal discussions in the community may influence people to reify a "quick death".

NEU7 stated that his knowledge and experience with palliative care meant that he did not need to perform euthanasia. There is a sense of a negative view of euthanasia in his stating that he did not "need" to perform this and representation of a demarcation point between euthanasia and no-euthanasia in the world "border". Palliative knowledge offered him other alternatives and there is a sense here of freedom to move both for the physician and the patient represented in the use of the words "space", "enough possibilities" and "broaden the scope". There is also a sense that this doctor acknowledges and agrees with patient self-determination (L617-618) and that he sees his role as important in maximising patient self-determination through offering wide choices to the patient (L620-621).

611 NEU7 *But I also do not have the need to pass through this border*
612 *[euthanasia], I do not feel it is necessary. I feel with the knowledge and experience I have*
613 *in dealing with these kinds of patients, enough space to deal with the patients, and enough*
614 *possibilities.*
615 *(gap)*
616 NEU7 *My Christian point of view, is that this is most important, give the*
617 *opportunity to the patient, but they have their own choices and their own autonomy to*
618 *choose. But very important to me, if the patient is choosing euthanasia because of pain,*
619 *which can be relieved maybe, and um, they are choosing euthanasia because they don't*
620 *know of other possibilities, that's a very big point, to try to broaden this scope of*
621 *possibilities so they can make a choice. (Dutch hospice doctor)*

NEU9 reinforced the concept of palliative care offering wide choices in treatment. She also differentiates between having palliative care knowledge and having "enough" knowledge to meet patient need. This doctor had previously emphasised the requirement for development of professional knowledge (L336-337).

622 NEU9 *I think, I think you can do a lot in palliative care, really. Um (.3) ... So I*
623 *think first of all you have to know what you are doing. You have to have knowledge about*
624 *the things you are doing and if you don't have it or don't have it enough (there are problems).*
625 *(Dutch nursing home palliative unit doctor),*

NEU6 represents having options to offer the patient as important for the patient to feel in control of their dying through exercising choice stating that the diagnosis takes a sense of control away from the patient and the request for euthanasia may be an attempt to regain this. Patient experience that palliative alternatives successfully meet needs may encourage patients to continue with life and exercise these choices. He argues that with support the patient finds that what was previously perceived as unbearable is in fact endurable and that euthanasia prevents the patient experiencing this. Euthanasia stops the struggle for solutions to the patient's problems and may limit the experience of the dying process for the patient. There is also a sense in this account that euthanasia may limit the experience for the doctor and that may be seen negatively (L641). This supports the statement by EU5 that addressing wider patient problems is satisfying for the practitioner (L325-327).

626 NEU6 *Many times when you see the patient for the first time, or the second*
 627 *time or the third time, he has made up his mind [to have euthanasia]. He or she is*
 628 *thinking about all the difficult (things) he is going to meet in the future, and then he tries*
 629 *to take (control) of all the big disasters that are coming and ask you "In case this horrible*
 630 *thing happens, in my opinion, it is horrible for me and I fear now that that mountain I*
 631 *can't climb. Please, is it possible if nobody can help me at that time, that I don't need to*
 632 *suffer and that I can find peace". And for this person it will be this item, and that person*
 633 *that item, but they want to deal with their fears with you at that moment and try to at least*
 634 *get (some control). Because the disease itself is taking away all the possibilities to*
 635 *manage their own life. ... Later on, they are changing their boundaries and then what*
 636 *was unbearable at one time is not so fearsome any more because they have found out that*
 637 *you can do a lot of things. That something that looked to be horrible is of course*
 638 *absolutely wrong, and not nice, and difficult and bad, but still (bearable) and then they*
 639 *are willing to continue, to try (this or that). With euthanasia, that isn't possible.*
 640 *(gap)*
 641 *Euthanasia will stop everything. You don't need to pain yourself in trying to find*
 642 *solutions. ... Euthanasia means the patient has no chance to make the steps he may need*
 643 *to make. (Dutch Oncologist)*

NEU10 recalled a specific case where a patient asked for euthanasia as a response to fear of protracted dying. When presented with palliative choices she "gladly" took these up. This suggests that palliative choices may in fact obviate a requirement for euthanasia for some patients and reinforces the concept of ongoing palliative alternatives increasing patient autonomy through choice.

644 NEU10 *And a few weeks ago ... a patient with cancer ... didn't want to have*
 645 *chemotherapy and she was not in a very well condition to have it, so she came to our*
 646 *department. And one of the reasons she would die was, she had no pain or anything like*
 647 *that, but yes, "If I have to die, perhaps it is easier to do it in a fast way". But then we*
 648 *talked over possible treatments at the hospice and yes, she gladly wanted to go there.*
 649 *(Dutch Oncologist).*

NEU6 states that being aware of palliative alternatives can provide choice in care options that may meet the distress of caregivers related to fear that the patient suffers too much, and of the patient related to feelings of being a burden to loved ones. Similarly the doctor may not know of other alternatives to offer. ("Doctor" implied in this context although the term "caregiver" has been used (L655). Contrast "caregiver" used (L651) followed by "husband" "wife" (L653))

650 NEU6 *For instance, you can have a patient who feels that he is going to die but still*
 651 *hangs onto his life, but his caregiver is so tired of all the suffering he sees all the time,*
 652 *that he feels and thinks it is too much for the patient. And the patient can also think that*
 653 *this is too much for my husband or my wife, "I am just a burden", based on different*
 654 *reasons or expectations. And then everybody thinks it is better to stop everything, but with*
 655 *a lot of other reasons. And maybe the caregiver thinks "I have done everything I could",*
 656 *not knowing about other possibilities, and everyone agrees this is the end, but maybe they*
 657 *have not seen other (options). (Dutch Oncologist)*

There is also a sense in this text unit of the confusion that may surround the dying process if open communication is not facilitated successfully among those involved (see comments germane to communication under "Palliative care requires a multi-disciplinary team approach").

A lack of palliative care knowledge limits the autonomy of the doctor by limiting treatment options

NEU doctors identified lack of choices as being implicated in agreeing to perform euthanasia. Lack of choices was associated with a palliative knowledge deficit.

NEU10 and NEU7 suggested that doctors in the community may feel the need to agree to euthanasia when patients requested this because they did not have enough experience with dying patients to increase their palliative care skills. In a challenging end of life situation, the "known" option of euthanasia may seem to be the best option. (This mirrors previous statements by doctors from both groups under "Delivery of palliative care to the consumer" that experience in caring for the dying is necessary to increase palliative knowledge to an effective level (L428-431, L454-456, L432-435, L438-440))

658 *NEU10 ... you also see the physician at home speaks about it, which I think is more*
659 *because they only see a few cancer patients a year and they are, ja, they don't know how*
660 *to, how they have to manage it, ja? ... sometimes when you speak with a doctor who*
661 *works at home, they are easier in talking about euthanasia than the doctors in the*
662 *hospital.*

663 *K Why do you think that is.*

664 *NEU10 I think because they don't know what the possibilities are for (treating) the*
665 *patient. They only have perhaps one such patient in two or three years, and they don't*
666 *know what to do with (the patient). They think "I only know about euthanasia, perhaps*
667 *the person wants euthanasia so I should give it to him, I should have the talk about it with*
668 *the patient". (Dutch Oncologist)*

669 *NEU7 You know, general practitioners have annually 3, 4, 5 terminal patients and*
670 *among them I think one or two are complicated, they need very intensive care. It's not*
671 *enough to learn everything about pain control. (Dutch hospice doctor)*

An example was given of a Dutch GP who considered euthanasia for a patient who had not responded to increased morphine to address restlessness (supposedly) secondary to pain (L673-674). The patient became delirious (L679) and the doctor began to "panic" (L675). The patient was referred to the hospice doctor as a last resort prior to giving euthanasia (L675-676). The patient was diagnosed with anuresis, settled and died peacefully after 1 1/2 litres of urine were drained off (L680-682). This was not an isolated case (L681). The GP was portrayed as very competent and NEU7 attached no "blame" to his forgetting to check the patient's bladder (L683). However, the family confronted the GP over his not recognising the need of the patient to pass urine (L684-685).

672 *NEU7 One time, I was asked by a GP to see the patient and I came in and*
673 *she was an older lady, very restless and she was dying. The GP was afraid the restlessness*
674 *was coming from the pain, and increased the morphine dose and the lady was more*
675 *restless, and he increased the dose, and he, he started to panic. He asked me to (come)*
676 *and he considered euthanasia at that moment, and wanted to give her something to calm*
677 *her down, (which could mean) she would die very soon afterwards. But he asked me to*
678 *see the patient. I came in and opened the door, and looked at the patient and it was clear*
679 *to me that she was getting too much morphine. She was in delirium because of morphine.*
680 *The problem was that in her bladder she had 1 1/2 ltr. of urine. Then I took a catheter –*
681 *and this happened many times, not only in this single case - to draw urine from the*
682 *bladder, and the patient died peacefully several hours later. And the problem is, that the*

683 *GP, a very good one, I would never blame him for this, forgetting about it, or nobody*
684 *drawing his attention to this, but, the family was very confronting to the GP. The family*
685 *said, "Doctor, didn't you know people need to urinate?". (Dutch hospice doctor).*

The hospice doctor expressed fear that the experience of being "confronted" at the bedside would stop the GP referring patients on to hospice in the future (L689-690). GPs were portrayed as having a high status in Holland enjoying the confidence of the family (L690-691). When this confidence was shaken, the family suffered (L692). A tension is expressed between the desire for GPs to know more about palliative care (through hospice consultation) and concern about undermining the GP's position in front of the family by exposing ignorance (L692). Such an incident was undermining to the hospice/GP relationship (implied by "*ruin more than you build*") (L692-695).

686 *NEU7* *And that's the biggest problem. I mean I prefer ten times more to*
687 *tell the doctor during training, or during a course, "Be aware of this kind of complication,*
688 *this kind of thing, it can happen to anyone", than to have it happen at the bedside, it is*
689 *very confronting for the GP. I am afraid this GP will never ask me for a consultation*
690 *again. The G.P's have a very important status in this country. For many people the*
691 *doctor is very high up - on the top of a ladder. And what he says must happen, and when*
692 *he's wrong, it's very very bad for the family who have (confidence) in him So on the one*
693 *side they want very much to know about it, learn about it, and on the other side it is*
694 *sometimes dangerous to confront them with a lack of knowledge and their attitude can*
695 *ruin more than you build. (Dutch hospice doctor)*

It was implied that the availability of hospice care could be seen as a threat by the GP when interventions occurred outside of the GPs hours. One GP reacted negatively to the hospice arranging medication for a patient without his knowledge (L700-702). Although families were positive about hospice involvement at this level, it was this doctor's experience that the GPs were not always happy (L704-707). It was suggested that in order to avoid the conflict between hospice and the GPs, the hospice doctor should stand in an advisory capacity to the GP only. This reduced the perceived threat to the GPs position (L706-708).

696 *NEU7* *The nurse was providing a sort of low threshold communication*
697 *between the family and the hospice so when somebody was sick at night, at 8o'clock in the*
698 *morning, the family would call the nurse - "Mother is not keeping well" and at 8.15 I*
699 *heard about it and was writing a prescription, and the family could then get medicine from*
700 *the pharmacy. And the GP would come to see this patient two days later. And he was*
701 *confronted with everything having been done or arranged behind his back, and he didn't*
702 *like this very much.*
(gap)
703 *Although the family rated these consultations very high, and the higher the ratings were*
704 *from the family, the lower they were from the GP. We had a lot of ratings that were 10 to*
705 *0. We did a study I think, two years ago ... the GP s didn't like us at all. At this time we only used*
706 *to provide medical consultations, and I am never, or nearly never prescribing drugs myself. I leave*
707 *it to the GP. I advise him, and he is my contact person. It is working much better, much more*
708 *clear who is doing what, and they are not threatened in their position. (Dutch hospice doctor)*

Sensitivity to the position of the general practitioner may possibly be related to a desire to see palliative care services more accepted in the community given the comments about the pioneering role of this discipline at this time in Holland (L465-466) (see also comments on the requirement for the multi-disciplinary team to be coordinated, (L347-353)).

While the accounts of NEU doctors focused on increasing autonomy through the availability of wider palliative options, EU doctors discussed autonomy in relation to the patient's right to have access to euthanasia as an option if palliative alternatives failed.

Autonomy in euthanasia decision-making

All of the EU doctors specifically stressed the role of patient autonomy and patient request in the euthanasia decision (to be discussed further later). EU4, who teaches euthanasia practice to registered doctors articulated this well.

EU4 described euthanasia as a "*dangerous liberty*" (L711) that required particular societal constraints to avoid abuse. Equality in the doctor/patient relationship was considered a prerequisite to allowing euthanasia. This doctor also suggested that the equal nurse/doctor relationship in the Netherlands ensured protection for the patient when euthanasia was being considered.

709 (EU4) *It would be a disaster if - at the moment I don't know enough about New Zealand*
710 *or Australia to have an opinion - but at the moment the only country I would trust with*
711 *this dangerous liberty which could be easily compromised, is the UK., but not Belgium,*
712 *not (.3)*

713 K *Why is that, why the UK?*

714 (EU4) *Because the doctor/patient relationship is reasonably equal. Because the*
715 *doctor/nurse relationship - I mean, nurses are the watchdogs of the patients, that's what I*
716 *teach - are reasonably equal (Retired Dutch GP)*

It was argued that the patient should have autonomy in choosing how far "curative" or "palliative" treatment should continue and in choosing euthanasia. However, there were limits to that autonomy. The doctor had to be satisfied the suffering of the patient was sufficient to warrant euthanasia. While acknowledging the need for limits on the practice to protect society (L726-728), this doctor places the autonomy of the patient making the euthanasia decision in a socio-political framework that legitimises the choice on the basis of the emancipation of the patient (L728-731).

717 (EU4) *I see it [euthanasia] on the same continuum. Not parallel, not one or the*
718 *other, but one after the other. But how far a patient will go, will undergo treatment,*
719 *whether curative treatment or palliative care, is that patient's choice, in our opinion. So*
720 *it's up to the patient to say "This has been enough" within reasonable limits of course. If*
721 *you hurt your big toe and you come to me and say "Now I want euthanasia because I hurt*
722 *my big toe", that's not a reason. But it's not up to me whether the patient says "I've had*
723 *enough" after 100mg or morphine a day or after 500mg. That's up to that patient and*
724 *that patient's biography. Ja?*

725 K *So, you're really advocating patient autonomy?*

726 (EU4) *Oh, I certainly do. There are some limits of course in every country, because*
727 *we live with many people in a small area, and every liberty and every autonomy has it's*
728 *limits, but if there is not patient autonomy, then who is the boss, the doctor? [shrugging].*
729 *No, we are passed that. We have had woman's lib, we have the emancipation of women,*
730 *of nurses, of GPs as opposed to specialists, and I think it's high time to stress, to fight for*
731 *the autonomy of the patient. (Retired Dutch GP)*

EU5 expanded on the limits to patient autonomy in the euthanasia decision. He agreed with EU4 that patient autonomy was paramount only in treatment decisions. When euthanasia was being considered, the autonomy of the patient ceased to be the sole consideration (L736). Patient request was necessary for euthanasia but not sufficient. The autonomy of the doctor now became equally important and the relationship between doctor and patient entered a period of negotiation around the euthanasia decision (implied, L736-737).

732 (EU5) *I think the autonomy of the patient goes as far as accepting treatment, life*
733 *prolonging treatment. I think it is the right of the patient to say "I don't want this form of*
734 *chemotherapy, I just want palliative radiation to ease the pain in my bones, but please*
735 *don't (make further) efforts to prolong my life, just look at the symptoms and try to take*
736 *care of me". I think that that's the end of the patient autonomy, as far as he can decide*
737 *totally on his own. (Dutch nursing home doctor)*

The involvement of the doctor was dependent on all other options being exhausted (see also L561-562). At the point euthanasia was requested, it was argued that the relationship between patient and doctor entered a phase of equal negotiation (L740-743). The patient was required to exhaust all palliative alternatives as a prerequisite to having euthanasia (L748-749). The doctor was justified in requiring the cooperation of the patient because of the enormity of being asked to "kill" the patient (L747-748) and having to live on with that knowledge. A balance was required between the need of the patient to see an end to suffering and the need of the doctor to know all other avenues had been explored.

738 (EU5) *Because, when we go further on, and ask for (involvement) of a physician in*
739 *euthanasia, you have to - it says something about the relationship between the two*
740 *persons. There is the one person who wants to be dead - who doesn't want his life to go on*
741 *with further suffering the way he or she does, and on the other hand, there is the*
742 *physician who will take action, and has to give an injection or to hand out the drink*
743 *whatever way it goes. And they have both to be convinced that there is no alternative ...*
744 *we have to come to a point where we say "Alright I understand that you want to go, I have*
745 *no alternatives to ease your life or give more comfort, and I understand that you suffer so*
746 *much that you can't handle it any more", that's the point when you can say you agree. At*
747 *that point the physician has had to have looked at all alternatives ... and as a human*
748 *being who is being asked to kill someone else, I have the right to ask (the patient) to look*
749 *into those alternatives, and I want him to try them before I go along with him ... On my*
750 *side, I won't do it unless I have no other options. Because I have to go on living, I have to*
751 *look in the mirror in the morning and I have to be able to say it was a good thing to do.*
752 *(Dutch nursing home doctor)*

EU2 alluded to the quality of the doctor/patient relationship by stating that the doctor was not the patient's "chaperone" (L760). Although agreeing that the patient should have control over treatment alternatives the euthanasia request altered the doctor/patient relationship marking a point of limitation in the autonomous-patient/assenting-doctor relationship. Consultation was one necessary prerequisite to having euthanasia (L759-760).

753 K *Okay, and in situations like that, do you believe in complete patient autonomy? ... do*
754 *what the patient wants you to do, that the patient should be the one that sort of leads the*
755 *team as it were, in their care.*
756 (EU2) *Leads the team (according) to his wishes - there are limits of course.*
757 K *What are the limits?*
758 (EU2) *Often, no not often - sometimes the patient asks you to terminate his suffering*
759 *Ja. That's a limit for that moment. You have to go with him, talk with him, talk with*

760 *others etc. Not always will I do what you wish. I'm not a chaperone. (Medical Director,*
761 *Dutch nursing home).*

However, once euthanasia was agreed between doctor and patient, EU5 spoke of the importance of the patient being in control in determining the timing and circumstance of his euthanasia. He portrays himself passively at this point by referring to himself as the "*instrument*" of the patient. The intimacy of the doctor/patient relationship is evident in this quote with the statement "*I had become close to him*" and also in the relationship implied by the "*instrument*" analogy.

762 *(EU5) I believe that it is proper for that person in that situation, that in the end he should*
763 *follow his own way too. It should come at the time and the moment he chooses. In that*
764 *sense, I was, I had become close to him, he was my patient, but in a certain way, I was his*
765 *instrument, because he was choosing was deciding the moment, the time (Dutch nursing*
766 *home doctor)*

EU5 expanded further to suggest that those who argue for euthanasia on the basis of patient autonomy are usually not those who actually have to make the decision (L775-776), implying that the experience of giving a patient euthanasia makes the doctor cautious about making euthanasia too readily available. Although agreeing with euthanasia as an option (see L762-763) this doctor stated that whatever moral reason you give for it, the doctor still killed the patient and it was necessary for the doctor to find a way to live with this knowledge.

767 *(EU5) But its (.2) every moral talk and all the reasons we can make for saying it is a*
768 *good thing - I think it is a good thing it happened but I'm very sceptical - however you put*
769 *it, you kill someone. It's as simple as that. One person asks the other person, "I suffer so*
770 *much, I think it is better that I die, can you kill me or can you help me to die". And that's*
771 *on the baseline, whatever morality or whatever you call it, comes on top of it to (allow you*
772 *to) live with it. I think that's exactly the point that you have to say it's a two way thing, not*
773 *a one-way thing. And it [performing euthanasia] sharpened me ... it sharpened my*
774 *senses to say, "Don't talk about it too easily, don't think it is a right you can obtain access*
775 *(too)". Um, people who tend to say that the autonomy of the patient is number one ... are*
776 *seldom the people who have actually to make these type of decisions. (Dutch nursing*
777 *home doctor)*

Effect on consumer of euthanasia availability in society

Doctors from both groups discussed the effect of euthanasia availability in Holland on patient expectations in end of life care. Concerns expressed were similar but ultimately EU doctors seemed more in favour of having the practice available than the NEU doctors.

NEU8 and EU5 both alluded to the role of the media in influencing the response of the public to euthanasia. This mirrors the proposal that the finding that Young European Laypersons were less likely to find it justified to increase medication at the risk of hastening death in an infant compared to an adult may have been related to possible inferences taken from media reports at the time that the Government and doctors had a superordinate position in decision-making, over parents (see Chapter 9, Section Two). NEU8 expressed concern over the possible effect of a public figure broadcasting his intention to have euthanasia the following day. This doctor

suggested that such publicity may influence persons watching who are in a similar situation to make a euthanasia request and are persuaded by a potentially influential source. This seems a reasonable concern when one considers the work in psychology related to attitude change and the role of the messenger in influencing change (Gleitman, 1991, p. 461).

778 *NEU8* A year ago there was a known person in the Netherlands who came on the
779 television. He had a laryngeal carcinoma that (had) reoccurred. He said "I have
780 decided to (stop living) tomorrow". And he had a discussion with the reporter a day
781 before he went to his death. The next day he got euthanasia somewhere in the
782 Netherlands. That is for me, strange. But by such a broadcasting that is seen by so many
783 patients, when (they are in a situation where they may want euthanasia) they should make
784 their own request (Dutch Oncologist).

EU5 deplored the assumption that euthanasia would easily be given on request. This doctor invoked "consumerism" implying that patients in Holland in response to publicity campaigns, may see elective death as a "short cut" solution to a problem that could respond to other measures. He expresses concern that the consumerist "movement" towards euthanasia may be related to lack of knowledge about other options and lack of knowledge about legal requirements.

785 (*EU5*) I have at the moment a nasty feeling that there is a tendency in Holland to think
786 that euthanasia is a normal part of the package ... I think due to publicity campaigns, due
787 to lack of knowledge about legislation, people think when it goes very badly with them, "I
788 just can ask it, and they will do it" ... It's a consumer society, I want it, you have to give it,
789 my bottle of milk, give me my syringe. And I don't like that movement, partly because I
790 think there is still a lot to learn about containment of symptoms, about giving comfort,
791 about ways to care for people. And when you take the short cut, you can tend to minimise
792 the other possibilities. (Dutch nursing home doctor)

Keizer (1997) seems to be alluding to this consumerist attitude towards euthanasia when he gives his account of Dophie's euthanasia request in his autobiographical account of terminal care in Holland.

"I ask him: 'Do you understand that you can't just call out for euthanasia as if it's an aspirin?' 'No,' he says drily. ... 'Cut all that crap, will you? I want to die. Just die. This is no life for me.'

I'm so accustomed to, 'Oh doctor, how marvelous of you to help me, I know very well how difficult it is for you,' etc that I don't know what to say in return. But Dophei couldn't care less about what it all means to the doctor. His message is: Hurry up, for God's sake and save all the sweet talk for after the cremation.

I hate this forceful way of demanding. You must ask nicely, first sit up, then shake hands, there's a good doggy, and here's your cookie." (Keizer, 1997a, p. 258).

Some responsibility was attributed by one doctor to general discussion about euthanasia in society that may degrade the dying experience for people and encourage them to avoid this by asking for a faster way of dying.

793 *NEU10* Because a lot of people are saying, "Oh when I have cancer, I don't want to
794 have chemotherapy, I don't want to be very ill in the last part of my illness. My goodness, I
795 want to have euthanasia because I want to pass from the living to the dead in only a few
796 minutes and that everyone should remember me how I was when I was well.
797 (Dutch Oncologist).

However, when commenting on the feasibility of exporting the Dutch euthanasia law to other countries, Griffiths et al. (1998) see the open discussion around euthanasia in Holland as one of the strengths of the procedure.

"Perhaps the most important lesson to be drawn from the Dutch experience ... (concerns) the quality of the Dutch public discussion itself. Perhaps it is not always as profound as one would wish. But nowhere else in the world are these questions being discussed so openly, so systematically, so calmly and thoughtfully, and with such a lack of ideological rigidity as in the Netherlands. Other countries may not choose to go the same way as the Netherlands but they can hardly fail to learn from the Dutch experience, if only they approach it with modesty, open-mindedness and respect." (Griffiths et al., 1998, p. 305).

It was emphasized that the doctor was not obliged to give euthanasia on request, even if all requirements had been met.

798 (EU4) *Even if (emphasis) you say that it is the right of the patient to realise*
799 *euthanasia or assisted suicide, it is quite another thing to say a doctor is obliged to, and*
800 *nobody has ever ever suggested that. (Retired Dutch GP)*

However if the doctor cannot comply with the patient's request because of personal scruples, the doctor was seen as obliged to refer on to someone who will help the patient.

801 (EU2) *But when a doctor hasn't the same feelings in the context of the law, ja?*
802 *When the doctor has the feeling that he can't do it, his principles, his religion, etc, well I*
803 *think he has to show the way to another colleague, another doctor or another hospital or*
804 *something where they can help him. Yes, that's my opinion. (Medical Director, Dutch*
805 *nursing home)*

This doctor acknowledged that giving euthanasia ran counter to his life purpose but when palliative care failed he agreed he saw it as part of the caring role. Although a leading question elicited the "caring role" response, the doctor elaborates on this. (EU2 alludes here to physician distress when it is difficult to relieve the patient's suffering as he has previously in L574-575).

806 (EU2) *It's not my, not philosophy, it's not my destiny to terminate life. I live to do*
807 *otherwise, quite otherwise.*
808 *K But you see it as being part of the caring role?*
809 (EU2) *Ja. I think so. Because I know my own feeling when some people are in very*
810 *very bad circumstances. Ja? And I cannot do anything for them, that happens, ja?*
811 *(Medical Director, Dutch nursing home)*

EU1 extended the concept of euthanasia as part of the caring role by terming it the "*ultimate care for the ultimate wish*".

812 (EU1) *I try, in my work I try to care for people, and I think the euthanasia is one of*
813 *the aspects of care. You might say it is the ultimate care for the ultimate wish, for*
814 *someone. (Dutch nursing home doctor)*

It was suggested that having this "ultimate care" available in society, which EU4 described as a "dangerous liberty" that required societal restraints to avoid abuse (see L711) was purchased at a cost. EU5 suggested that those who argue that euthanasia should be made available in a society to satisfy patient autonomy did not really grasp the significance of what they were asking of doctors.

815 EU5 *I think it is a good thing it happened but I'm very sceptical - however you put*
816 *it, you kill someone. It's as simple as that.... I think that's exactly the point that you have*
817 *to say it's a two way thing, not a one-way thing ... people who tend to say that the*

818 *autonomy of the patient is number one are seldom the people who have actually to make*
819 *these type of decisions. (Dutch nursing home doctor)*

To summarise, there were differences in the way the two groups of doctors represented autonomy in their accounts. NEU doctors represented autonomy in terms of empowerment for both doctors and patients through practitioner knowledge and experience. EU doctors represented autonomy in more direct terms related to self-determination for patients and doctors pertaining to end of life care and the euthanasia act.

NEU doctors represented a comprehensive knowledge of palliative care by the doctor as enhancing the autonomy of the patient by providing choices in end of life care. Such knowledge was portrayed as providing the doctor with room to move within the palliative relationship by the provision of options to offer the patient, other than euthanasia.

Conversely, some NEU doctors observed that a lack of palliative care knowledge was implicated in decisions to perform euthanasia for some doctors, particularly doctors in the community and those who have little experience caring for the dying. Four of the NEU doctors stated that euthanasia could be considered if necessary but palliative care choices had rendered this unnecessary to date.

EU doctors stated that they had performed euthanasia only after palliative alternatives had been exhausted. Physician distress at patient suffering may play a role in the physician agreeing to the request for euthanasia, strengthening the view that palliative care knowledge increases physician autonomy by providing alternatives to euthanasia (however none of the EU doctors specifically identified this link between knowledge and autonomy). Euthanasia is a "dangerous liberty" that should only be exercised in an egalitarian society with low power differentials. When the euthanasia request is considered the autonomy of the doctor becomes equal to that of the patient because of the enormity of what the doctor is being asked to do. Performing euthanasia for a requesting patient is judged to be the "ultimate" in care.

Both groups of doctors expressed concern over a possible consumerist approach to euthanasia as a result of having euthanasia available and freely discussed in their society. Such concern was directed at publicity related to euthanasia of celebrities, media representations of euthanasia and informal discussions among laypersons that encourage the reification of a "quick death" through euthanasia.

CHAPTER 16

CATEGORY 4: EUTHANASIA

The euthanasia request

Doctors from both groups had received requests, and had responded in a similar way by exploring palliative alternatives (see previous section). However the group who had performed euthanasia allowed for agreement to the request if palliation was unsuccessful while the other group had not found such an action necessary (although some said euthanasia could be considered if necessary) (see Table 16.1, p. 263).

EU doctors gave reasons for requests for hastened death which covered physical and psychological suffering and social concerns. "Symptom control" was mentioned as a generic term several times with specific symptoms as under. The request was ultimately granted when there were combinations of these symptoms. Such a combination was usually portrayed as "suffering".

Physical

Pain

820 (EU1) *He was in physical pain ... The pain was difficult to control with morphine.*
821 *We went to the higher doses and he became very drowsy, he didn't want it, and he said it*
822 *was enough. (Dutch nursing home doctor)*

Implicit in this statement is the patient's concern with altered cognitive function secondary to increased medications.

See also (L837-841)

(b) Suffering*

823 (EU5) *And I have had some discussions here already because I look at it as a two*
824 *way thing, my path and the patient's path have to cross each other, and we have to come*
825 *to a point where we say "Alright I understand that you want to go, I have no alternatives*
826 *to ease your life or give more comfort, and I understand that you suffer so much that you*
827 *can't handle it any more", that's the point when you can say you agree (Dutch nursing*
828 *home doctor)*

829 (EU2) *But on the other hand, when the position of people is so very very bad, with*
830 *no possibility of (recovery), well, then they are only suffering and that is more awful [than*
831 *giving euthanasia]. (Medical Director, Dutch nursing home)*

*(which may include physical pain (L842) but could also be included under Psychological)

(c) Dyspnoea

832 (EU2) *The first was lung cancer. And that is always difficult of course, because*
833 *when they are terminal then often you have too (little) time to talk with other people from*
834 *the team. Because there might be an emboli, the dyspnoea may be horrible, but it was*
835 *alright, it was euthanasia and it was ah - spoken with the patient of course, his family, the*
836 *team. (Dutch nursing home doctor)*

Implied here is the sense that dyspnoea secondary to lung cancer may precipitate a crises. In such a crisis there may be no time to implement the normal consultative process when considering euthanasia.

Table 16.1: Table showing issues arising around the request for euthanasia for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not²

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>The euthanasia request</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Reasons patients gave for requesting euthanasia were physical, psychological and social. <p><u>Physical</u></p> <ul style="list-style-type: none"> - Pain - Dyspnoea - Suffering (which may be psychological) <p><u>Psychological</u></p> <ul style="list-style-type: none"> - Altered consciousness - Depression - Fear* <p><u>Social</u></p> <ul style="list-style-type: none"> - Dependency - Altered body image (disfigurement) <p>*Previous vicarious experience with intractable pain and suffering may prompt requests for euthanasia from patients who fear they will suffer also.</p> <ul style="list-style-type: none"> • The euthanasia request may be made to "test" the doctor's commitment to the patient. • The euthanasia request may result in increased efforts by the doctor to find a palliative alternative because performing euthanasia is emotionally difficult for the doctor. • When the patient is confident that they have control over their dying and their treatment options, the request rarely persists. • Patients have a limit to what they will tolerate. Although they may tolerate more than they would initially have expected, there may come a time when they can endure no more. • Agreeing to give euthanasia to a patient may be preferable to the patient committing suicide both for the patient and the doctor. For the patient the responsibility and the action is shared with the doctor which will reduce stress. For the doctor, a personal perception of lack of commitment to the patient who has requested euthanasia may be difficult to bear when the patient meets all the requirements for euthanasia, is refused, then suicides. • Granting a patient's request for euthanasia can have a therapeutic and calming effect on the patient. 	<p><u>The euthanasia request</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Receiving a request for euthanasia is seen as an opportunity for doctors to offer palliative alternatives to address issues such as <ul style="list-style-type: none"> - Fear - Anxiety - Desperation - Depression - Pain • The euthanasia request may be made to test the doctor's commitment to the patient. • The request is not sustained when palliative alternatives meet patient need. • Some patients may not be committed to finding a palliative alternative to euthanasia. • Prior experience with disease and/or dying may undermine the patient's commitment to finding alternatives to euthanasia. • Oncology specialists may be less likely to consider euthanasia than GPs possibly because they believe that there are more alternatives available. • Doctors who are committed to palliative alternatives over euthanasia find some symptoms impossible to palliate. <p><u>Considering the euthanasia request part of commitment to patient</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • The doctor would perform euthanasia if palliative options had failed. • Euthanasia would be considered despite strong personal cost to the doctor but was seen as part of the doctor's commitment to the patient. • Believing that the patient had been abandoned by the doctor would be harder to live with than the knowledge that the doctor had performed euthanasia.

Psychological

(a) Altered consciousness

837 (EU5) *What made it very difficult for me was that we had agreed at a certain point,*
838 *on euthanasia. His pains, bone metastases with all kinds of complications, breathing, and*
839 *it came to a point that his consciousness changed a bit. And (he said), "I want to be in my*

840 *own mind, I don't want to wander off, I don't want to hallucinate" - things like that.*
841 *(Dutch nursing home doctor)*
See also (L820-821).

(b) Depression

842 (EUI) *Well it's not just the pain, it's more the uncontrollable suffering, which can*
843 *be pain but can also be - well, there has been some cases in Holland where for example*
844 *severe depression was the reason for euthanasia. (Dutch nursing home doctor)*

(c) Fear

Several doctors reported that the patient being exposed in the past to the suffering of others prompted requests for euthanasia.

845 (EUI) *He had some experience years ago in the family with someone who was*
846 *chronically ill who said that he had wanted euthanasia and this request was not granted*
847 *and that man was in a lot of suffering ...he said he didn't want that to happen [to him].*
848 *(Dutch nursing home doctor)*

849 (EU5) *... an independent man who had taken care of his wife when she was ill,*
850 *she had had cancer and a very prolonged sickness at home and he wanted to prevent*
851 *himself from getting in the same dependent circumstances as his wife was. (Dutch nursing*
852 *home doctor)*

1. Social

(a) Dependency

853 (EUI) *The man with malignant disease was all his whole life, independent. Well*
854 *right now he was dependent, he was in pain, he was depressed, he couldn't cope with it.*
855 *In spite of talks I had with him, despite the talks the psychologist had with him, the*
856 *chaplain also talked with him, he insisted on having euthanasia. ... And I think the pain*
857 *and the fact that he was dependent now were the most important things. (Dutch nursing*
858 *home doctor)*

859 (EU5) *He always was an independent man who had taken care of his wife when she*
860 *was ill, she had had cancer and had a very prolonged sickness at home, and he wanted to*
861 *prevent himself from getting in the same dependent circumstances as his wife was ... He*
862 *had two daughters, both lived in the village where I lived, and a son who he didn't see*
863 *anyhow, and they couldn't take care of him 24 hours a day. So he had already discussed*
864 *euthanasia with his own physician, and it was one of the first things he talked about when*
865 *he arrived in our nursing home. (Dutch nursing home doctor)*

(b) Disfigurement

866 (EU3) *She was 22 ... mutilation of the ear and the nose and blind and ... the eye*
867 *had to be taken out because she had carcinomas all over her body and the orbital and the*
868 *eye had to be taken out ... so I can speak very peacefully about euthanasia. (Medical*
869 *Director, Dutch nursing home)*

NEU doctors agreed with EU doctors on the reasons for the euthanasia request. Moreover, both groups appeared to concur that receiving a request for euthanasia was an opportunity to explore patient fears and provide or suggest palliative alternatives. There is a sense in the accounts that NEU and EU doctors both accept the euthanasia request as part of the care of the dying. This is exemplified in a quote from the hospice doctor who goes further to suggest that receiving palliative alternatives to euthanasia is a "human right" (L876).

870 NEU 7 *But very important to me, if the patient is choosing euthanasia because of*
871 *pain, which can be relieved maybe, and um, they are choosing euthanasia because they*
872 *don't know of other possibilities, that's a very big point, to try to broaden this scope of*
873 *possibilities so they can make a choice. And if the patient is asking for euthanasia*
874 *because he is depressed, to me the first thing is not accept the situation like it is, but to try*
875 *to treat depression, to try to address this. So this I find a much more creative way to deal*
876 *with his question, and to accept it as a human right, and to proceed with it. (Dutch hospice*
877 *doctor)*

EU4 suggested that sourcing acceptable palliative alternatives was also in the best interests of the doctor, given the difficulty for the doctor of performing euthanasia.

878 EU4 *Euthanasia is very difficult, emotionally time-consuming, so as a doctor who*
879 *has the option of euthanasia, he or she will do everything to avoid it ... (my colleague)*
880 *used to say to me, "If you want the best medical care, ask for euthanasia and everybody*
881 *will do everything to try to avoid it". (Dutch general practitioner)*

Doctors from both groups agreed that requests may occur early on in the diagnosis but are not sustained when the patient has confidence that their needs will be met. Once the patient had confidence that the doctor could be trusted to follow patient wishes regarding the withdrawing of treatment the patient rarely persisted in the request for death, focusing rather on leave-taking issues.

882 NEU8 *Most patients ask for that because they want to have that security*
883 *that you when there are problems in the future, they can trust you, you will help them, but*
884 *most patients don't ask for that in the later phase. ... It's a difficult point always when*
885 *there is such a request. We say always when the patient comes to us, firstly we want to*
886 *have the chance to try to cope, to treat the symptoms. (Dutch Oncologist)*

887 (EU5) *It was um, quite intense, it was not the first time the question arose, because*
888 *more people want to be informed about it, ask about it, but most people seem to talk about*
889 *euthanasia (with another agenda) - you won't prolong my life if I become unconscious, I*
890 *don't want to have syringes and things, oxygen, you won't send me to a hospital when I*
891 *get my next (attack), and they want to check out if you will go along with their wishes on*
892 *the life-prolonging path and the conditions on the path of controlling symptoms. And*
893 *most people are quite satisfied if you answer their questions, if you can go along with*
894 *them for symptom control. It is very rare in my experience that people actually want to die*
895 *at a certain point, at a certain time. Most people tend to say, "No, no, I want to talk to my*
896 *kids", "I want to see my daughter who is in Canada", things like that (Dutch nursing*
897 *home doctor)*

This doctor also spoke of the boundaries that the patient put up about what was acceptable to bear.

While the patient may tolerate more than they may have expected.

898 (EU5) *Every 18 year old boy says, "I'll never sit in a wheelchair", until they have their*
899 *accident and they are in the wheelchair and they say, "No, I can live like this". The*
900 *illness doesn't come suddenly, you don't get old in a day, you get old gradually, and you*
901 *tend to grow along with it and accept a lot of things that happen. And I think the same*
902 *tendency goes for people that get ill and also for people who get terminally ill (Dutch*
903 *nursing home doctor).*

...his experience was that these boundaries were not always moveable, and a point does come when the patient who has inquired about euthanasia formalises the request.

904 (EU5) *What we did was talk about what he accepted as being part of his life, his*
905 *illness, and where is the line that you say "I cannot live with that". And it took us about*
906 *two or three months to get to that point, and one morning when I went into his room, I*
907 *went there two or three times a week, and he looked at me and said "Now is the time, doc"*
908 *(Dutch nursing home doctor)*

It was stated that not all patients appear to be prepared to continue to seek a palliative alternative and patients may actively pursue the euthanasia option from an early stage. NEU8 described a case that was typical of accounts from other NEU doctors who expressed concern over the precipitous implementation of euthanasia. The patient, a nurse, requested euthanasia after a diagnosis of melanoma because she feared the known effects of metastatic disease. Palliative radiotherapy relieved her pain but the request persisted. Supported by her GP and husband, the patient found an alternative source and received euthanasia at another hospital. This doctor expresses concern over the patient receiving euthanasia so early on in the process which had only lasted four days particularly when interventions had relieved the pain. This case seems also to raise the issue of prior experience affecting attitudes towards the dying experience, given that the patient was a nurse. (see also L845-851).

909 *NEU8* Last year we had a patient, a nurse with a melanoma that was discovered in
910 our department at the beginning, a Monday, and we (learned) that she had metastases in
911 the lumbar spine. And she asked for euthanasia. She said "I know exactly what it means
912 to have metastatic disease". We said, we can irradiate it, we can help you with that, and at
913 this moment we don't think we will do that. She got the irradiation, the pain was relieved,
914 and then on Thursday she came again with her request - "I want to have euthanasia".
915 We said "No, the symptoms are under control". Then she said the husband had asked a
916 local physician to our hospital to see whether the request of the patient was real, and
917 whether she fulfilled the criteria under the law. We were saying it is not at that moment
918 the right time. He said, "I agree with the request, it is okay". But we don't do that here,
919 and the patient was transferred to another hospital, and the day after she got (euthanasia).
920 ... And that is for us a strange situation. I have difficulties with that.
(gap)

921 *K* So the period of time you were treating her was how long?

922 *NEU8* Well, we know her for four days. (Dutch Oncologist)

According to this account, the pain was controlled but the patient's fear of what was coming had apparently not been addressed (see L225-235). NEU10 described another case, explicitly addressing the requirement for psychological interventions to address anxiety and fear related to the terminal illness as a more appropriate treatment than euthanasia.

923 *NEU10* But in the hospital, sometimes when I was working in the University hospital,
924 there was a patient who came every week or every two weeks and he was working, and
925 then there came a letter from the doctor at home, he had euthanasia. And we really didn't
926 know why he had it. Only because it was very hard to live with cancer? Then you could
927 give other kinds of treatment. Psychological treatment or something like that, or treat the
928 depression if it's part of the illness, but not give euthanasia (Dutch Oncologist)

Both of these doctors were Oncologists, and it was stated that Oncologists are reluctant to perform euthanasia implying that they had other options available to them such as medication or psychological input whereas GPs, through lack of experience, may not (see L456-458, L669-671). Such interventions were sufficient to prevent euthanasia.

929 *NEU10* Also in this hospital it is not done to do euthanasia ... as oncologists, we are
930 not very (willing) to do euthanasia. I think mostly there is written outside the hospital
931 about it and you also see the physician at home speaks about it, which I think is more
932 because they only see a few cancer patients a year and they are, ja, they don't know how
933 to, how they have to manage it, ja? To speak perhaps with the people or to give the right

934 *medicines. But I think most of the time, it is possible to give the patient that treatment he*
935 *needs so that the question for euthanasia is also not done any more. (Dutch Oncologist)*

However doctors from both groups did agree that there were some instances where palliative care is not sufficient to meet patient need. Such statements coming from doctors who have not performed euthanasia and are committed to finding palliative alternatives to euthanasia highlight the dilemma that may be experienced when caring for the dying patient who suffers intractable pain.

936 *NEU9 But sometimes of course, you don't solve the problem. For example, we have*
937 *great problems sometimes with rectal carcinoma, and then you get the pain in the sacral*
938 *(region) when the tumour is growing in. You get terrible pain, really terrible pain, and it*
939 *is neuropathic pain and, well, we know more about it but sometimes you don't feel that*
940 *you know enough or can do enough to relieve people and those people get mad with their*
941 *pain. And you try everything, I mean, (they've) just written more about it, you try*
942 *everything, and sometimes you don't, you just don't get it. [exasperated sounding]. And I*
943 *think the first important thing is to admit that you try, but that you don't manage, and that*
944 *you can keep trying things, but first of all, take this patient seriously. That's one kind of*
945 *pain which sometimes you can't help as much as you would like to [slowly, thoughtfully].*
946 *(Dutch nursing home doctor)*

NEU9 had argued elsewhere that she considered euthanasia as the most compassionate alternative for the young woman who would not tolerate terminal sedation (L592-593). She may be indicating here that intractable physical pain is also a justification for euthanasia. NEU10 is more direct in advocating euthanasia for intractable distress.

947 *NEU10 When you have a patient who is, who has a cancer in the neck and he is*
948 *going to strangle from the cancer, when you have no possibilities to treat that patient,*
949 *when they have had chemotherapy, radiotherapy, I think that is one of the only reasons*
950 *that euthanasia is given. (Dutch Oncologist)*

EU3 stated that it was preferable for him to give euthanasia on two occasions than to have the patients commit suicide. This is reflective of doctors in Oregon who were psychologically affected by the suicides of patients who had requested but not received physician-assisted suicide (Kohlwes, Koepsell, Rhodes, & Pearlman, 2001). Although it is unclear what the psychological effect specifically related to in this article.

951 *(EU3) I have had the experience of giving two people myself active end treatment*
952 *because those situations were in my [emphasis] experience, so terrible - we had done all*
953 *the things (possible) and we were very afraid that those people were (going to) die by*
954 *suicide so we gave them (active end treatment). (Dutch nursing home doctor)*

A therapeutic effect of the agreement to the euthanasia request was reported.

955 *K Was there a difference, once the patient knew that um, he was suffering, once he*
956 *knew that his euthanasia had been sanctioned, was there a difference in him?*
957 *(EUI) He became very (.3) quiet, (.3) he was more at ease, ja.*

Considering the euthanasia request part of commitment to patient

Doctors who had performed euthanasia entered into the process of negotiating the request using the protocols and processes laid down by the Royal Dutch Medical Association and the Dutch

judiciary system if palliative interventions were unsuccessful (see following sub-section). NEU doctors did not discuss this part of the process although four of them did state that they would be willing to consider negotiating euthanasia if palliative options were unsuccessful. One doctor stated that being willing to consider euthanasia was considered the preferable option despite the potential negative effect on the doctor....

958 NEU6 *I must be honest, I hate it, but I hate it much more to leave them alone. So if*
959 *not other solution than euthanasia may help ... I will give euthanasia. And even if I*
960 *won't sleep for the nights before and I also won't be able to sleep the nights afterwards, I*
961 *will do so. I won't leave you. (Dutch Oncologist).*

.....because of the potentially worse negative effects on the doctor of abandoning (L966) the patient once a commitment had been made to help them with their dying.

962 NEU9 *I in fact, till now, never did it. And that's not because I think you are now*
963 *allowed to do it, I think there are circumstances when you said you would help someone*
964 *until the end, and you are with your back to the wall, then it might happen that you have*
965 *to do it. That is the consequence of saying "Okay, I will be there". ... Otherwise I have*
966 *other problems, and I leave my patient which I promised not to do. But I get out of those*
967 *things until now, by comforting them and paying the price of shortening their lives.*
(Dutch nursing home doctor)

NEU8 represents this in contractual terms – a process that marked the negotiation around euthanasia noted in the accounts of the EU doctors.

968 NEU8 *... firstly we want to have the chance to try to cope, to treat the symptoms ...*
969 *when we don't succeed, when we can't help you sufficiently, then we are on your side*
970 *(Dutch Oncologist)*

In summary, reasons given for the euthanasia request were similar for both groups and covered physical, psychological and social concerns. Both groups of doctors responded similarly to a request for euthanasia by exploring palliative alternatives. The psychological effect of performing euthanasia was given as one motivation for aggressive exploration of alternatives once the request was received. Doctors from both groups suggested that the euthanasia request could be a way of testing doctor commitment.

The experience of all doctors from both groups was that when palliation was successful the request stopped. When palliation was unsuccessful EU doctors agreed to the request and agreeing to the request could have a therapeutic effect on the patient's suffering. NEU doctors said that they would be prepared to consider euthanasia when palliation was not successful in preference to abandoning the patient. The implication here is that leaving the patient to suffer is abandonment.

NEU doctors expressed concern that euthanasia may be given precipitously because some patients were not committed to finding an alternative. Negative prior experiences with the dying process may be implicated in this. However EU doctors stated that it was up to the patient to decide how much suffering they can endure.

Protocols and processes – facilitative function

Doctors who had performed euthanasia discussed the protocols (or guidelines, both terms used interchangeably here) controlling the practice in the context of the events they had been involved in and as a commentary on the efficacy of the protocols. NEU doctors did not discuss these protocols. Although this is not a vehicle for comparison between the two groups, it has been included because it is considered to be valuable in gaining insight into the whole experience of doctors providing euthanasia to patients (see Table 16.2, p. 270).

The protocols that control euthanasia and physician-assisted death were discussed positively by all doctors who had performed euthanasia.

971 *EU5* *And because there are very strict rules and you can control yourself - "Did*
972 *you follow the rules", there is also a kind of confidence that you didn't miss anything,*
973 *forget anything that you should have done" (Dutch nursing home doctor)*

When the decision-making process was under way, it appeared helpful to have a second consultation to ensure that the action would be the appropriate one for the patient in that particular context. It was suggested that having a second opinion was also important to ensure that the doctor was capable of assessing the situation objectively, the consultation process providing the opportunity for reflection and feedback that the doctor had made the correct decision. It was argued that this peer review protected the patient from a doctor who may be influenced by personal issues and provided the doctor with confidence that the decision was the correct one.

974 *(EU5)* *And at some point we had said, we will ask a consulting physician, and we got*
975 *a physician it's a formality and I think it's a good thing in that sense, in that another*
976 *physician can play with your thoughts, your thinking, and correct you if you are depressed*
977 *for that is also a possibility, we do not want all kinds of physicians wandering off.*
978 *K* *So the second physician is for the doctor as well as the patient.*
979 *(EU5)* *Yes, you have to check out if you are correct about this. If you have seen all*
980 *the alternatives, if you think you have balanced the pros and the cons, and that you have*
981 *on a professional basis, worked it out well. (Dutch nursing home doctor)*

Moreover it was argued that correctly following protocols provided the opportunity for discussing the decision openly with the family and the caring team through transparency of practice. EU5 stated that he felt more comfortable performing euthanasia according to the protocols than he had giving a patient terminal sedation and feeling concerned that the practice may not be legal*. Having guidelines to follow also assisted with a more comfortable resolution of the practice for the doctor because it was more "sanctioned".

Table 16.2: Table showing issues arising around protocols and processes associated with delivering euthanasia for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not²

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Protocols and Processes – Facilitative Function</u></p> <p><u>Issues Arising</u></p> <ul style="list-style-type: none"> • Protocols that control the practice of euthanasia are seen positively by doctors for several reasons. <ul style="list-style-type: none"> - Provide confidence that the action was legal - The consultation process provides the opportunity for reflection and feedback on decision-making. The consultation process protects the patient from a doctor who may have personal issues and/or aberrant thinking. - Encourages transparency in practice. This allows wide discussion between doctor and family and colleagues and gives confidence that the decision was the correct one. This helps the doctor to come to terms with the actions post event and to feel confident that they acted in the patient's best interests. - Transparency in practice allows patient to effectively leave take from loved ones and facilitates healthy grieving for the family post event. - Correctly following guidelines ensures that appropriate drugs can be obtained and used which provides the most humane outcome for the patient. <p><u>Difficulties with protocols and processes.</u></p> <ul style="list-style-type: none"> • The requirement for a consistent and enduring request in euthanasia may result in some patients asking that the euthanasia request be actioned prematurely, fearing that experienced altered states of consciousness secondary to brain metastases or alzheimer's may become worse and invalidate the euthanasia request in the future. • The necessity to meet legal requirements pertaining to the euthanasia may place added stress on the doctor if the involvement of other services or personnel in the event are not co-ordinated. Waiting for the coroner post event and filling many forms was identified as an added stressor for the doctor. • Education is necessary to teach doctors who give euthanasia the way to best facilitate an elective death both for themselves and for the patient. This includes <ul style="list-style-type: none"> - Identifying who needs to be involved in the euthanasia to meet legal requirements and at what point. This includes consultation for second opinion. - Having necessary paperwork collated and completed before the event. - Ordering the correct drugs. - Encouraging the patient to take control of and personalise the euthanasia including appointments with hairdresser and/or manicurist, choosing clothes etc. - Facilitating with the patient/family a date and time for the euthanasia - Arranging with the patient who will be present at the euthanasia. 	
	<p>Doctors who had not performed euthanasia did not discuss the protocols and processes that surround this practice, apart from NEU9. She referred to it briefly in the context of her story about the 22 year old woman she had accompanied while she had her euthanasia - <i>"So it all happened as it should happen, you know, telling the police"</i> (NEU9 L593-594).</p>

982 (EU5) *And the second time, the official time, it felt better because it was official. It*
983 *was very well, very good records, second opinion, ah the whole team had been talked to,*
984 *the children had been talked to. It was more sanctioned. Also, that made it more*
985 *easy to get over it. To look back and say it was difficult but it was a good thing to do.*
986 *And with the woman beforehand, I kept (thinking) was this correct, or was this crossing*
987 *legal lines, could we get into trouble. And because there are very strict rules and you can*
988 *control yourself - "Did you follow the rules", there is also a kind of confidence that you*
989 *didn't miss anything, forget anything that you should have done.(Dutch nursing home*
990 *doctor)*
991 **see (L520-522)*

Following the protocols encouraged transparency of practice which allowed/encouraged all those who were affected by the euthanasia to be involved. One participant maintained that not following correct procedures when practising euthanasia rendered the physician vulnerable to psychological "blackmail" from family members who were aware of this. The doctor may feel unable to take control in future dealings with the patient's family, which could undermine his professional value to the family.

992 (EU4) *I think it's a bad thing to break the law. To break the law as a professional*
993 *group ... It is very bad for a doctor to do something against the law because you can be*
994 *blackmailed all your life. And I don't mean blackmailing for money because that's not so*
995 *usual in this country but it's blackmailing in all kinds of small things. If you would not*
996 *notify the authorities and the widow of that man would be in your practice still, you are*
997 *not free to go, "I insist you go to the Specialist" or "I insist you not go" you are not free*
998 *to say. (Retired Dutch GP)*

If the euthanasia was secret because it did not meet legal guidelines, it is plausible that it could complicate grieving in the family. The number who grieved would be greater than the number who knew the circumstances of death and the grief of those who knew or were having euthanasia may be complicated by being unable to share their experience with loved ones and leave-take appropriately.

999 (EU4) *if you do not notify the authorities, you have to tell the patients, "You keep your*
1000 *mouth shut, do not talk about it with anyone", which means that the group of people who*
1001 *know about it is much smaller than the group of people who grieve, and well, Grandma*
1002 *cannot say goodbye to her grandchildren properly, to put it in a nutshell. (Retired Dutch*
1003 *GP)*

Similarly, professional relationships with colleagues could be affected. If correct protocols were not followed the doctor could be open to censure from the pharmacist who is responsible for supplying the euthanatic (Onwuteaka-Philipsen et al., 1997b). Worse still from the patient's viewpoint, if the doctor was acting in secret, it may not be possible to get the correct drugs, which could impact negatively on the dying experience. Using inappropriate drugs for euthanasia can lead to unpleasant deaths (Ogden, 1994).

1004 EU4 *...doctors who do not notify the authorities might not trust the pharmacist ...*
1005 *and the effect of that is that he does not go to the pharmacist and get effective and proper*
1006 *drugs for euthanasia and will use morphine or will use insulin which are not good drugs*
1007 *for euthanasia. (Dutch general practitioner)*

This doctor had performed euthanasia 15 years before the protocols were in place and spoke of the difficulty of finding out exactly what drugs to use and how to perform euthanasia in a climate of secrecy.

1008 (EU4) *I called the Euthanasia Society which was very young then, I think it was*
1009 *about 20 years ago. I called the Euthanasia Society and said "I want to perform*
1010 *euthanasia on a patient, how do you do that, what do you use for that". And they said,*
1011 *"We fight for a change in the law, we never thought anybody would do it. And we don't*
1012 *know"*
1013 K *So you had to wing it?*
1014 (EU4) *No, they called me back and they said "We've found an anaesthetist who will*
1015 *contact you to give you instructions". (Retired Dutch GP)*

Difficulties with protocols and processes

However, having strict protocols that control the practice of euthanasia may also have some negative effects. The guidelines specifically state that the request is enduring and that the patient must be competent when the death occurs. Immediately prior to giving euthanasia, the doctor must ask the patient if they are sure they want to go ahead to ensure that there has been no last minute change of mind. The patient may have requested and been granted euthanasia, but at the time the euthanasia is to be performed the doctor may be unsure of the competency of the patient to make the request. EU5 discussed a patient who had fluctuating consciousness secondary to brain metastases. In this case he maintained it was not possible for either him or the consultant physician to determine if the request of the patient was valid from the point of view of competency or whether it was enduring (a legal requirement for euthanasia). Patient's who have cerebral involvement may be incapable of pursuing a sustained request.

1016 EU5 *I had a patient who was so ill and so terminal there was not time to talk*
1017 *things through thoroughly because she had brain metastases and had fluctuating*
1018 *consciousness ... when she had a lot of pain we talked about the possibility of ending her*
1019 *life ... one day she was bright and clear and the next she would be crying "I want to die, I*
1020 *want to die". So both physicians in the house couldn't decide whether it was a consistent*
1021 *attitude. (Dutch nursing home doctor)*

This requirement may also result in some patients requesting to die while they still have some quality time left, concerned that their cognitive function may change to the extent that euthanasia will not be possible even though the patient may have been previously consistent in the request. The patient who suffers brain metastases or alzheimer's disease will often experience a period of time between diagnosis and the effects of the disease rendering the patient incompetent during which there is insight into the progressive nature of the condition. EU5 stated that the patient who had said he would not tolerate an altered conscious state asked for euthanasia at the point his consciousness changed, but while he still had insight.

1022 EU5 *The man I met was relatively young, a very strong character ... we had*
1023 *agreed at a certain point on euthanasia ... and it came to a point that his consciousness*
1024 *changed a bit and he said "I want to be in my own mind, I don't want to wander off, I*
1025 *don't want to hallucinate" ... this man was very clear-minded about what he wanted so we*
1026 *did it. (Dutch nursing home doctor)*

A further procedural difficulty identified related to the strain of having the doctor incriminate him or herself by reporting the death to the Coroner as unnatural. EU2 agrees with a reporting procedure as necessary for control of the practice, but spoke of the strain of having to do this.

1027 EU2 *Well of course we have the control from the law. And that's a very good thing ...*
1028 *there must be, there should always be, a very good control system ... not only for us, but*
1029 *for any country for any people. I think that is very essential. It's not very nice for us,*
1030 *because they are always looking, lawyers are very sharp in looking at what we are doing,*
1031 *but I think it is a good thing (Medical Director, Dutch nursing home)*

Another doctor spoke of the strain of having to wait around for the coroner to arrive after the euthanasia was performed. He found the added wait afterwards so stressful that he said at the time that he would never perform euthanasia again.

1032 EU1 *Right after it happened I said it was the first and the only time. ... this was*
1033 *one of the main reasons I said I would never do it again. It took me all night. And*
1034 *waiting, waiting for the coroner. It took place at 2 o'clock and he finally showed up at 9*
1035 *in the evening. And we had to wait. (Dutch nursing home doctor).*

This doctor spoke very movingly about this patient and chose to remember the euthanasia event in existential terms (see L1215-1223) which supports the view that the wait exacerbated stress related to the performance of euthanasia rather than reflecting the inconvenience of the wait, per se.

The stress for doctors was acknowledged by one of the practitioners who lectures to registered practitioners on euthanasia practice. He suggested that this stress could be minimised to some degree by forward planning of the euthanasia event. This would involve

- ordering the correct drugs
- having paper work collated and completed
- advising the coroner beforehand to expect a call about a euthanasia that was to be performed at a certain time, which would speed up the post-event process.

1036 (EU4) *You may call the coroner beforehand and say "I will call you for an occasion*
1037 *of euthanasia Wednesday night at 8 o'clock or Saturday morning at 10 o'clock, without*
1038 *telling him when or where or who. It just means, "Make sure you are ready".*
1039 (gap)
1040 *So if everything is alright from the moment of death until the permission for the funeral*
1041 *and the departure of the examiner, can be no longer than 40 minutes. (Dutch*
1042 *general practitioner).*

He also argued that planning for the euthanasia should include facilitating the process for the patient and family by encouraging them to

- choose an appropriate day and time, avoiding a family anniversary.
- suggesting a visit to the hairdresser or manicurist.
- planning what to wear

- deciding who will be at the euthanasia event

1043 (EU4) *You should stipulate that the patient will shape or create his or her end in a*
 1044 *very individual and personal way. Yes. I would certainly ask the patient "What are you*
 1045 *going to wear". I would certainly ask that. "Would you like to have a hairdresser, would*
 1046 *you like a manicure". Oh yes, I would certainly ask and, and (.4) You have to make a*
 1047 *date, that day, that hour. You can't be vague about it. So you have to say "What about*
 1048 *Wednesday, 9 o'clock" or "What day do you suggest" and as a doctor you have to make*
 1049 *sure there is nothing else that night or that morning, or whenever it is. I check, is that not*
 1050 *a special day, the day you choose? Is that another special day in your family? It is not the*
 1051 *wedding day of your son or something like that? And they might say "Yes", and you try to*
 1052 *get another day so as not to poison that day. (Retired Dutch GP).*

Such attention to detail was likened by EU4 to the approach of practitioners when they facilitate the dying process while delivering palliative care. He suggested that training in palliative care assists in such attention to detail. This mirrors assertions by EU doctors that euthanasia is an extension of palliative care.

1053 EU4 *I think being a GP I'm more intimate with patients than a doctor in the*
 1054 *hospital, and the attention to details, all these small things I have learned from palliative*
 1055 *care, because that's part of palliative care (Dutch general practitioner)*

To summarise, doctors who had performed euthanasia viewed the protocols and processes involved in controlling the practice justified and helpful. They protect the doctor and patient from inaccurate assessment through consultation, protect the patient from the doctor's personal biases through consultation, encourage healthy leave-taking and open discussion through transparency of practice and encourage consultation on correct drugs to use through transparency of practice.

Negative aspects of the protocols (which is not to say these were inappropriate) include the requirement for a consistent and enduring request which may encourage patients who are experiencing cognitive changes to action euthanasia prematurely to avoid the request being voided. Physician distress related to the euthanasia event may be addressed by education to teach doctors to plan the euthanasia event to (a) reduce practitioner stress and (b) facilitate a good death for the patient.

Effect on doctor of performing euthanasia

Although one group had not performed euthanasia, they spoke of the anticipated effect on the doctor of such an action, while the doctors who had performed euthanasia reported varying implications of the action for themselves (see Table 16.3, p. 275).

Whether euthanasia is legal or not, the doctor is involved in killing an innocent person. The difficulties the doctor is exposed to in performing euthanasia appears to follow two main areas. The first is the doctor's need to know that all procedural requirements have been met and that there is no chance of a backlash from the judiciary following the euthanasia. The second is more personal.

Table 16.3: Issues arising for Dutch doctors who have performed euthanasia¹ and Dutch doctors who have not² around effect on doctor when delivering euthanasia.

<u>EUTHANASIA¹</u>	<u>NO EUTHANASIA²</u>
<p><u>Effect before euthanasia is performed</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • The period between agreeing to a request for euthanasia and actioning the request may be difficult for doctors. This difficulty manifested itself in <ul style="list-style-type: none"> - problems sleeping - difficulty facing the patient each day in the preceding weeks when the patient had control over the timing of the euthanasia - worrying each day that "this would be the day" - fear that something would go wrong with the delivery of the euthanatic <p><u>Effect after euthanasia is performed</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Doctors reported after-effects from performing euthanasia. These included <u>Negative Effects</u> <ul style="list-style-type: none"> - emotional reactions that were unexpected and distressing - an acute personal awareness that the doctor had killed - feeling awful - feeling that the sacred process of dying had been disturbed by the euthanasia - feeling exhausted, feeling doubt - finding it harder to do each time - feeling like a line had been crossed and there was no going back - feeling that doing euthanasia was in conflict with the perceived role of the physician <u>Positive Effects</u> <ul style="list-style-type: none"> - feeling enriched by the experience - believing that the patient had been freed from suffering - believing it was a good thing - believing it was an appropriate action • Because euthanasia has such a profound effect on the doctor, granting it must remain the exception and each request must be carefully considered. • Because euthanasia has such a profound effect on the doctor it should be performed infrequently and time must be allowed for psychological recovery. <p><u>Relieving the dissonance associated with performing euthanasia</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • Recalling events that occurred around the euthanasia event in metaphysical terms may contribute to a sense of meaning about the death. Feeling a sense of meaning is identified as helpful to the doctor. • Talking about the euthanasia after the event with family and/or colleagues helps the doctor to come to terms with the event and work through residual issues. • The family may find it helpful to talk with the doctor about the euthanasia after the event. This may take place on several occasions over time. 	<p><u>Implications of performing euthanasia for the practitioner</u> <u>Issues Arising</u></p> <ul style="list-style-type: none"> • The doctor may not consider euthanasia because of personal cost including fear of <ul style="list-style-type: none"> - Personal change (negative implied) - Undermining professional position - Personal belief systems being undermined - Unforeseen consequences - Becoming desensitised to euthanasia events • The doctor may not consider euthanasia believing that palliative alternatives are sufficient to address patient need. • Performing euthanasia despite personal cost to the doctor is worthy of respect. • Personal cost to the doctor is a requirement of performing euthanasia. Euthanasia that was performed too easily was judged a lack of care. • Performing euthanasia required a deep and committed relationship with the patient.

It involves the doctor's need to know that, on a moral level, the action is sanctioned and that the gravity of the personal step being taken is recognised. EU5 articulates this effectively.

1056 EU5 *But it's (.2) every moral talk and all the reasons we can make for saying it is a*
1057 *good thing - I think it is a good thing it happened but I'm very sceptical - however you put*
1058 *it, you kill someone. It's as simple as that. One person asks the other person, "I suffer so*
1059 *much, I think it is better that I die, can you kill me or can you help me to die". And that's*
1060 *on the baseline, whatever morality or whatever you call it, comes on top of it to allow you*
1061 *to live with it. (Dutch nursing home doctor)*

None of the doctors who had performed euthanasia appeared indifferent or unmoved by the experience. Similarly, none of them stated that they wished they had not done it. This suggests that these doctors had successfully deployed the coping mechanisms necessary to live with the knowledge that they had purposely killed the patient. However the psychological effects seemed intense. These were divided into two areas; pre-euthanasia effects and post-euthanasia effects.

Effect before euthanasia is performed

After the request was agreed to the patient decided when the euthanasia would occur. Although EU5 saw patient control at this point as appropriate, waiting for the decision to be made was difficult. He had to force himself to enter the patient's room each day, fearing that that would be the day the euthanasia would occur. He expresses his passivity in this part of the process by likening himself to an "instrument" of the patient.

1062 EU5 *It was very difficult to make myself enter that room every day in the weeks*
1063 *that followed because I felt that I made a commitment ... and having made that*
1064 *commitment, I didn't know when it would take place. And it was very hard to make myself*
1065 *go and ask him time after time "How are you feeling, how is the pain" things like that. ...*
1066 *I believe that it is proper for that person in that situation that in the end he should follow*
1067 *his own way too. It should come at the time and the moment he chooses. In that sense, I*
1068 *was, I had become close to him, he was my patient but in a certain way, I was his*
1069 *instrument because he was choosing, was deciding the moment, the time. (Dutch nursing home*
1070 *doctor).*

Portraying himself as the "instrument" of the patient, increases the concept of the doctor as passive in events. This may be a way of emphasizing the control of the patient over the euthanasia. By portraying himself as under the control of the patient, the doctor appears to be de-emphasizing his role in the euthanasia and positioning the patient as the person in charge.

This period lasted for three or four weeks during which EU5 dreamed about killing the patient. The doctor stated that actually giving the patient euthanasia was easier than the period of time beforehand when he awaited the final decision from the patient.

1071 EU5 *... the time to get to the point where I got his drink ... and I got a syringe*
1072 *which stopped his heart. That moment was easier than the weeks before when I had to say*
1073 *to myself "Come on"*
1074 K *So what were you thinking during that time. Were you thinking "I am going to kill*
1075 *somebody". [leading question]**
1076 EU5 *Ja [quick, definite] Ja, I dreamed about it too [tearful]. (Dutch nursing home*
1077 *doctor)*

*The rapid agreement to the leading question and expansion on that theme suggests this is what the doctor was thinking.

Another doctor agreed that the period between the request being agreed to and giving euthanasia was difficult for the doctor. This doctor's anxiety expressed itself in fear that something would go wrong with the delivery of the euthanatic.

1078 EU1 *It affected me more before it happened, than the euthanasia itself ... he was*
1079 *given an infusion and the only thought I had at that moment was "Please don't". You*
1080 *know I've given thousands of infusions on the wards and I can only say I never missed,*
1081 *but I worried that this will be one of the times I am going to miss. (Dutch nursing home*
1082 *doctor).*

The doctor who spoke of concern about whether the patient's request was valid or not on the grounds of possible incompetence (see L1016-1021) also raises the issue of the struggle that may be experienced by doctors prior to the euthanasia as they face the responsibility of assessing the viability of the patient's request and strengthens the importance of consultancy in such decision-making.

Effect after euthanasia is performed

The after-effects of performing euthanasia seemed profound. The event was described by one as a "terrible mountain to climb" and this doctor said that the doctor did not get used to it, it was harder to do each time.

1083 (EU4) *Still, for the doctor, it's a terrible mountain to climb. Every time the*
1084 *mountain becomes higher and higher, not easy, higher every time. (Retired Dutch GP)*

EU5 graphically articulated the effect of performing euthanasia. He likened it to crossing a line (see also L611). Crossing the line, which was proscribed by the Catholic church, placed the doctor beyond the point that human beings can legitimately place themselves. EU5 seems to be suggesting that he has "played God" by performing euthanasia. It was not until he had performed the euthanasia that he was aware of these feelings, and they took him by surprise. He perceived that the "line" he had crossed now became a barrier between him and any future relationship with catholicism.

1085 (EU5) *I haven't been in church for nine years. I quit church. But at that moment*
1086 *I thought, you can't go back there either. You have crossed a line where the Catholic*
1087 *church says you can never cross that line, it is not for a human being a human person to*
1088 *decide to cross that line. So, it, it took me by surprise. I wouldn't have thought that after*
1089 *all these years I would think in such a way about the line that you cross. (Dutch nursing*
1090 *home doctor)*

The "line" was not only proscribed by the church, but by society and the prohibition against the intentional taking of life.

1091 (EU5) *Which is a line that is put upon you by church, but also by the normal*
1092 *Christian-Jewish morality which has been there for ages. The whole culture, the whole*
1093 *way of approaching ethics, morality, society as it runs, is based on some agreement that*
1094 *you do this and you don't do that. (Dutch nursing home doctor)*

Agreeing to give someone euthanasia may be justified but once it happens there is no going back. EU5 portrays performing euthanasia as "*losing your innocence*" emphasising the exceptional nature of the event. Giving euthanasia made this doctor more aware that the practice should not be entered into lightly and should not be granted as a "*right*" for patients. By likening performing euthanasia to losing virginity, he seems to imply that for the doctor there is a before-euthanasia state and an after-euthanasia state and that the latter is perhaps baser than the former.

1095 (EU5) *And it is one of the agreements, maybe on good grounds, but it is one of the*
1096 *agreements you cross, it is like losing your innocence, or losing your virginity or*
1097 *something like that. It is very important, and one time it happens. You make it one time,*
1098 *and you never can go back. And it sharpened me in the way that I always thought it was*
1099 *a two way thing, but I am very - it sharpened my senses to say "Don't talk about it too*
1100 *easily, don't think it is a right you can obtain access (to)". (Dutch nursing home doctor)*

This doctor stated that assisting the patient this way had enriched his life but he had doubts about it. He still believed it a "*good thing*" but that it should only be given in "*extreme*" cases. The decision should not be routinized, it must be carefully worked through and this requires time. For this reason euthanasia cannot be done "*every week or every month*". He reiterated that once a doctor has performed euthanasia he cannot "*go back*". He became very emotional at this point.

1101 K *Mmmm. Are you sorry you did it?*
1102 (EU5) *No, I think I - I think it made me richer, but I have my doubts now and again.*
1103 *I think in that case, it was a good thing to do, but I think that it should be the very*
1104 *extreme, and very (careful) decision. It shouldn't be part of the package. It shouldn't be*
1105 *the routine in the clinic every month, or every two weeks, or something like that. ... you*
1106 *should make a careful decision, and you can't do that every week or every month, you*
1107 *have to take your time. You can't turn back. [emotional] (Dutch nursing home doctor)*

The gravity of the action was reinforced by EU3 who described dying as a "*sacred process*" that was "*disturbed*" by euthanasia.

1108 (EU3) *Because dying is a sacred process and disturbing it by such a difficult process*
1109 *of, for the doctor as well as the patient and the relatives and society, by giving, pushing a*
1110 *needle and so on. (Medical Director, Dutch nursing home)*

EU5's experience brings up the issue of unexpected reactions to performing euthanasia. It may be that physicians believe they had thought through the issues involved fully, but are surprised and negatively effected by other issues they had not previously considered.

The difficulty of intentionally hastening death was mentioned by several doctors who considered it contrary to their perceived roles. The doctor who saw withdrawing nutrition and hydration as analogous to euthanasia vividly recalled the incidents of the death. The rapid response with which this doctor recalled the length of time it had taken the patient to die indicates that the details of this case (which had occurred a year previously) were well remembered. He spoke of feeling "*awful, awful*" after this death occurred. This suggests that at least some aspects of the death were memorable because they were upsetting. (The length of time it took to die may have been implicated in this.)

1111 K ... *So when the nasogastric tube was withdrawn in this particular case, the feeding*
1112 *was withdrawn, how long did it take the person to die?*

1113 (EU2) 7 days [definite, immediate response]. 7 days, I remember it very well, ja.

1114 (gap)

1115 K *This first time that you did euthanasia ... how was that for you?*

1116 (EU2) *Awful [quick response]. Awful. And not only the first time, the second time*

1117 *was awful. (Medical Director, Dutch nursing home)*

Other doctors agreed with EU5 that euthanasia should be an exception on the grounds that it was "so difficult" and potentially exhausting for doctors to perform

1118 (EU3) *It has to stay an exception because it's so difficult, also for doctors. It takes*

1119 *such a lot of energy and it's so difficult. (Dutch nursing home doctor)*

.....and that because of this time was needed for the doctor to recover psychologically.

1120 K *Do you think ... there is time needed to come to terms with it [performing*
1121 *euthanasia]?*

1122 (EU1) *Ja. I think that's very important, psychologically. (Dutch nursing home*

1123 *doctor)*

EU4 spoke of a euthanasia that had occurred 20 years before. He appeared to struggle to resolve his own feelings over his actions. The pause between "positive doubt" and the final statement, "Not only positive", suggests that the doctor may be expressing some diffidence about his actions.

1124 (EU4) *In the first place, relieved that my ordeal was over, and the second place*

1125 *relieved that her ordeal was over. In doubt, did I do the right thing, and is this the right*

1126 *policy, but it was a positive doubt. (.6) Not only positive.*

1127 K *So you struggled with it?*

1128 (EU4) *Ja. (Dutch GP)*

Implications of performing euthanasia for the practitioner

NEU doctors seemed aware of the psychological effect on the doctor of performing euthanasia. Although maintaining they had not performed euthanasia themselves, there was no sense of condemnation for doctors who had. Rather NEU doctors spoke of respect, empathy and understanding of the position that the EU doctors took.

Although he could see that euthanasia may be necessary in "exceptional cases", NEU7 stated that he would not perform euthanasia for two reasons. Firstly, the personal cost to himself. He expressed fear that going through this "border" would (a) alter him in some way (L1135), (b) prevent him from continuing in his present professional discipline (L1135), (c) "ruin" his personal belief systems (L1139-1142), (d) expose him to unknown pressures (L1142). Secondly, he felt no need to perform euthanasia because his palliative care knowledge had always been sufficient to meet patient need (L1143-1149). He acknowledged that many other doctors do not have that knowledge (L1147-1148). His statement that he had "respect" (L1136) for doctors who performed euthanasia came after his statement "Afraid of this" (L1136). This suggests his respect

may be for doctors who perform euthanasia despite the personal cost to themselves, rather than doctors who perform euthanasia per se.

1129 K *Do you see a place for euthanasia at all?*

1130 NEU7 *In very exceptional cases, I can imagine very well that this may be one of the possibilities ... I would be very afraid to do this. I think several times in my treatment of patients I came very close to it, and ahh, giving very strong medicines, combinations of them, which I expected to work on the pain and suffering, but um, also knowing very well that the patient would die soon because of this. ... Um, I think if I will get through this border, I will not be the same person. I will not be able to do this - what I am doing now. Afraid of this. So I can accept that this border exists, and also have respect for people who are providing euthanasia, but I would be very reluctant to do this myself.*

1138 K *Is that um, because of your personal belief system?*

1139 NEU7 *Yes, I think this system would collapse, or not collapse, but would be different, would change. You know, you have a system which is built up on some beliefs and some strong things which you took from the past, what you learned, and they will be ruined I think I don't know what would come up, I think that is something that is difficult to accept. But I also do not have the need to pass through this border, I do not feel it is necessary. I feel with the knowledge and experience I have in dealing with these kinds of patients, enough space to deal with the patients, and enough possibilities. I cannot exclude situations where I am short of possibilities, but um, well, I do not have a need to cross this. Many doctors I come across say I cannot help the patient, but this is the way to help. But for me it's very rare that I come across patients I cannot help with good palliative care. (Dutch hospice doctor)*

NEU8 suggested that those who condemned Dutch doctors for practising euthanasia did not understand the personal cost to the doctor of such decisions although he does allow that some doctors may seemingly remain unaffected by the practice possibly allowing them to perform euthanasia regularly.

1150 NEU8 *I (received) a question from a Spanish colleague. He said to me "So, you in the Netherlands (teach) the students to kill a patient and not to cure a patient". And that is rude. I don't like such things. Because when such a euthanasia is done, it does a lot to the physician. Perhaps not to all, because in all kinds of professions you have strange persons, but to me this (is hard). So I don't like to do it. ...when you hear it, about also how often they do it, it occurs, then there are people, physicians who are doing that regularly ... apparently easily making such a decision. (Dutch Oncologist)*

Although the statement about desensitisation is hearsay and supposition (L1154-1156) this doctor had previously spoken of personal distress at the seemingly precipitous euthanasia given to his patient by a community doctor (L917-922). This suggests he has some personal experience of "apparently easily making such a decision".

NEU7 described anecdotal evidence for the desensitization of doctors who performed euthanasia as "chilling". This quotation suggests that the demarcation point between no euthanasia/euthanasia may be more than an apparently moral one as implied in L1085-1089. Crossing this demarcation point may have future adaptive behavioural implications for the doctor that may need to be considered prior to agreeing to perform euthanasia.

1157 K *... on what do you base the idea that if this doctor crosses that line, something will be different afterwards.*

1159 NEU7 *This is something that many doctors in Holland are saying about after the first time of euthanasia. "The first time, I didn't sleep for three weeks before euthanasia" - many doctors are saying that, "and the second one was much easier, and the third and the fourth was no problem at all, I was getting used to it". That's something*

euthanasia in the hospice setting, despite stating that he could imagine euthanasia may be necessary in "exceptional cases" and "respecting" those doctors who perform it (L1129-1149).

If, as he states, NEU7 sees no place for euthanasia in the hospice setting despite saying that he can see there may be a need for it in exceptional cases, his statements that his palliative care knowledge has rendered euthanasia a non-issue for him so far, may contain an element of rationalisation.

1176 NEU7 *I also do not have the need to pass through this border [euthanasia], I do not*
1177 *feel it is necessary. I feel with the knowledge and experience I have in dealing with these*
1178 *kinds of patients, enough space to deal with the patients and enough possibilities. I*
1179 *cannot exclude situations where I am short of possibilities, but um, well, I do not have a*
1180 *need to cross this. (Dutch hospice doctor)*

He stated that he believed he had come "very close to it" in his palliative treatments (L1181).

This doctor may have difficulty representing these palliative actions as "euthanasia" even if he believes that they may be, because the personal cost would be too great. Doctors who are not so committed to an anti-euthanasia philosophy may be open to construe such treatments more liberally as euthanasia.

1181 NEU7 *I think several times in my treatment of my patients I came very close to it, and*
1182 *ahh, giving very strong medicines, combinations of them, which I expected to work on the*
1183 *pain and suffering, but um, also knowing very well that the patient would die soon*
1184 *because of this. (Dutch hospice doctor)*

It may be that some of the respect this doctor feels for doctors who perform euthanasia (L1136) could relate to their willingness to fully engage with the consequences of their actions.

EU2 stated that withdrawing nutrition and hydration was analogous to euthanasia (see L547-549) and he described feeling "awful, awful" after his involvement in this action (L1116). This may suggest that doctors who do not perceive a moral difference between hastening death actions that are termed "euthanasia" or "physician-assisted suicide", and hastening death actions that are termed "palliative care", may suffer the same negative effects of such actions as are experienced by doctors who perform euthanasia and feel morally ambivalent about that. EU2 appears to rationalise his involvement in this hastening death action by seeing it as justified to prevent the further suffering of the patient. Despite the negative personal consequences for himself, he judges it "fair" that the doctor should be asked to do this.

1185 K *Okay. Well, afterwards, um, did it take you a while to get over it?*

1186 EU2 *For myself? Well, it's not that you are groggy or something, but you are*
1187 *thinking about it. You do your work afterwards but also you are thinking about it. And*
1188 *also what it means. . . When you are 38 and you have left this life, that's very (sad). But*
1189 *on the other hand, when the position of people is so very very bad, with no possibility of*
1190 *recovery, well then, they are only suffering, and that is more awful.*

1191 K *Do you think as a human being, and knowing what you went through, and what it*
1192 *means to you, do you think it fair that a doctor should have to do this?*

1193 EU2 *Yes, I think it's fair. (Dutch nursing home doctor)*

Rationalisation on the basis of preventing further suffering for the patient may also be implicated in a decision to perform euthanasia by EU3 who judged euthanasia to be a more humane option for two patients rather than suicide (see L951-954). EU3 may also be using a higher authority as an authorising agent for the two euthanasias he performed. Although he said he felt comfortable with the decision he had made

1194 (EU3) *Of course, sometimes it is necessary, and I have had the experience of giving*
1195 *two people myself, active end treatment, because those situations were, in my [emphasis]*
1196 *experience, so terrible ...And I am feeling at the moment, still quite (good about) giving*
1197 *that treatment, handling treatment in that way.*

...he goes on to invoke his own father's experience in asking for euthanasia and also Christ's words on the cross.

1198 (EU3) *Also my father was very against euthanasia asked for this at his bed, at his*
1199 *end. He had very bad weeks in hospital, and we had done a lot of things, but I was*
1200 *surprised that also he asked "Why don't you make an end of my life? I want to go to*
1201 *God". And also Christ asked "Let their be an end of my life". (Medical Chief Nursing Home)*

After euthanasia is performed the relationship between the physician and the family may continue in a symbiotic way, each finding it helpful to receive confirmation from the other that the euthanasia was the best thing for the patient. This mirrors previous statements indicating the usefulness of post-death debriefing (see L310-312).

EU2 expressed concern around the event in terms of concern for the apparently dysfunctional family of the patient. He stated that he contacted them for reassurance that they were coping. He reports that they portrayed the euthanasia in positive terms.

1202 EU2 *... in the time before termination there was one awful thing -that was his wife*
1203 *was not on speaking terms with his parents and also the parents were very close with their*
1204 *son of course. But they were not communicating about the decision-making, talking*
1205 *about what to do etc. So after the death, I believe a week or ten days later, I take the*
1206 *telephone and talk to them, and ask how they are, how it has been that week. And they*
1207 *say, "We believe it was good for him" (Dutch nursing home doctor).*

EU1 spoke of the family and physician having reassuring talks with each other. There is a sense of the positivity of group consensus.

1208 EU1 *Afterwards we had some talks with his wife and his children, and I think we*
1209 *all had the idea that it was a good thing. (Dutch nursing home doctor).*

The relationship between physician and family may be intensified by the morally and legally consequential nature of euthanasia. In a separate case another family had stayed in contact with EU1 for two years. Given this length of time the post-euthanasia relationship between physician and family may go on for some time after the death, presumably until neither feels the continued need for this reassurance.

1210 EU1 *[referring to a different patient from the one above] I think about 2 weeks after the*
1211 *euthanasia, his wife came back, both times at Christmas she sends me a card. And I think*

1212 *that about a month after the euthanasia that there was another case of euthanasia*
1213 *somewhere in Holland and it reached the papers and his wife called me because she was*
1214 *very concerned that I was the doctor arrested. (Dutch nursing home doctor)*

There may also be a role for re-framing the euthanasia event in positive terms. EU1 precisely recalled the time and date and who was present at one euthanasia event although the event had occurred over two years previously. He related his memory of the event in metaphysical terms. He agreed that the "metaphysical" explanation was meaningful and elaborated, "*To everyone*", implying that he personally found it meaningful. There is a sense in this account also of the psychological helpfulness of "group" involvement in the death.

1215 (EUI) *Let's see. It was 18 November, 1995. Ja. 2 o'clock in the afternoon. His*
1216 *wife was there, the children were there, I was there and one of the male nurses.*
1217 (gap)
1218 (EUI) *10 minutes past 2 and the sun was shining and the blinds went down. I mean*
1219 *this is probably all coincidence but his daughter said that that's his way of saying he has*
1220 *arrived in heaven. Then the sun went away, and the blinds went up again. It was very*
1221 *very curious, ja.*
1222 K *And very meaningful?*
1223 (EUI) *Ja (.2) To everyone. (Dutch nursing home doctor)*

To summarize, doctors from both groups seem aware of potential negative psychological effects for the doctor when performing euthanasia. Performing euthanasia can have deeply experienced and life-changing effects on the doctor involved. Fear of these effects appears to be implicated in decisions not to perform euthanasia for the NEU doctors. Positive effects of performing euthanasia were also reported, but as these were post-event, psychological adjustments to events may be implicated here.

The psychological effect on the doctor of palliative decisions that hasten the death of the patient may be similar to the psychological effects of performing euthanasia. Those who have performed euthanasia may be more willing to examine their psychological responses to other actions that hasten death that are not usually judged to be euthanasia.

To reduce the dissonance associated with hastening death actions, doctors may need to employ defence mechanisms that will reduce dissonance and allow the doctor to live with what they have done. Such mechanisms could allow them to psychologically justify their hastening death actions. These include **rationalisation** by constructing the treatment as palliative only and **justification** by constructing the treatment as necessary to reduce further suffering.⁴³ Successful deployment of defence mechanisms to cope with the after effects of performing euthanasia could see the practitioner apparently desensitised to the act. Doctors who successfully deploy defence mechanisms may be more likely to agree to further euthanasia acts in the future.

⁴³ Under Dutch law this is a defense for euthanasia on the basis of *overmacht* - (the result of a force it is reasonable not to resist) (Griffiths et al., 1998, p. 99).

CHAPTER 17

DISCUSSION

Palliative Care

Critics of the Dutch euthanasia practices have cited poor availability of palliative care as a reason for the development of euthanasia policies in Holland (Block & Billings, 1994; Szlosarek, 2001). Moreover it is suggested that "(u)ncritically legalising euthanasia may well paralyse the development of creative palliative care" (Janssens, ten Have, & Zylicz, 1999, p. 411). These authors cite the case of a 55 year old who suffered intractable pain to the point where euthanasia was requested. Successful palliation was eventually achieved, but the patient went ahead with the euthanasia. The authors concluded that the availability of euthanasia "may lead to excesses" (Janssens et al., 1999, p. 411). Thus the availability of euthanasia may be implicated as both cause (of not using palliative alternatives) and effect (prevents the development of palliative alternatives) of present elective death practices in the Netherlands.

Both groups of doctors spoke of palliative care as a discipline that addresses the physical and psychological suffering associated with disease processes for which there is no cure. Doctors who had not performed euthanasia elaborated on this suffering and suggested that intractable suffering may have an underlying etiology in unresolved issues from the past that surfaced at the end of life. Psychology has long recognised that repressed unpleasant memories may manifest in the patient as physical or psychological symptoms. "Enabling such a patient to recover the memory of the experience, to go through it in detail, and to discharge or 'abreact' the emotions of fear and horror which accompanied the experience does indeed have beneficial results, as those who treated wartime neuroses have repeatedly demonstrated" (Storr, 1989, p. 13).

In past times, the mind and body were considered together but Cartesian dualism facilitated the separation of medicine (the physical) from the church (spiritual). However, people are more complicated than such simplistic duality would suggest and it is now recognised that we are not well served by having medicine address the physical divorced from the influences of the mind (Cassel, 1982). Cassel concurs with one respondent in this study by placing physicians' failure to adequately address the existential suffering of the patient as a reason for the failure of modern medicine to control pain in some patients (Cassel, 1982). To be fair, the responsibility for such a difficult task should be placed with the caring team, not one member of the team. One of the

doctors in this study emphasized that he would never attempt to care for such a patient on his own (L308-309). When death approaches, and the person knows that death approaches, the physical can become of less importance to the person, and a psychological review can take place in which the person attempts to find a meaning for their lives and for their suffering (Frankl, 1959; Cassel, 1982). Such an "existential review" can be religious or spiritual in nature, the two considered in palliative care as different. While religion always incorporates the spiritual, being "spiritual" does not necessarily involve an attachment to any religion. Both can be implicated in an exacerbation of suffering at the end of life (Speck, 1998).

One of the issues that arises from accounts from doctors who have not performed euthanasia is that the patient may require assistance and support to disclose and resolve issues that are implicated in intractable suffering prior to death. Conversely, patients may prefer assistance and support to continue repressing issues.

Rather than the approaching death being a catalyst (to precipitate the need to address long buried issues), it may be that the debilitation that accompanies dying erodes the resolve that has allowed the person to maintain the defence mechanisms that have kept the issue buried (Cooper, 1994). Freud maintained that an individual invokes psychological mechanisms that act as protection against anxiety related to disturbing events that have occurred in the past. Memories or thoughts related to such issues are repressed. To remain effective, repression often requires adjunct psychological mechanisms such as displacement (rechannelling the memories to safer areas), reaction formation (a preoccupation with an opposing position), rationalisation (reinterpreting and reforming the issue), projection (attributing to others) and isolation (separating the subject from the issue) (Freud, 1952/1917). Successfully repressing unpleasant issues from the past would seem to require energy, albeit arguably unconscious, that may not be available to the patient as death approaches and may therefore break down. This breakdown of defence mechanisms may be welcomed by the patient as a way forward to expressing the deeply felt emotions that have been repressed for so long. Conversely, the patient may prefer not to address these issues and would rather have assistance in the form of sedation to nullify any adverse experienced effects that occur from such issues intruding into conscious thought. The importance of listening to the patient and providing a suitable environment in which issues may be addressed and hopefully resolved at the end of life, is well understood in palliative care. Care must be taken to ensure that this process is facilitated, not forced on the patient.

The needs of the patient must remain paramount as death approaches. While the needs of family members are important, and a requirement by them for closure on some issues may be relevant, if the patient chooses not to address outstanding issues, their wishes must be respected. If closure

on issues is not achieved to the satisfaction of family members prior to death, professional assistance is required to attempt some resolution of these after the death.

The unconditional commitment necessary to meet patient need was expressed by several participants and was articulated well by NEU9 (L159-168, L177-189), whether this was in relation to performing euthanasia or determining not to perform euthanasia. It is tempting to draw parallels between this and humanistic psychology in which Carl Rogers advocated unconditional positive regard as necessary to achieve a sense of self-worth and mental health (Gleitman, 1991, p. 734). Although none of the participants identified as “Humanist” (see Table 13.1, p. 216) Humanism as a “religion” has a high profile in the Netherlands (Shetter, 1997) and it may be that Humanist philosophy is widely discussed. Indeed the chaplain at the institution where NEU9 practised was interviewed and identified himself as a “Humanist” chaplain.

Point: Addressing the existential suffering that can accompany dying may involve the practitioner in facilitating disclosure and closure of issues for the patient, or in facilitating the continued repression of issues. Practitioner recognition of patient need to disclose or not to disclose is required.

Point: Unconditional commitment to the patient is a philosophical approach that may involve the practitioner in activities that challenge personal beliefs when the paramount goal is meeting patient need.

Treatment withdrawal, terminal crises and euthanasia

Dutch research indicates that a non-treatment decision was made in 39% of non-sudden deaths and that life may be shortened by more than a month in 8% of cases involving such a decision (Pijnenborg et al., 1995). Such decision-making should take into account clinical judgments on efficacy of treatment plus patient goals for therapy (Lantos et al., 1989). A recent study indicates that the patient goal for quality of life that received the most support from different patient populations (dialysis 47.9%; HIV/AIDS 72.5%, long-term care 65.8%) was avoiding the inappropriate prolongation of dying (Singer et al., 1999). It is proposed that withdrawal/withholding treatment decisions should be made using a therapeutic ratio, balancing the cost/risk of continued treatment to the patient, recognising that these goals of treatment may differ from that of professional caregivers and family (Ashby & Stoffell, 1991).

Both groups expressed concern that life-sustaining treatment in the terminal phase can continue for too long. Practitioners need to balance the needs of the patient to receive curative care or comfort care that has a curative purpose, with the need of the patient to die. It is acknowledged that this may be more difficult to do when the patient is being cared for in a medical unit dedicated to cure,

particularly in intensive care units. Staff in such units may perceive a switch to palliative care only as giving up on the patient, given that so much of their work is to strive for the life of critically ill persons. Withdrawing or withholding life-sustaining treatment is an important decision requiring careful analysis. If the decision to withdraw treatment comes too late, a terminal crisis may occur when a more aggressive death-hastening decision may be required to address the crisis. When terminal crises arise, palliative treatment that shortens life may be justified but euthanasia may not. The time required to complete the protocols that surround euthanasia, if they have not been completed prior to the crisis, would render euthanasia inappropriate. Doctors from both groups acknowledge that decisions to withdraw or withhold treatment should be made with care, recognising the role of physician intent and patient consent.

Point: Inappropriate prolongation of life is a cause of suffering for patients and may lead to a terminal crisis. Addressing a terminal crisis may involve the practitioner in a hastening death decision. When hastening death decisions are being made, the role of intent must be carefully considered. In a terminal crisis euthanasia is not an option as there would be no time to meet protocols controlling this action.

A multi-disciplinary approach to care

The complex needs of the dying patient appear to require a multi-disciplinary approach to care (Doyle, 1998b; Emanuel & Emanuel, 1998; Mount & Hamilton, 1994; Saunders, 1994). It is also suggested that the absence of a coordinated multi-disciplinary team has a negative impact on the dying experience (Chan & Woodruff, 1991). Such a team must be managed. Poor coordination within the team can occur through communication problems and "a poorly developed awareness of other colleagues' roles and possible contributions" (Doyle, 1998a, p. 961, Melia, 2001). Caring for the dying patient can be stressful but this has not always been reflected in higher stress among this population of caregivers compared to other medical and nursing populations. It is speculated that the reason for this is the recognition of potential stress in the caring team early in the establishment of the palliative care discipline that has led to effective interventions to address staff stress (Vachon, 1995).

Both groups of doctors emphasized a multi-disciplinary approach to the care of the dying patient. Such an approach was deemed instrumental in addressing staff stress by providing a supportive environment that fostered, and was reliant on, equality within the professional team. Similarly, it was acknowledged that this approach provided the patient with available resources to address needs on every level, physical, social, psychological and spiritual. The importance of effective communication within the team was emphasised and this will require management. Given the time constraints of practitioners who work in the clinical situation, an accessible centralized unit for information gathering and processing for each patient would be advantageous. This suggests that a

primary health care provider for each patient should be appointed within the team to coordinate patient care.

The importance of speedy communication among the team is particularly pertinent in the dying situation. Crises can occur almost without warning i.e. spinal cord compression, and demand immediate intervention to avert disaster for the patient. In this case, numbing and tingling in the legs of a patient who has spinal metastases should be reported so that a scan can be organised. If compression is the cause, radiotherapy can be immediately commenced to reduce the swelling that threatens the patient with paralysis (Doyle et al., 1998, p. 729). This would involve rapid communication between

- (a) the attending nurse/caregiver with whom the patient would discuss day to day concerns
- (b) the referring doctor to order a scan
- (c) the radiographer to communicate immediately with the radiologist to ensure speedy reading of the scan
- (d) immediate radiotherapy at the oncology unit.

Some cancer cells proliferate faster than others, but there may be a window of only a few short hours in which it is possible to help the patient. Good team coordination is crucial in such an event.

Doctors from both groups emphasized that the responsibility of the team was to meet patient needs. Doctors who had not performed euthanasia elaborated on this, seeing such a multi-disciplinary patient centred approach to care as a *requirement* to facilitating a good death.

Point: A multi-disciplinary approach to care meets the complex needs of the dying patient and also provides a choice of potential confidantes for the patient. A well-managed team also meets the needs of the practitioners by supplying support and thereby addressing the stress of the professional caregiver.

Point: The appointment of a primary health care provider to manage each case would provide a central point for the gathering and dissemination of information on patient care to all relevant team members.

The development of palliative care as a discipline in Holland.

Palliative care has not been developed in the Netherlands as a separate hospice entity. Recent moves by the Dutch government to integrate a palliative care service within the present health

system are premised on a need to provide access to palliative care to terminally ill patients and to improve palliative care knowledge of medical and nursing staff providers. This need is fuelled by projections that see an increased need for such services from an aging population (Francke & Kerkstra, 2000).

Both groups acknowledge that the Dutch government recognises the importance of palliative care and is committed to increasing the availability of palliative care for consumers. However, respondents from both groups also questioned whether the incorporation of palliative care into existing institutions was the best approach to achieve this, which is not to say that palliative care should not be available in these institutions. The advantage of offering palliative care in the dying phase in existing institutions is that the dying patient can be cared for in their known caring environment. The disadvantage is that the development and dissemination of palliative care knowledge may be compromised given that there is support from both groups that concentrating palliative care in dedicated units enhances and deepens the development of knowledge.

Effective palliative care may also be difficult to deliver in existing institutions dedicated to cure. The time and commitment required to address the suffering of patients may not be available on busy wards. Similarly, although a large institution may have a commitment to the delivery of palliative care, the "needs" of the institution may become invasive on such care. Hospital palliative care would say it is non-invasive, and certainly would be in a medical sense (most of the time). However, the very reality of being part of a routine and cost-driven institution which may find the individualisation of care protocols difficult (a hallmark of palliative care), means that the dying patient must, to a certain extent, fit in with the organisation. Therefore "invasive" in this sense means that cleaners will still clean, nurses will come on and go off duty according to the clock/roster (often exposing the dying person to a new staff member when they most need the familiar around them). Meal trolleys will bang and clatter, and high patient loads will almost certainly see an "invasion" of time constraints on staff when the person most needs a quiet and supportive presence. "Invasion" here refers to the imposition of institution-based barriers to true patient needs-driven care in spite of the best intentions of the caregivers. Hospice care, by its very nature, resists these institution-based influences.

The role of palliative care in mitigating potential euthanasia decisions seems to be acknowledged by policymakers. Wide dissemination of palliative care knowledge is seen as important given that "a well-considered policy with regard to euthanasia can only be developed on the basis of a well-developed system of palliative care" (Gordijn & Janssen, 2000, p. 35).

Point: The establishment of dedicated palliative care units may best achieve effective development and dissemination of palliative care knowledge in Dutch society. The effective delivery of palliative care to the patient may be difficult to achieve in busy wards.

Terminal sedation and euthanasia

When palliative interventions fail and pain is intractable, a legal palliative intervention that doctors may offer to patients is terminal sedation. Terminal sedation occurs when the patient is sedated and sleeps until death occurs (Cherny & Portenoy, 1994). Food and fluids are not given during this time.

There have been lengthy discussions on this treatment option by palliative care physicians with some likening it to "slow euthanasia" (Billings & Block, 1996) or positing it as a possible legal alternative to physician-assisted suicide or euthanasia (Bernat et al., 1993). Others defend the practice as palliative care and distance themselves from an association of terminal sedation with euthanasia (Cherny & Portenoy, 1994; Mount, 1996). However it has also been argued that euthanasia sits on the same continuum as palliative care when the best outcome for the patient is considered (Ogden, 1994).

The unintended, although foreseen, outcome of the patient's hastened death secondary to palliative care invokes the rule of double effect. A critique of the rule of double effect has been made on several counts including (a) its particular religious traditions that may be inappropriate in multi-cultural societies (b) that it may not acknowledge the complexity and ambiguity of human intentions and (c) that physicians are not held morally responsible for the foreseen outcome of the death of the patient (Quill et al., 1997a). Although undoubtedly some practitioners find it ethically challenging, terminal sedation, which invokes the principle of double effect is a legal palliative option in Holland when the practitioner judges this to be the best option for the patient, and the patient agrees to the action.

The two groups have differing viewpoints on the status of terminal sedation in relation to euthanasia. Doctors who have not performed euthanasia state that terminal sedation is different from euthanasia and a palliative solution to the difficulty of (a) the patient who experiences intractable suffering (b) disagreement between patient and family when the patient requests euthanasia. However terminal sedation may not always be a viable option. It can be technically difficult to implement and sustain and it may not be the most compassionate option for the patient.

Doctors who had performed euthanasia stated that medical decisions that hastened the death of the patient were analogous to euthanasia and should be placed on the same continuum as euthanasia when the physician knew that death was the expected outcome. For this reason, it was stated these decisions should be subjected to the same scrutiny as euthanasia decisions. This is in line with research from the United States which indicates that 13% of 56 oncologists who reported that they had performed euthanasia, had been found upon interview to have engaged in death-hastening

practices that were representative of palliative care, not euthanasia (Emanuel et al., 1998). This raises the question of the variability in physician understanding of what constitutes euthanasia and what constitutes palliative care and the effect that personal assumptions may have on practitioner comfort and practice.

Point: Terminal sedation is a palliative option to address intractable suffering. Some physicians may interpret this action as euthanasia and would benefit from having the action subjected to the same protocols as euthanasia or physician-assisted suicide. It is acknowledged that terminal sedation may not always be a compassionate treatment of suffering.

Autonomy

The two central positions when medical decisions at the end of life that hasten death are considered are related to sanctity of life and self-determination or autonomy (Sanson et al., 1998). The first relates to the position that innocent life is sacred and must not be taken (Bleich, 1995); (see Edelheit, 1995, for an opposing argument). The second relates to the individual's right to choose whether to live or die premised on the concept of sovereignty over self (Dworkin, 1995); (see Meilaender, 1995, for an opposing argument).

There were autonomy discourses around end of life decisions available in interviews from both groups of doctors. The doctors who had performed euthanasia discussed autonomy in relation to the euthanasia decision, and how autonomy should be respected and protected when making the decision. The doctors who had not performed euthanasia represented autonomy as freedom to move by having choices available that would invalidate a requirement for euthanasia. Both perspectives follow the argument that autonomy exists on a continuum, an individual always has it but it can be diminished or enhanced in the context of health care by the endeavours of health care practitioners (Seedhouse, 1998).

Doctors who had not performed euthanasia portrayed palliative care as enhancing the autonomy of the patient and practitioner by providing choices in end of life care. Sufficient knowledge to meet patient needs was representative of empowerment for both doctors and patients. Such knowledge provided patients with choices and ongoing possibilities during the dying process. It also increased their confidence that their needs would be met and may therefore have been instrumental in decreasing anxiety and fear. This in turn impacted favourably on physical symptoms.

For practitioners, NEU doctors constructed palliative care knowledge as “a way” that prevented the necessity of performing euthanasia. In this context knowledge provided the doctor with room to move by providing other opportunities. Whether this “way” was real in terms of an actual

alternative to euthanasia, or figurative in terms of how the end of life care was signified is debatable and will be discussed further later. Conversely, these doctors perceived a lack of palliative care knowledge as limiting autonomy (or freedom to move) and implicated in decisions to perform euthanasia.

Although NEU doctors stated that there may be cases where euthanasia should justifiably be considered, palliative care choices had rendered this unnecessary for them to date. The stated willingness of four in this group to consider euthanasia suggests that these doctors are open to the concept of palliative care not necessarily meeting patient needs. This, in conjunction with their never having performed euthanasia suggests that their comments that palliative care is an effective alternative to euthanasia may be based on experiential confirmation that euthanasia is rarely necessary, rather than a rigid adoption of the palliative care dictum that this is so.

NEU doctors and one EU doctor stated that many general practitioners may not have sufficient experience with dying patients to develop their palliative knowledge. General practitioners are the primary caregivers of patients in the community and in the homes for the elderly⁴⁴. There are approximately 1400 homes for the elderly in Holland and in 1997 only 23 of these had palliative care units (Francke & Kerkstra, 2000). General practitioners are responsible for approximately three-quarters of euthanasia acts per year in Holland (van der Maas et al., 1996). The combination of insufficient knowledge to meet patient need and physician distress at patient suffering may encourage a view that euthanasia is the only compassionate option for the patient. One doctor stated that the relationship between hospice/palliative care services and general practitioners needs to be nurtured to encourage the consultative process. The consultative process would educate GPs and ensure patients in the community received effective palliative care, therefore decreasing a perceived requirement for euthanasia.

Although patient autonomy was necessary for a request for hastened death, it was not deemed sufficient for the request to be granted by physicians in the United States. When physician-hastened death is being considered the autonomy of the patient ceases to be the primary consideration and competes with other ethical and legal considerations (Fried, Stein, O'Sullivan, Brock, & Novack, 1993). In this study, doctors who had performed euthanasia concur, emphasising a negotiation process once the request is made. During this process both patient and doctor must be satisfied that euthanasia is the only alternative. Further, EU doctors stated that the autonomy of the doctor becomes equal to that of the patient when euthanasia is considered because of the enormity of what the doctor is being asked to do.

⁴⁴ Not to be confused with verpleeghuizen that have resident medical staff dedicated to the institution.

Public discourse on euthanasia occurs in Holland on a regular basis (Griffiths et al., 1998). It is suggested that the tenor of euthanasia discourse can, and does, affect the opinions of those who are privy to it (Roy, 1996, p. 5). Both groups of doctors expressed concern over the normalising effect on consumers of having euthanasia available and freely discussed in their society. There is a tension evident between having euthanasia available and mitigating the potentially, and arguably benignly, coercive effects on the consumer of such availability. Accounts from doctors in this study raise the issue of euthanasia discourse in society and the potentiating circularity of the consumer affecting the wider discourse and the wider discourse in turn affecting the consumer, each interchange strengthening discursive practices. This is reminiscent of Foucault's work on power and knowledge and although this approach has not been taken in this thesis, further research along this line would be illuminating.

Point: Euthanasia is to be considered only if effective, acceptable palliative options are not available. Doctors who had performed euthanasia had done so because palliative alternatives were not available to them to meet the needs of the patient. This may be due to a deficit in the palliative alternatives or a deficit in the practitioner's knowledge of palliative alternatives.

Point: Euthanasia may be seen by the Dutch as a freedom they can access at will. However, the gravity of the act and the part the doctor plays in this renders access reliant on the doctor being satisfied that this is the best and only alternative available to the patient.

The euthanasia request

Ethnographic studies of doctors in Oregon who have received requests for assisted suicide under their physician-assisted suicide law (Oregon Death with Dignity Act, 1997) indicates that regardless of personal attitudes towards assisted death, the initial response of physicians to a request was similar. Palliative options were explored to address physical and psychological symptoms (Kohlwes et al., 2001). Both groups of Dutch doctors in this study also responded to the request by seeking palliative options. This is hardly surprising given that the protocols surrounding euthanasia specifically state, "if the patient's suffering is based on a somatic condition, other possibilities for treating the condition or relieving the suffering must have been exhausted or have been rejected by the patient". And in the case of non-somatic suffering, "there must be no realistic possibility of treatment" (Griffiths et al., 1998, p. 102).

The emotional effect on the doctor when performing euthanasia was given as a motivation for aggressive exploration of alternatives once the request was received. When palliation was successful (the experience of NEU doctors) the request stopped. When palliation was unsuccessful (the experience of EU doctors) the request was agreed to. Reasons given for the

euthanasia request were similar for both groups and covered physical, psychological and social concerns.

One EU doctor noted that agreeing to the request had a therapeutic effect on the suffering of his patient (L955-957). An alleviation of suffering objectively evident after the request is agreed to suggests some psychological involvement in the suffering that may be lessened by knowing that death will soon occur and suffering will be ended. This raises the question of whether psychological interventions may have had a similar effect on the alleviation of symptoms and suggests that psychological assessment of euthanasia requests should be a requirement.

Psychiatric evaluation of requests for euthanasia are only mandatory in Holland if the euthanasia is being requested to alleviate psychiatric illness such as depression (Griffiths et al., 1998). While doctors are alert to the implications of depression in euthanasia requests, there may be other psychological issues such as a perceived lack of control which exacerbate distress (Muskin, 1998). Requesting and receiving agreement to euthanasia may have “therapeutic” value by enhancing the patient’s sense of control over events. An observable improvement in symptoms after the request is agreed to, and in the presence of no other intervention, should alert the practitioner to a possible underlying psychological reason for the request. On the other hand, there will always be some psychological relief if suffering has been relentless and the patient sees an end to it.

Doctors from both groups suggested that the euthanasia request could be a way of testing physician commitment to non-abandonment, a view supported in the literature (Block & Billings, 1995; Quill, 1993). Doctors who had not performed euthanasia said that they would be prepared to consider euthanasia when palliation was not successful in preference to abandoning the patient. The implication here is that these doctors perceived that leaving the patient to suffer is abandonment. The doctor may have difficulty reconciling a perception of self as carer with the “abandonment” of the patient.

Advocates of self-perception theory in psychology maintain that our perception of who and what we are derives from the attributions we attach to our person or persona (Bem, 1967). Thus, if a person is a doctor, there is an attribution attachment of non-abandonment of the patient, willingness to serve and commitment to the sanctity of life. This perception of self may be tested when the euthanasia request is made and it is considered justified by the doctor. On the one hand the doctor may feel committed to the patient and a belief that they should be freed from suffering in their preferred way. On the other hand a commitment to the sanctity of life would disincline the doctor to agree to the request. Such opposing views may produce psychological discomfort related to the doctor's perception of the doctor's role.

Point: Physician response to the euthanasia request is to seek acceptable, effective palliative alternatives. If these fail to address patient need, euthanasia is considered as the preferred option to leaving the patient in their suffering by both groups of doctors. Leaving the patient in their suffering was identified as "abandonment". Considering euthanasia may produce psychological discomfort for doctors who view this as in conflict with the perceived role of the physician.

Protocols and Processes of Euthanasia

Although the practice of euthanasia has been legalised since these interviews were done, the guidelines that control the procedure have not altered in a way that would impact on the points covered in this section. The practice has been subject to strict controls as laid down in formalised and ratified protocols and codes of conduct including

- Personal, voluntary, preferably written and verbal request
- Be competent adult
- Doctor to perform euthanasia (preferably in treatment-relationship)
- Request enduring over time
- Unbearable and hopeless suffering (not necessarily physical)
- Know and refuse palliative options
- Second independent opinion
- If psychiatric disorder, second opinion to be psychiatrist
- Be resident of Holland (Griffiths et al., 1998, pp. 89-107)

Before legalisation, the doctor was required to report the euthanasia to the Coroner and stay with the body until the coroner was satisfied that all the paperwork and procedures related to the euthanasia had been completed satisfactorily, in which case the body was released for burial.

Doctors who had performed euthanasia viewed the protocols and processes involved in controlling the practice justified and helpful. The process of consultation protects the doctor and patient from inaccurate assessment and protects the patient from the doctor's personal biases. Transparency of practice encourages healthy leave-taking and open discussion and encourages consultation on correct drugs to use. After the death, reviewing the process by which the decision was reached was helpful in reducing psychological discomfort related to the death both for the doctor and the family.

Meeting the legal guidelines for euthanasia may also have a negative impact. The requirement for a consistent and enduring request may encourage patients who are experiencing cognitive changes to action euthanasia prematurely to avoid the request being denied later. If the patient is not able to articulate their previous wishes for euthanasia at the point they are to receive it, the request is void. Similarly, a person who is cerebrally altered is not the same person as the one who requested the euthanasia, and therefore the request could be regarded as void on these grounds. Similar problems have been noted with such situations with regard to advance directives in countries where euthanasia is not legal. If the person for whom the directive is to be enacted has changed cognitively from the person who originally filled out the directive it may be difficult to argue that enacting the directive is justified (Emanuel, 1994b).

Similarly, meeting some legal guidelines had a negative impact on doctors in this study. Reporting the death to the coroner, and having procedures surrounding the euthanasia being investigated was identified as stressful. Similarly, insecurity about whether all the paperwork had been filled correctly and having to wait for the body to be cleared after the death was identified as stressful for the doctor. Although the situation in Holland has now changed in that euthanasia is legal, EU doctors spoke of the strain of having to wait between reporting the death to the coroner and being cleared of any wrong-doing - a process that could take months. The wider issue of self-incrimination is also of concern when protocols are set up in this way. While on the face of it self-incrimination may form a defence, Griffiths et al. report that, "(t)he doctor who falsely reports euthanasia as a natural death is prosecuted for filing a false death certificate (article 228 (1) of the Criminal Code); if he then raises the issue of self-incrimination he can expect to be told that the privilege gives no license to lie" (Griffiths et al., 1998, p. 117).

Point: The protocols that control euthanasia and physician-assisted suicide are helpful by providing the doctor and patient with security that the decision is legal and justified. They can also be stressful for the practitioner who is not experienced with euthanasia, and who is insecure about whether protocols have been correctly met. There is a requirement for education to teach doctors to plan the euthanasia event to (a) reduce practitioner stress and (b) facilitate a good death for the patient. A good death in this context is taken to be one where the correct drugs are used and the event is planned according to patient preference.

Effect on doctor of performing euthanasia

Doctors from both groups are aware of negative psychological effects for the doctor when performing euthanasia. Fear of these effects is given as a reason for not wanting to perform euthanasia for the NEU doctors. This raises the point that palliative care may be portrayed by these doctors as sufficient to meet patient needs because of their fear of performing euthanasia. Although as previously argued, their stated willingness to consider euthanasia when palliative care

is ineffective may indicate that their experience that palliative care has always been effective is probably the correct conclusion. Support that their stated willingness to consider euthanasia if necessary may be an accurate predictor of possible future behaviour is given by the NEU doctor who actually sat with a patient while she received euthanasia, and stated that she considered it justified in that case (L585-599).

Performing euthanasia can have deeply experienced and life-changing effects for the doctor involved. Doctors who had performed euthanasia stated that the psychological effect on them of palliative decisions that hasten the death of the patient such as withdrawing food and fluids or terminal sedation can be similar to the psychological effects of performing euthanasia. This suggests that living in a society where euthanasia is sanctioned, may allow doctors who feel ambivalent about the ethical status of terminal sedation and withdrawing food and fluids to be open about questioning the morality of these actions. Openly questioning palliative alternatives in such a society would not expose these actions to the threat of censure leading to the possibility of these palliative alternatives no longer being available. The worst that could happen would be that they could become subject to the same protocols that govern euthanasia, which has already been suggested as desirable by one of the EU doctors. Critical scrutiny may assist the doctor to come to terms with the action by encouraging honest and open debate (Roy, 1996).

Alternatively, those doctors who conflate terminal sedation, withdrawing food and fluids and euthanasia, may not have a good grasp of palliative care as a discipline that has adopted and legitimised certain hastening death practices under the palliative care umbrella (Doyle et al., 1998). Regardless of the ethical debate surrounding some of these practices this allows doctors who engage in such practices to invoke the authority of “palliative care” as a legitimiser of certain hastening death actions. This means that certain hastening death actions, in the name of palliative care, may no longer be ethically problematical to the doctor and may therefore not produce the same dissonance as say, euthanasia. Support for this explanation may derive from none of the doctors who had not performed euthanasia reporting negative psychological effects from using palliative options that hasten death.

One further point needs to be considered. Not all clinical practicing environments in Holland permit the practice of euthanasia. One explanation for the difference between these two sets of doctors in performing euthanasia or not may relate to organisational dictates. However, one of the doctors who had performed euthanasia worked for an institution that did not permit this. He arranged for the patient to be taken elsewhere for the euthanasia event. This suggests that those who work in institutions where euthanasia is not permitted can and will find a means of delivering euthanasia if they believe this is in the patient's best interests.

Point: Invoking the authority of the law and/or palliative care when hastening death actions are considered, may lessen the dissonance associated with such actions by providing legitimization of the action for the doctor.

In summary, both groups of doctors had a good understanding of palliative care as physical and psychological symptom control for the dying patient. Both groups recognised that the psychological suffering of the dying patient may be profound and may be implicated in physical pain. Doctors who had not performed euthanasia expanded on the nature of suffering and how this may be addressed in the dying phase by an interdisciplinary palliative care team.

Both groups of doctors exhibited a strong commitment to patient care. The doctors who had performed euthanasia represented this as an indication of their level of commitment. Despite extreme personal cost to the physician they stated that they had agreed to patient requests for elective death after a period of negotiation believing that this was the only compassionate way left for them to address the suffering of the patient.

Doctors who had not performed euthanasia represented their commitment as one of creative problem solving. The commitment was to finding a *solution* to the problem of intractable suffering that did not involve the elective death of the patient. As a group they had been successful in finding palliative alternatives to euthanasia thus far. However, four of the five doctors in this group stated that if they had not been successful in addressing the suffering of the patient, they would have agreed to perform euthanasia if that was the only option to produce a compassionate outcome. This was despite recognition by the group of the potential sacrifice involved for the physician. Two of them specifically stated that that was a consequence of being committed to the patient.

A comprehensive knowledge of palliative care alternatives to intractable pain and suffering and a commitment to finding an alternative appears to invalidate the requirement for euthanasia in most cases. However having euthanasia available in cases where the best palliative care does not meet patient need was judged by nine of the doctors to be a compassionate option for the patient.

Cognitive work to reduce dissonance may be engaged in by doctors who perform euthanasia or other medical decisions that hasten death when these are contrary to their belief in the sanctity of life. Dissonance reduction would be necessary to allow them to live comfortably with their actions and possibly repeat those in the future.

Using dissonance theory as a theoretical framework within which to examine one approach that may be taken to resolve any psychological discomfort related to death hastening actions.

Dissonance theory proposed that when psychologically inconsistent elements were present, one or more cognitions would be distorted to achieve consonance. In this context, the doctor may rationalise the actions taken that hasten the death of the patient on the basis that these were palliative only and therefore justified in order to reduce further suffering.⁴⁵ There appears to be an element of rationalisation in the accounts given by NEU doctors who were asked to perform euthanasia and did not want to do so. They spoke of finding a "solution" (L479, L500) and rationalised the solution on the basis that this was different from euthanasia. Even though it was recognised that the death would be hastened it was stated that that wasn't the same as giving an infusion from which the patient would die an hour later (L507). The suggestion here is that it is the length of time that it takes the patient to die after the hastening death action which classifies it as euthanasia or not. This seems a somewhat untenable distinction in the light of accounts from Oregon which can place death from physician-assisted suicide as occurring up to 38 hours after the ingestion of the suicide agent (Smith, 2001).

The doctors who had performed euthanasia spoke of the psychological difficulty of contemplating the action and coming to terms with the action. Despite this, the doctors interviewed stated that they would be prepared to perform euthanasia again. Moreover, doctors who had not performed euthanasia, expressed concern over the effect of doing so on themselves, but were still prepared to say that they would consider this action under certain circumstances.

Festinger, who first proposed the theory of cognitive dissonance suggests that "reduction of dissonance is a basic process in humans (and) it is not surprising that its manifestations may be observed in ... a wide variety of contexts" (Festinger, 1957, p. 4). The theory proposes that cognitive dissonance occurs when a person engages in an activity that produces an inconsistency among the elements involved in that activity - what Festinger calls the "nonfitting relations among cognitions" (p 3). These elements would consist of beliefs, attitudes or feelings (Festinger, 1957). The resulting dissonance can become so unpleasant that it provides a *motivation* to engage in dissonance reduction activities to achieve consonance. The motivation to reduce dissonance will be a function of the magnitude of the dissonance. The greater the magnitude of the dissonance, the greater the motivation to address this. Moreover, Festinger proposes that the magnitude of the dissonance between elements will be a function of the importance of the elements. The element most resistant to change is the point where most of the cognitive work is

⁴⁵ Under Dutch law this is a defense for euthanasia on the basis of *overmacht* - (the result of a force it is reasonable not to resist) (Griffiths et al., 1998, p. 99).

done. The magnitude of the element most resistant to change ⁴⁶ increases as dissonant cognitions are increased. Conversely, the magnitude of the element most resistant to change decreases as the number of consonant cognitions increases (Festinger, 1957).

Wicklund & Brehm represent this schematically.

Dissonance associated with most resistant cognition	[dissonant cognition X importance of cognition]
	[consonant cognition X importance of cognition]

(Wicklund & Brehm, 1976, p. 4)

Further, Festinger proposed that when "dissonance is present, in addition to trying to reduce it, the person will actively avoid situations and information which would likely increase the dissonance" (Festinger, 1957, p. 3). If hastening death practices have been engaged in, whether euthanasia, physician-assisted suicide, terminal sedation or withdrawing/withholding food and fluids or treatment, dissonance may be experienced by the doctor and dissonance reduction work engaged in. If this is successful, part of the ongoing maintenance of psychological wellbeing may involve avoiding information that will destabilise consonance. The consequences of this could be that the doctor who purposefully kills a patient may avoid information that could indicate that such an action was unnecessary and that other ways of meeting patient need are available. On the other hand, if the doctor has performed terminal sedation and/or removal of food and fluids where the death of the patient is foreseen, it may be necessary to avoid any information that could indicate that such actions, foreseen, are analogous to euthanasia (Quill et al., 1997a).

Cognitive dissonance theory stimulated a huge volume of research, some of which supported the motivational basis of dissonance reduction that Festinger had originally proposed. The presence and influence of *regret* was exposed when dissonant elements were created (Brehm & Wicklund, 1970). Similarly it was shown that cognitive dissonance could energise behaviour *unrelated* to dissonance arousal (see Wicklund & Brehm, 1976, Chapter 6) but also that arousal is necessary for the subject to engage in dissonance reduction behaviours (Zanna & Cooper, 1974).

Dissonance theory has evolved since the first inception, particularly elevating the importance of *responsibility*. It is suggested that cognitive imbalance occurs more when the subject feels personally responsible for the inconsistencies that produce dissonance (Wicklund & Brehm, 1976).

⁴⁶ A later emphasis on commitment as a prerequisite to change was argued to be "encompassed by the idea of resistance to change" (Wicklund & Brehm, 1976, p. 315).

The magnitude and foreseeability of harm from actions was implicated in dissonance arousal. When harm occurring was perceived as large (and hastening the death of a patient could be thus perceived) and foreseen (i.e. when removal of food and fluids occurs there is only one foreseeable outcome), then dissonance increases (Nel, Helmreich, & Aronson, 1969; Scher & Cooper, 1989). There are three categories into which we can divide the consequences of our actions; foreseen, foreseeable and unforeseen consequences and evidence suggests that dissonance occurs when consequences are harmful from both foreseen *and* foreseeable acts (Goethals, Cooper, & Naficy, 1979). Thus a doctor may invoke the principle of double effect as an authority when a hastening death decision is considered, but the very fact that the hastened death is a *foreseeable* outcome may be sufficient to produce feelings of dissonance in some doctors.

The potentiating effects on dissonance motivation of attributions about consequences, responsibility and cause of arousal have also been noted. "Such mediating steps were not envisioned in 1957. ... At the same time, the central concepts of motivation and arousal still lie at the heart of the dissonance process" (Cooper & Fazio, 1984, p. 261). Such research indicates a link between dissonance phenomena and moral reasoning, but elsewhere research suggested that dissonance phenomena were related to self-perception.

Self-perception theory was proposed as an alternative to the dissonance phenomena attributed to motivation (to reduce dissonance) in dissonance theory (Bem, 1967). Attribution theory, suggests that internal forces are inferred by observers when there is no evidence of external forces implicated in the actor's behaviour, giving rise to the fundamental attribution error (Ross, 1977). Bem extended this theory by proposing that an individual performed self-attributional analysis, becoming in fact the observer *and* the actor. Several experiments suggested it was self-perception that created dissonance phenomena. Subjects made rational inferences from the data available to explain why they acted the way they did (Bem, 1967).

Aronson concurs

"at the very heart of dissonance theory, where it makes its clearest and neatest prediction, we are not dealing with any two cognitions; rather we are usually dealing with the self-concept and cognitions about some behavior. If dissonance exists it is because the individual's behavior is inconsistent with his self-concept. (Aronson, 1969, p. 27).

This influential argument proposed an alternative explanation for the dissonance experienced when counter-attitudinal elements were operating within a person . However Sabini concludes when considering the debate between self-perception and dissonance theorists that

The evidence suggests that: (1) the circumstances that produce dissonance do produce some drive state (arousal), and (2) this drive state doesn't directly produce the attitude change involved in dissonance; rather, it serves as a cue, suggesting that the subject has done something wrong. ... Apparently finding ourselves aroused is a hint that we have done something wrong. This cue, combined with a knowledge of our own behavior and a knowledge of our own initial attitudes (perhaps known by generalization as Bem suggests), is

enough to lead us to distort our views. On the whole then, this evidence supports the dissonance view rather than Bem's self-perception interpretation. (Sabini, 1995, p. 549)

Sabini suggests that a partition has occurred between the conflicting theories of self-perception and dissonance.

The conflict between dissonance theory and self-perception theory has given way to a truce, in which the domain of attitude change has been partitioned into the territory of dissonance theory, when behavior flies in the face of attitudes, and the territory of self-perception theory, when attitudes and behavior are in closer approximation. (Sabini, 1995, p. 553).

When a physician is faced with suffering for which there seems to be no relief, and a request for euthanasia is considered, the elements producing dissonance could include the desire, or even perceived duty, to reduce suffering and the desire or perceived duty to protect the sanctity of life. These are both important elements and when one can only apparently be achieved by sacrificing the other, the cognitive work to be done to achieve consonance would place this decision-making in “the territory of dissonance theory”, using Sabini’s analogy. If the only *perceived* way of reducing suffering was to agree to perform euthanasia (action), this would run counter to the important element of protecting the sanctity of life (belief). In order to reduce the resultant dissonance and achieve consonance, one of the elements would have to be changed in some way to bring it into line with the other. Either the euthanasia (action) will not be performed which will achieve consonance with the belief in the sanctity of life, or euthanasia will be performed but the belief in the sanctity of life will be changed. In this context the belief could be reformatted to question whether sanctity of life refers to "life" reduced to vitalism, or whether "life" in this context might refer to say, "an existence of value to the patient". If the life is of no value to the patient and the patient has requested for it to be ended, then the sanctity of life ethic (belief) as applied to that particular life may be altered (other elements added to it) so that it becomes less compelling. Thus consonance is achieved by altering one of the elements to bring this into line with the action proposed.

The compassionate first-hand account of a doctor from Oregon who had assisted the suicide of one of his patients indicates such a psychological process (Kade, 2000). He indicated he had voted against the adoption of Oregon’s Death with Dignity Act. Several times in the account the author states that he “lost” his composure as he and the patient negotiated the suicide process over time. Months after the experience he reported that he was now “more settled and comfortable with (his) role in her suicide ... more confident that (I) made the right decision for her” (p 506). He wrote that he had “redefined intolerable suffering”, his patient had the “right to choose” and the “emotional turmoil” he recalled at the time of the suicide was due to his unfamiliarity with such an action (p 506). Finally he invoked the “disruption to (his) emotional stability that this experience

precipitated” as a marker of the extreme decision and an indication of the difficulty for physicians who struggle with the “solutions to active roles in aiding patients in accomplishing their deaths”(Kade, 2000, p. 506).

Some doctors in the present study questioned whether hastening death actions that are sanctioned under palliative care are in fact different from euthanasia. They questioned why it was ethically or morally correct to engage in some actions to reduce the suffering of patients, knowing that those actions will bring about the death of the patient, and yet not others. Festinger proposed that

If a cognitive element that is responsive to reality is to be changed without changing the corresponding reality, some means of ignoring or counteracting the real situation must be used (Festinger, 1957, p. 21).

In this case, the "cognitive element responsive to reality" (foreseeing death and death being hastened) can be altered by "counteracting the real situation" (portraying the action as something other than euthanasia/killing the patient). There is a strong motivating factor present; to reduce the suffering of the patient. In order to be able to address this suffering by a death hastening action the action may be presented as "palliative" only and a philosophical principle, double effect, is invoked as the legitimising agent for the death hastening action.

Festinger expands his theory to include a wider group becoming involved in a process that serves to install and maintain the dissonance reducing mechanism in society. Those who use such actions to address the suffering of the patient can invoke the warrant of palliative care (as has been discussed previously) because the hospice movement has embraced the concept of double effect as part of the way they may address the suffering of the dying patient. Thus there are a large group of like-minded individuals under the auspices of the hospice movement who provide authorisation for some hastening death actions over others.

Usually for this* to occur the person would have to be able to find others who would agree with and support this new opinion. In general, establishing a social reality by gaining the agreement and support of other people is one of the major ways in which a cognition can be changed when the pressures to change it are present. It can readily be seen that where such social support is necessary, the presence of dissonance and the consequent pressures to change some cognitive element will lead to a variety of social processes. (Festinger, 1957, p. 21).

*(change a cognitive element although the reality remains the same)

The ability of modern medicine to keep people alive for longer, thus increasing the incidence of cancer and other painful diseases in the elderly has led to prolonged and often painful dying experiences. The need to address the suffering of this population was, in part, what drove the formation of the modern hospice movement and the development of the relatively new discipline of palliative care. Included in this was the adoption of certain philosophical principles, such as the principle of double effect, which enabled practitioners to meet their goals of reducing suffering, even at the expense of hastening the death of the patient.

Identical dissonance in a large number of people may be created when an event occurs which is so compelling as to produce a uniform reaction in everyone. For example, an event may occur which unequivocally invalidates some widely held belief (Festinger, 1957, p. 262).

In this case, the perceived suffering of dying patients was universally agreed to be inhumane and unacceptable. The "widely held belief" in the sanctity of life came under threat when the only way of addressing suffering seemed to be by increasing drugs to the point where the death of the patient was hastened. The principle of double effect has long been invoked in medicine and is recognised as an acceptable ethical principle (Sulmasy, 1999). However, it could also be recognised as a psychological mechanism employed as a way of addressing the resultant dissonance between engaging in death hastening actions and a prohibition on killing the patient (Loewy, 2001), an action that hospice philosophy has traditionally eschewed. Thus the "real situation" (hastened death) was "counteracted" as Festinger proposes, by representing this as a secondary consequence to the primary intent of reducing pain. The inception of a "movement" that addressed suffering in this way incorporated those who subscribed to this philosophical principle and provided "social support" for this approach to the problem of terminal suffering.

The existence of dissonance will lead to seeking out others who already agree with a cognition that one wants to establish or maintain and will also lead to the initiation of communication and influence processes in an effort to obtain more social support ... In situations where many persons who associate with one another all suffer from the identical dissonance, dissonance reduction by obtaining social support is very easy to accomplish (Festinger, 1957, p. 265).

The terminology used to explain certain actions that may be taken to hasten death at the end of life are specific to that area of care. "Palliative care" is an umbrella term to cover many treatment options/actions and inherent in the term is the understanding that some actions *may* hasten death. "Terminal sedation" refers specifically to the sedation of the patient until they die, and inherent within this term is the underlying understanding that food and fluids will not be provided. "Double effect" refers to actions taken with the primary intention of preventing harm (addressing suffering) with a secondary effect of harm (death of the patient). Potter and Wetherall (1987) proposed the concept of the interpretative repertoire.

Interpretative repertoires are recurrently used systems of terms used for characterizing and evaluating actions, events and other phenomena. A repertoire ... is constituted through a limited range of terms used in particular stylistic and grammatical constructions. Often a repertoire will be organized around specific metaphors and figures of speech (tropes) (Potter & Wetherell, 1987, p. 149).

Such repertoires may be adopted or even authored by specific social groups (such as hospice or palliative care workers) but are not exclusive to any social group (Burr, 1995). Thus the repertoires are available to be widely used when accounts are being constructed related to end of life care in any situation or by any person. Interpretative repertoires are represented as a "tool-kit of resources for people to use for their own purposes" (Burr, 1995, p. 119). Inherent in this is the concept of those who use these repertoires constructing an account that warrants a version of

events that is both socially (Burr, 1995) and personally acceptable. The moral distinctions between end of life care practices that hasten death intentionally or unintentionally "are critical to some but relatively inconsequential to others" (Quill et al., 2000, p. 488).

Authoring and adopting interpretative repertoires around end of life care, may be one way that those who subscribe to hospice as a philosophy in terminal care have "initiated communication" and influenced "processes" to obtain social support, as Festinger proposes (Festinger, 1957, p. 265). The palliative care movement under the auspices of hospice has provided a compassionate alternative to the care of the dying patient. Those who do not believe it is in society's best interests to legalize euthanasia or physician-assisted suicide are likely to endorse this compassionate alternative. In fact it has been argued that such "clinicians need a rule of double effect" (Sulmasy, 1999, p. 549). Thus hospice both informs society by offering alternatives to the legalisation of euthanasia and is strengthened by those thus informed who join the ranks of those who oppose euthanasia as unnecessary given the palliative alternatives (Sulmasy, 1999). It is suggested that "the most interesting discourses are those which are implicated in some way with the structure of institutions" (Parker, 1992, p. 17).

Physicians who do not subscribe to the principle of double effect as a warranting agent (criticisms of the principle have previously been mentioned) may see little moral difference between hastening the death of the patient through terminal sedation, removing food and fluids or euthanasia. Similarly as has been argued, a doctor may invoke the principle of double effect as an authority when a hastening death decision is considered but the very fact that the hastened death is a *foreseeable* outcome (Goethals et al., 1979) may be sufficient to produce feelings of dissonance as indicated by some doctors in this study.

Long before the modern hospice movement was developed, and the discipline of palliative care was refined to its present level, the Dutch used euthanasia as a way of addressing the suffering of dying patients. In the same way that New Zealand and other countries may arguably have addressed and rationalised treatment that hastens death as a way of addressing the suffering of some dying patients by invoking the principle of double effect, the Dutch may have rationalized their adoption of euthanasia policies. The dissonance experienced between seeing intractable suffering and feeling helpless to control this in any other way than by killing the patient, was resolved by invoking the defence of *overmacht* as a warrant for an action that elsewhere would be called murder. In this way "overmacht" may have been adopted by the Dutch as part of the interpretative repertoire surrounding their particular end of life care practices.

Wetherell et al (1987) concluded from their study on gender and employment opportunities

"the important psychological variables are not personal attributes as such but the limitations on individuals' systems for making sense of themselves and their environment: the limitations, in other words, inherent in the ideologies to which people have access. We have attempted, therefore, to lay bare some of the understandings, theories, and rationalizations of one sample of people through an analysis of their discourse." (Wetherell et al., 1987, p. 69)

This study has been an attempt to "lay bare" some of the ways in which these doctors have approached their care of the dying patient, and to propose and possibly expose some of the psychological mechanisms that may be at play in their accounts of how they say they have made sense of their experiences.

Beliefs or attitudes that may be altered (strengthened or weakened) when the doctor receives a euthanasia request might involve those to do with

- commitment to the patient (a belief that physician commitment meant performing euthanasia when there seemed no other alternative to control suffering, despite the effect this may have on the physician *or* alternatively commitment meant continuing to affirm life and accompanying the patient in their suffering)
- non-abandonment of the patient (the belief that not performing euthanasia, would constitute abandonment of the patient to their suffering *or* alternatively non-abandonment meant that killing the patient should never be considered)
- the impact of the action on self perception (whether performing euthanasia, was consonant with the physician's perception of self. Similarly, was that view of self one that integrated the professional self with the self as a moral human being and if so, were these views consonant? Further, did that personal morality incorporate intentional killing of innocent life if "justified" or not)
- the conviction that there were no other alternatives to the action or non-action (a belief that palliative care may not *always* be an appropriate or acceptable option for some patients *or* a belief that palliative options will always meet patient need and therefore invalidate a requirement for euthanasia)
- impact of the proposed action or non-action on personal philosophy (a belief in the warrant of authorising agents such as a higher authority, the law or codes of medical practice or even, if operating for instance at Kohlberg's Level 5 of moral reasoning as discussed in Section Two, Chapter 6, personal morality as authorising agent to agree to euthanasia *or* to continue to deny euthanasia).

Discourse that seemed to express "felt" dissonance by doctors was evident in the account that likened terminal sedation and removal of a nasogastric feeding tube to euthanasia and concern over the lack of protocols that controlled such actions (see L559). Similarly, two doctors expressed discomfort at an action that they discerned as counter to their perceived "role" as doctor (see L806). The doctor who saw the action as a barrier to his religion (see L1086) and the doctor who had not performed euthanasia who was "frightened" of such a barrier (see L1139) suggest dissonance related to the morality of the act.

There appeared to be dissonance reducing cognitions evident in the discursive accounts of the two groups of doctors. Authorisation from a higher authority appeared to be invoked by two doctors, one who overlaid a discursive account of a euthanasia with a favourable metaphysical illustration (L1218-1220) and another who invoked Christ's request from the cross that his life should be ended (L1201). Similarly an avoidance of a dissenting higher authority may have been present in the account of the doctor who said he would not be able to go back to church after performing euthanasia because the church says this is wrong (L1086). Doctors may have been invoking *socialisation* and *normalisation* as warranting agents by endorsing support for the social practice of allowing euthanasia (L581) and endorsing support for individualisation which encouraged respect for patient autonomy (L731). Endorsing and projecting the *normality* of euthanasia may have been evident in the Dutch GP's account of how euthanasia should be planned - hair and manicurist appointments made and choosing clothes (L1045). An emphasis on individualisation and patient autonomy as warranting agents may have been supported by the doctor who portrayed himself in passive terms as the patient's "instrument" in the euthanasia process, endorsing the control of the patient to choose the date and time of the death (L765).

In summary, cognitive dissonance theory (Festinger, 1957) provides one possible perspective on the adoption of hastening death practices by doctors who are committed to the sanctity of life ethic, both professionally and personally. A perceived need to reduce the suffering of dying patients may operate in tension with a requirement to preserve and maintain life, when the only available means of reducing suffering is by hastening the death of the patient. In order to achieve a psychologically acceptable outcome for the physician, the hastening death action must be represented in a way that is consonant with the physician's belief system. This allows the physician to proceed to address the suffering of the patient in the best way known, even if this is only achieved by hastening the patient's death.

CONCLUSION AND IMPLICATIONS

Notwithstanding the cultural and societal differences between New Zealand and Holland, there are things to be learned from the discursive accounts of these two groups of Dutch doctors of how

it is for them to care for the dying patient in a society where euthanasia is available. The following points that have arisen from this study may be germane to the euthanasia debate in New Zealand.

- 1 The psychological effect on the physician who performs euthanasia may be profound and long lasting.
- 2 The implementation of a euthanasia policy may need to include an accessible and acceptable debriefing/support service made available to the practitioner and other staff involved.
- 3 The effect of performing a hastening death action that is sanctioned under normal codes of medical practice and palliative care may have a profound and long lasting effect on the physician. Further research should be done to see if such an effect exists in New Zealand and if so, formalised protocols surrounding such actions may be helpful in reducing the negative effects associated with such actions and debriefing and staff support may be appropriate.
- 4 Because of the gravity of the act, the autonomy of both practitioner and patient should be recognised by the layperson, practitioner and society when euthanasia is considered. In practical terms this would incorporate an opportunity for the practitioner to decline involvement while allowing the patient access to another source of assistance for euthanasia.
- 5 Those who have had negative experiences in the past in the community may have little confidence that palliative care will successfully meet their dying needs. If euthanasia is available it may be seen by these people as the preferred option. Before euthanasia is made available in New Zealand, there would perhaps need to be widespread confidence among doctors and their patients that palliative care can successfully address most of the problems encountered in the dying process.
- 6 Doctors and arguably the public, would need to be informed of what medical decisions that hasten death constitute "euthanasia", and what medical decisions that hasten death constitute "palliative care", according to New Zealand laws and medical codes of practice.
- 7 The implementation of a euthanasia policy without the prior implementation of a comprehensive palliative care education and re-education policy as part of medical training and ongoing training may impede the dissemination of palliative care knowledge and thus alternatives to euthanasia.

- 8 The particular needs of rural GPs or those who care for the dying in isolated areas need to be considered. A palliative care advisory service should be highly visible and accessible eg through an interactive website to encourage individualised care for dying patients.
- 9 Palliative care knowledge may develop further and faster when palliative care is concentrated in dedicated units. The development of palliative care knowledge should be encouraged in dedicated units of care, in-patient and community based. Community-based here refers to palliative care that is delivered within the patient's own home but coordinated from a dedicated unit. Such units of care could be standardized and monitored by one governing body.
- 10 This governing body could be charged with the task of disseminating the knowledge derived from dedicated units of palliative care to all health care service providers, whether involved in curative care, long term care or terminal care.
- 11 The effective delivery of palliative care may be difficult to achieve within a busy ward setting. The future development of institutional health care could incorporate dedicated units for the delivery of palliative care to the dying patient by trained staff or a separate palliative care team working alongside staff in an advisory/support capacity to ensure the effective delivery of palliative care on busy wards particularly in light of an increasing aging population in New Zealand and an almost certain escalation in need for services for the dying.
- 12 The implementation of a euthanasia policy should include an accessible education and advisory program to assist practitioners in the performance of euthanasia.

SHORTCOMINGS OF THE STUDY

- (i) When Dutch doctors were talking to me they were aware of two important things. (a) euthanasia is not sanctioned in NZ and (b) criticism has been expressed about Dutch euthanasia practices. This may have impacted on how they presented their stories to me. They may have felt constrained in how they told the story or moulded it to suit their purpose. Their purpose may have included wanting to "convert" me to agreeing with their philosophy *or* their actions or at least wanting me to understand and sympathise with why they had performed euthanasia. Taking a critical perspective, the core theme of *Commitment* that was identified in the accounts may have been a product of the need for the doctors to formulate their stories to expose compassion and commitment.
- (ii) Those who did not perform euthanasia did not criticise doctors who had. In fact, one hospice doctor stated that he had "respect" for doctors who had performed euthanasia.

This may have been because this doctor considered that euthanasia was a viable option in certain situations as was stated. However it may have been that an affinity was felt with a colleague that was greater than an affinity with "my" (assumed) position or me. This may have encouraged a "loyalty" to Dutch doctors that precluded being critical of their practices to me and encouraged identification with them. International condemnation of Dutch practices has been very pointed (Hendin, 1996).

- (iii) There may be other explanations for their tolerance. NEU doctors may have feared that they may be in a position requiring them to perform euthanasia some time, and therefore feared to condemn a possible future practice (psychologically keeping the door open). Four non-euthanasia doctors stated that they would consider euthanasia if all palliative interventions failed.
- (iv) NEU doctors may have secretly done euthanasia but would not admit it to me. This may have silenced their condemnation of those who openly practice it. Alternatively, they may have secretly done euthanasia but would not admit it to themselves i.e. double effect with the *intent* to kill, and this silenced their condemnation of those who openly practice it.
- (v) NEU doctors may have engaged in practices that do not necessarily constitute "euthanasia" as it is defined under the guidelines, but which they personally feel "cross the line" towards that definition and this perception of their actions silences their condemnation of those who openly practice euthanasia.

The upshot of all this is that what I had to work with was stories that told the Dutch view, but constructed by those who are aware that their practices are frequently perceived as being ethically and morally reprehensible. This may have affected the way the stories were presented to me.

- (vi) The issue of English as a second language may also have been a confounding factor in the discursive expression of what was internally felt or perceived. This was addressed to some extent by confining analysis to thematic analysis rather than discourse analysis which assumes a closer interpretive function.
- (vii) While an effort has been made to make the process of interpretation of data available to the reader, qualitative analysis is always a subjective process and there was more to the interviews than what is presented here. Therefore, the interpretations and conclusions drawn can only apply to this researcher and these participants within the context of a

relationship as outlined previously in the reflexive account. As such they cannot be regarded as generalisable to the wider population of Dutch physicians.

- (viii) In a similar way, the accounts of Dutch physicians may not be generalisable to New Zealand physicians. However both countries engage in western medical practices and the dying patient would presumably offer similar challenges for both groups.

SECTION IV

CHAPTER 18

“THE PAUSE”

The springs of our moral concern involve an attitude which is extremely sensitive to the presence, bodily form, activity, and feelings of another human being and thus will respond to certain potent (even symbolic) cues - a child's cry, the peaceful and helpless face of the comatose, the dependence and vulnerability of those who are in great pain – which we cannot blot out nor even down-play if we wish to retain our moral integrity. It will be symptomatic of having the sensitivities involved in grasping the import of the moral dilemmas in medicine that one will evince certain reactions, or feel ‘the pause’ when confronted by such cues (Gillett, 1988, p. 65).

Certain compacts between patient and doctor will be of such private and deeply personal significance that the law cannot intrude without distortion of their essential dynamics. I believe that euthanasia is one such and that there is a difference between killing and letting die ... It is right to relieve pain, even where the tacit understanding between doctor and patient is that this may hasten death or at least weaken one's biological tenacity for life. It is also right to discontinue a medical treatment, such as life-sustaining intensive care, for a person who will not recovery meaningful life. But it seems that to approach a patient with an intent to kill is at fundamental odds with what we ought to sanction. I occupy that position because I feel that the act involved is of such deep, widely ramifying and intensely personal significance that the law has no way to provide a context for it. Our official ethic, enshrined in our statutes as firmly as it is graven in our character, and thus proclaimed with all the gravity which justice can lend to any moral conviction, must be, and be seen to be, that human life is inviolate. Any doctor who feels bound by conscience to contravene this sanction must, I think, be prepared to submit his action to the deepest scrutiny that society can undertake and be vindicated by the overwhelming humanity of his act and that alone. Only in this way will we remain faithful to that magnificent obsession which is the sole adequate guarantee of continued medical excellence (Gillett, 1988, p. 67).

Medical decisions at the end of life (MDELs) are arguably the most controversial of medical decisions. While the care of the dying patient involves medical decisions related to all aspects of care, there is the potential for medical decisions that hasten death. Whether such decisions are morally and legally sanctioned in a society or not, they cause those involved to pause and consider what is about to be done (Gillett, 1988). The "intent" in such decision-making is the point of departure for delineating the action under consideration as lawful and socially sanctioned, or unlawful and therefore questionable under societal precepts (Gillett, 1991). The difference

between the two representations of medical action in New Zealand (lawful or unlawful) relate to the difference between foreseeing that death may be hastened by an action and intending that death should be hastened (Gillon, 1999). It is argued that foreseeability does not necessarily equate to intent (Gillon, 1999).

The purpose of this thesis was to explore the nature of medical decisions at the end of life that hasten death in New Zealand – the attitude of laypersons to such decisions and the attitude and practice of general practitioners in such decisions. This exploration led to conclusions that medical decisions were being made by general practitioners explicitly with the intention of hastening the death of the patient. Moreover, such decisions were being made, at times, without prior discussion with the patient – so-called “life-terminating acts” without the consent of the patient (Kuhse et al., 1997; van der Maas et al., 1992). While some practitioners who responded in Study Two clearly felt that such actions were justified and acceptable, others clearly did not and had either found it unnecessary to take actions “explicitly” to hasten death when caring for the dying patient, or arguably had taken such actions and portrayed them as something else.

Possible differences in the approach to the care of the dying patient were explored between doctors who subscribed to actions explicitly to hasten death, including prescribing, supplying and administering drugs for that purpose, and doctors who would not do so. Because of the sensitive nature of such an enquiry, this work was completed in Holland where doctors were free to openly discuss their actions related to the intentional hastening of the patient’s death.

Results from Study Two indicate that medical decisions that have the potential to hasten death are being made by a majority of general practitioners in New Zealand (63%) (see Table 11.3, p. 167). In Study One, nearly a third of general practitioners stated that they considered it justified to intentionally end the life of a terminally ill patient with intractable pain on request (see Table 7.3, p. 94). Evidence from Study Two indicates that in fact, 5.6% of general practitioners who had made a MDEL in the previous 12 months had prescribed, supplied or administered a drug with the explicit purpose of hastening the end of life (see Table 11.3, p. 167). Given the stringent parameters of the research question which asked for details on the last death in the last 12 months, this could be a conservative indication of the number of times this action is occurring in general practice in New Zealand.

A potentially concerning result from this research is that which relates to the non-discussion with the patient or family when MDELs were made. Over half of MDELs made, were taken after no discussion with the patient. Results from Study One indicated that over a third of doctors considered that increasing medication to address pain at the risk of hastening death was

considered justified by some general practitioners without consent (see Table 9.3 (4, 5), p. 138). This strengthens the argument that was made in Study Two that this action may be considered by doctors to be normal medical practice and may give some indication why there was no discussion with the patient in 54.8% of such cases in Study Two (see Table 11.6, p. 172).

Of the 380 practitioners who made a decision with no discussion with the patient, 19% made a decision with the partial or explicit intention of hastening death (or not prolonging life) (see Table 11.6, p. 172). While there were understandable reasons given for a discussion not being possible (see Table 11.9, p. 176), a discussion arguably should have taken place with a family member in such cases. In 188 of these cases (49.5%) no discussion took place with a family member, or anyone else (see Table 11.11, p. 177).

Prescribing, supplying or administration of a drug to the patient with the explicit intention of hastening death is physician-assisted suicide, or euthanasia. This action occurred in 39 cases and no discussion occurred with the patient in 17 (43.6%) cases making the action non-voluntary euthanasia. A previous wish expressed by the patient was known in 6 cases and one case was missing. This leaves 10 cases where the action was taken with no discussion with the patient and no previous wish known (see Tables 11.6, p. 172, 11.8, p. 174 & 11.11, p. 177). This contravenes the guidelines recommended internationally to control the practices of euthanasia or physician-assisted suicide (Haley & Lee, 1998; Griffiths, Bood & Weyers, 1998; Rights of the Terminally Ill Act, 1995).

The difficulty of initiating or contributing to discussions of such actions when euthanasia or physician-assisted suicide is not legal, has been discussed in conjunction with Study One. However reports from Study Three indicate that Dutch doctors considered not discussing such actions prior to implementation are unethical not only from the legal perspective. There is the issue of not seeing other alternatives to consider as well as the effect on the doctor when such actions occur in secret. As Gillett maintains,

Any doctor who feels bound by conscience to contravene this sanction (not taking life) must, I think, be prepared to submit his action to the deepest scrutiny that society can undertake and be vindicated by the overwhelming humanity of his act and that alone (Gillett, 1988, p. 67)

The results from Study One indicate that many more than the 5.6% of physicians who prescribed, supplied or administered a drug explicitly to hasten the end of life indicated in Study Two may consider such actions justified. More comprehensive research among the medical fraternity in New Zealand, without prejudice, as occurred in Holland in 1990 may give even deeper insight into the difficulties facing doctors who provide terminal care. Some doctors will have undoubtedly made decisions and provided care that they believe is tantamount to euthanasia when

these could more properly be classified as palliative care. Others are clearly providing terminal care that contravenes New Zealand law. Guidelines and open discussion from the New Zealand Medical Association on the treatment options that can be offered to patients is clearly needed. However this present research is enough to indicate that the law does not always reflect preferred medical practice either for the physician in some cases, or the patient.

Research in the United States indicates that a majority of the public would prefer the option of assisted death in some circumstances (Blendon, Szalay & Knox, 1992). Similarly, this present research in New Zealand indicates that the number in favour of physician assisted death for a terminally ill patient with intractable pain has remained constant for the last twenty years (Heylen Poll, 1982; Roy Morgan Poll, 1992) (see Table 7.3, p. 94).

Results from Study One indicate that the majority of laypersons considered many of the actions that were reported by general practitioners in Study Two, are justified, even when these would clearly hasten the death of the patient with the exception of withholding dialysis and in the case of Young Laypersons, withholding nutrition and hydration (discussed previously). When euthanasia or physician-assisted suicide are considered for a terminally ill patient, 72% of laypersons (averaged between the two groups) consider this justified (see Table 7.3, p. 94).

It seems that the MDELs that have been reported by doctors, including euthanasia and physician-assisted suicide, are in line with the preferred treatment options of the general public.

When the issue of consent is considered by Laypersons, the majority of Older Laypersons in Study One considered increasing medication for pain at the risk of hastening death is justified without discussion (although lack of discussion significantly reduced support for the action). As discussed elsewhere, support for this action without discussion dropped to less than 10% for Young Laypersons (see Table 9.3 (4, 5), p. 138). Similarly, the presence of a Living Will on decision-making had most influence on Younger Laypersons (see Table 8.2, p. 121). These two results suggest that some persons in the community may not be supportive of the actions taken without discussion with the patient, as reported by physicians in Study Two. Conversely, the majority of Older Laypersons were supportive of increasing medication at the risk of hastening death without discussion in Study One and this support may extend to other actions taken at the risk of hastening death, without discussion. This would be in line with comments by some doctors in Study Two that patients preferred a “doctor knows best” approach to such decision-making.

Medical decisions at the end of life that hasten death, whether death is intended or not, are weighty and important considerations. Accounts from doctors in Holland reported in Study

Three suggested that the line between what is ethically and/or legally appropriate may be blurred for some doctors. The two case studies reported in Study Two related to children, clearly show how similar actions can be presented by the doctor as either palliative care or as euthanasia. The doctors' subjective understanding of what constitutes euthanasia and palliative care and any perceived need to preserve a self-image that eschews the intentional taking of innocent life, may affect self-report of actions.

The role of nurses in decision-making and actions taken to hasten death is evident in results from Study Two. More research on this population is needed to determine the extent of involvement in MDELs that hasten death, and the effect on nurses of such participation.

Transparency of decision-making when medical actions are taken that may hasten death whether death is intended or not, allows full exploration of options. Fully exploring options prior to the decision being made and death occurring will assist with the resolution of any residual doubts about actions taken, after the death. Such resolution can occur through debriefing within the professional team and a successful leave-taking for both patient and patient's family.

We may believe, with Gillett, that there is a difference between "killing and letting die" (Gillett, 1988, p. 67) or we may believe that the line is sometimes forever blurred and palliative actions taken with death as the foreseen and only outcome are analogous to euthanasia (Billings & Block, 1996). Either way, transparency of medical decision-making and practice, although perhaps difficult at times, is desirable and healthy in today's environment of professional accountability.

REFERENCES

- Advance Directives: A policy paper approved by National Policy Council (1995, 20 June) . Wellington: New Zealand Medical Association.
- A matter of death and the living dead. (1992, 29 August). *New Zealand Herald*, p. 9.
- Ahdar, R. J. (1996). Religious parliamentarians and euthanasia: a window into church and state in New Zealand. *Journal of Church and State*, 38(3), 569-593.
- Airedale NHS Trust v Bland. (1993). *AC 789* .
- Aitken Jr, P. V. (1999). Incorporating advance care planning into family practice. *American Family Physician*, 59(3), 605-610.
- Alpers, A., & Lo, B. (1996). Physician-assisted suicide in Oregon: A bold experiment. *Journal of the American Medical Association*, 274(6), 483-487.
- Alpert, H. R., & Emanuel, L. (1998). Comparing utilization of life-sustaining treatments with patient and public preferences. *Journal of General Internal Medicine*, 13, 175-181.
- American Geriatrics Society Ethics Committee. (1996). Making treatment decisions for incapacitated older adults without advance directives. *Journal of the American Geriatric Society*, 44, 986-987.
- Andrews, M. R., & Levine, A. M. (1989). Dehydration in the terminal patient: perception of hospice nurses. *The American Journal of Hospice Care*, 3, 31-34.
- Aoki, T. T., Muller, W. A., Brennan, M. F., & Cahill, G. F. (1975). Metabolic effects of glucose in brief and prolonged fasted man. *American Journal of Clinical Nutrition*, 28, 507-511.
- Applebaum, P. S., & Grisso, T. (1988). Assessing patients' capabilities to consent to treatment. *New England Journal of Medicine*, 319, 1635-1638.
- Aronson, E. (Ed.). (1969). *The theory of cognitive dissonance: A current perspective* (1st ed.). (Vol. 4). New York: Academic Press.
- Asch, D. A. (1996a). The role of critical care nurses in euthanasia and assisted suicide. *The New England Journal of Medicine*, 334(21), 1374-1379.
- Asch, D. A. (1996b). Use of a coded postcard to maintain anonymity in a highly sensitive mail survey: cost, response rates, and bias. *Epidemiology*, 7(5), 550-551.
- Asch, D. A., & Christakis, N. A. (1996). Why do physicians prefer to withdraw some forms of life support over others? *Medical Care*, 34(2), 103-111.
- Ashby, M. (1997). The fallacies of death causation in palliative care. *Medical Journal of Australia*, 166, 176.
- Ashby, M., & Stoffell, B. (1991). Therapeutic ratio and defined phases: proposal of ethical framework for palliative care. *British Medical Journal*, 302(6788), 1322-1325.
- Ashraf, H. (1999). BMA address the issue of withholding and withdrawing treatment. *The Lancet*, 353(9171), 2220.
- Auckland Area Health Board v Attorney General* [1993] 1 NZLR 235
- Auckland Healthcare Services Ltd v L & L* (NZFLR 998, 1998)
- Bachman, J. G., Alcsér, K. H., Doukas, D. J., Lichtenstein, R. L., Corning, A. D., & Brody, H. (1996). Attitudes of Michigan physicians and the public toward legalizing physician-assisted suicide and voluntary euthanasia. *The New England Journal of Medicine*, 334(5), 303-309.
- Barbeliuk, A. (2000, April 24). Opening of euthanasia advice clinics delayed. *Hobart Mercury*, p. 05.
- Barnett, E. H. (1999, February 18). Oregon doctors not eager to include assisted suicide on their list of services. *The Oregonian*, p. D5.
- Barnett, E. H. (2001, February 18). Few use it, but suicide law still has impact. *The Oregonian*, pp. A1 & A14.
- Batavia, A. (2000). The relevance of data on physicians and disability on the right to assisted suicide - Can empirical studies resolve the issue? *Psychology Public Policy & Law*, 6(2), 546-558.

- Batavia, J. D. (1997). Disability and Physician-assisted suicide. *The New England Journal of Medicine*, 336(23), 1671-1673.
- Baume, P. (1998). Voluntary euthanasia: responses of medical practitioners in NSW and the ACT to six open-ended questions. *Australian and New Zealand Journal of Public Health*, 22(2), 269-270.
- Baume, P., & O'Malley, E. (1994). Euthanasia: Attitudes and practices of medical practitioners. *Medical Journal of Australia*, 161(2), 137+140+142+144.
- Becker, L. C., & Becker, C. B. (Eds.). (1992). *Encyclopedia of Ethics* (2nd ed.). NY: Routledge.
- Bedell, S. E., & Delbanco, T. L. (1984). Choices about cardiopulmonary resuscitation in the hospital: when do physicians talk with patients? *New England Journal of Medicine*, 310, 1089-1093.
- Bem, D. J. (1967). Self-perception: an alternative interpretation of cognitive dissonance phenomena. *Psychological Review*, 74, 183-200.
- Berghmans, R. L. (1999). Ethics of end-of-life decisions in cases of dementia: views of the Royal Dutch Medical Association with some critical comments. *Alzheimer Disease & Associated Disorders*, 13(2), 91-96.
- Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., Lipsitz, L., Steel, K., & Mor, V. (1998). Management of pain in elderly patients with cancer. *JAMA, Journal of the American Medical Association*, 279(23), 1877-1882.
- Bernat, J. L., Gert, B., & Mogielnicki, R. P. (1993). Patient refusal of hydration and nutrition. An alternative to physician-assisted suicide or voluntary active euthanasia. *Archives of Internal Medicine*, 153 (December 27), 2723-2727.
- Beswick, D. G. (1978). Attitudes to taking human life. *Australian and New Zealand Journal of Sociology*, 6, 120-130.
- Biegler, P., Stewart, C., Savulescu, J., & Sken, L. (2000). Medicine and the Law. *Medical Journal of Australia*, 172, 545-548.
- Billings, J. A. (1985). Comfort measures for the terminally ill: Is dehydration painful? *Journal of the American Geriatrics Society*, 33(11), 808-810.
- Billings, J. A., & Block, S. D. (1996). Slow euthanasia. *Journal of Palliative Care*, 12(4), 21-30.
- Bleich, J. D. (1995). Assisted suicide is contrary to Judeo-Christian beliefs. In C. Wekesser (Ed.), *Euthanasia - opposing viewpoints* (pp. 39-43). San Diego: Greehaven Press Inc.
- Blendon, R.J., Szalay, U.S., & Knox, R.A. (1992). Should physicians aid their patients in dying? The public perspective. *JAMA, Journal of the American Medical Association*, 267(19), 2658-2663.
- Block, S. D., & Billings, J. A. (1994). Patient requests to hasten death. Evaluation and management in terminal care. *Archives of Internal Medicine*, 154, 2039-2047.
- Block, S. D., & Billings, J. A. (1995). Patient requests for euthanasia and assisted suicide in terminal illness. *Psychosomatics*, 36(5), 445-457.
- Bostrom, B. A. (1989). Euthanasia in the Netherlands: A model for the United States? *Issues in Law and Medicine*, 4(4), 467-486.
- Bowker, L., Stewart, K., Hayes, S., & Gill, M. (1998). Do general practitioners know when living wills are legal? *Journal of the Royal College of Physician*, 32, 351-353.
- Bowman, K. W., & Singer, P. A. (2001). Chinese seniors' perspectives on end-of-life decisions. *Social Science & Medicine*, 53(4), 455-464.
- Bradley, E. H., Wetle, T., & Horwitz, S. M. (1998). The patient self-determination act and advance directive completion in nursing homes. *Archives of Internal Medicine*, 7(Sept/Oct), 417-423.
- Brahams, D. (1992). Euthanasia: doctor convicted of attempted murder. *The Lancet*, 340(8822), 782-784.
- Brehm, J. W., & Wicklund, R. A. (1970). Regret and dissonance reduction as a function of postdecision salience of dissonant information. *Journal of Personality and Social Psychology*, 14, 1-7.

- Breitbart, W., Rosenfeld, B. D., & Passik, S. D. (1996). Interest in physician-assisted suicide among ambulatory HIV-infected patients. *American Journal of Psychiatry*, 153(2), 238-242.
- British Medical Association. (1999a). *BMA guidance: The main points*. BBC News [online]. Available: http://news.bbc.co.uk/hi/english/health/newsid_375000/375981.stm
- British Medical Association. (1999b). *BMA publishes new ethical guidance on withdrawal of treatment*. BMA Public Affairs Division [online]. Available: <http://www.bma.org.uk/news/withdraw.htm>.
- British Medical Association. (1999c, June 23). *Withholding and withdrawing life prolonging medical treatment: Guidance for decision-making*. BBC News [online]. Available: http://news.bbc.co.uk/hi/english/health/newsid_375000/375981.stm.
- British Medical Association. (1999d). *Withholding and withdrawing life-prolonging medical treatment: Guidance for decision making*. London: BMJ Books.
- Brock, D. W. (2000). Misconceived sources of opposition to physician-assisted suicide. *Psychology, Public Policy, & Law*, 6(2), 305-313.
- Brodeur, D. (1991). Is a decision to forgo tube feeding for another a decision to kill? *Issues in Law & Medicine*, 6(4), 395-406.
- Brody, H. (1996). Commentary on Billings and Block's "Slow Euthanasia". *Journal of Palliative Care*, 12(4), 38-41.
- Brownstein, E. G. (1997). Neonatal euthanasia case law in the Netherlands. *The Australian Law Journal*, 71(January), 54-58.
- Buchanan, J. (1995). Euthanasia: The medical and psychological issues. *Journal of Law and Medicine*, 3(November), 161-168.
- Burr, V. (1995). *An introduction to social constructionism*. London: Routledge.
- Caddell, D. P., & Newton, R. R. (1995). Euthanasia: American attitudes toward the physician's role. *Social Science and Medicine*, 40(12), 1671-1681.
- Campbell, N. (1999). A problem for the idea of voluntary euthanasia. *Journal of Medical Ethics*, 25(3), 242-244.
- Canetto, S. S., & Hollenshead, J. D. (2000). Older women and mercy killing. *Omega - Journal of Death & Dying*, 42(1), 83-99.
- Carroll, P. (1997, 19 September). Dialysis criteria limit treatment. *New Zealand Herald*, p. A9.
- Cassel, E. J. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, 306, 639-645.
- Caution on degrees of murder. (1999, October 14). *The New Zealand Herald*, p. A14.
- Chan, A., & Woodruff, R. K. (1991). Palliative care in a general teaching hospital. *The Medical Journal of Australia*, 155(4), 597-599.
- Charlton, R. (1993). Education about death and dying at Otago University Medical School. *New Zealand Medical Journal*, 106, 447-449.
- Charlton, R., Dovey, S., Mizushima, Y., & Ford, E. (1995). Attitudes to death and dying in the UK, New Zealand and Japan. *Journal of Palliative Care*, 11(1), 42-47.
- Chater, S., Viola, R., Paterson, J., & Jarvis, V. (1998). Sedation for intractable distress in the dying - a survey of experts. *Palliative Medicine*, 12(4), 255-269.
- Cherny, N. I., & Portenoy, R. K. (1994). Sedation in the management of refractory symptoms: Guidelines for evaluation and treatment. *Journal of Palliative Care*, 10(2), 31-37.
- Chin, A. E., Hedberg, K., Higginson, G. K., & Fleming, D. W. (1999). Legalized physician-assisted suicide in Oregon - the first year's experience. *New England Journal of Medicine*, 340(7), 577-583.
- Chochinov, H. M. (1999). Patients with amyotrophic lateral sclerosis and physician-assisted suicide. *New England Journal of Medicine*, 340(10), 817.
- Chochinov, H. M., Wilson, K. G., Enns, M., & Lander, S. (1998). Depression, hopelessness and suicidal ideation in the terminally ill. *Psychosomatics*, 39(4), 366-370.

- Chochinov, H. M., Wilson, K. G., Enns, M., Mowchun, N., Lander, S., Levitt, M., & Clinch, J. J. (1995). Desire for death in the terminally ill. *American Journal of Psychiatry*, *152*(8), 1185-1191.
- Christakis, N. A., & Asch, D. A. (1993). Biases in how physicians choose to withdraw life support. *The Lancet*, *342*(8872), 642-645.
- Christakis, N. A., & Lamont, E. B. (2000). Extent and determinants of error in doctors' prognosis in terminally ill patients: a prospective cohort study. *British Medical Journal*, *320*, 469-473.
- Churchill, L., & Danis, M. (2001). Conflict resolution at the end of life. *Critical Care Medicine*, *29*(5), 921-925.
- Churchill, L. R., & King, N. M. P. (1997). Physician-assisted suicide, euthanasia, or withdrawal of treatment. *British Medical Journal*, *315*(July 19), 137-138.
- CNN Newsnet, Dutch legalise euthanasia. (November 28, 2000)
<http://www.cnn.com/2000/WORLD/europe/11/28/holland.euthanasia/>
- Cohen, J. S., Fihn, S. D., Boyko, E. J., Jonsen, A. R., & Wood, R. W. (1994). Attitudes toward assisted suicide and euthanasia among physicians in Washington State. *New England Journal of Medicine*, *331*, 89-94.
- Cohen, L. M., Germain, M. J., Poppel, D. M., Woods, A. L., Pekow, P. S., & Kjellstrand, C. M. (2000). Dying well after discontinuing the life-support treatment of dialysis. *Archives of Internal Medicine*, *160*(16).
- Coma guides reassessed. (1996, 18 March). *New Zealand Herald*, p. A4.
- Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters and Dame Silvia R Cartwright. (1988). *The report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters*. Auckland, N.Z.
- Cooper, J., & Fazio, R. H. (1984). A new look at dissonance theory. *Advances in experimental social psychology*, *17*, 229-266.
- Cooper, M. D. (1994). Commentaries. When palliative care fails to control suffering. *Journal of Palliative Care*, *10*(2), 27-28.
- Crook, D. J. (1997). *Voluntary Euthanasia: A report on a visit to the Netherlands, England and the Northern Territory of Australia by a New Zealand General Practitioner*. Dunedin: Winston Churchill Memorial Trust.
- Coolican H. (1990). *Research methods and statistics in psychology*. London: Hodder & Stoughton.
- Cruzan v. Director Missouri Department of Health. (1990). *Missouri Department of Health 110, Supreme Court*, 2841 .
- Curtis, J. R., Donald, L. P., Caldwell, E. S., & Collier, A. C. (2000). The attitudes of patients with advanced AIDS toward use of the medical futility rationale in decisions to forego mechanical ventilation. *Archives of Internal Medicine*, *160*, 1597-1601.
- Cusveller, B., & Joshemsen, H. (1996). Life-terminating actions with severely demented patients: Critical assessment of a report of the Royal Dutch Society of Medicine. *Issues in Law and Medicine*, *12*(1), 31-45.
- Daniels, C. (1998, September 23). Disabled people argue for baby. *New Zealand Herald*, p. A5.
- Death of patient who begged to die. (2000, 16 November). *The Dominion*, p. 19.
- Deigh, J. (1998). Physician-assisted suicide and voluntary euthanasia: some relevant differences. *Journal of Criminal Law and Criminology*, *88*(3), 1155-1165.
- Deliens, L., Mortier, F., Bilsen, J., Cosyns, M., Vander Stichele, R., Vanoverloop, J., & Ingels, K. (2000). End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *The Lancet*, *356*, 1806-1811.
- Dent, R. B. (1997, 21 September). *Open letter to federal parliamentarians*. The Melbourne Age [online]. Available: <http://www.theage.com.au/>

- Devereaux, M. (2001, 8 June). Terminally ill invite Dr Death to homes. *New Zealand Herald*, p. A3.
- Dexter, P. R., Wolinsky, F. D., Gramelspacher, G. P., Zhou, X-H., Eckert, G. J., Waisburd, M., & Tierney, W. M. (1998). Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. *Annals of Internal Medicine*, *128*, 102-110.
- Dickens, B. M. (1996). Commentary on "Slow euthanasia". *Journal of Palliative Care*, *12*(4), 42-43.
- Dickenson, D. L. (2000). Are medical ethicists out of touch? Practitioner attitudes in the US and UK toward decisions at the end of life. *Journal of Medical Ethics*, *26*, 254-260.
- Diggory, P., & Judd, M. (2000). Advance directives: questionnaire survey of NHS Trusts. *British Medical Journal*, *320*, 24-25.
- Dillman, D. A., Singer, E., Clark, J. R., & Treat, J. B. (1996). Effects of benefits appeals, mandatory appeals, and variations in statements of confidentiality on completion rates for census questionnaires. *Public Opinion Quarterly*, *60*(3), 376-390.
- Dillmann, R. J. M. (1996). Euthanasia in the Netherlands: the role of the Dutch medical profession. *Cambridge Quarterly of Healthcare Ethics*, *5*, 100-106.
- Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., Fagerlin, A., Gready, R. M., Houts, R. M., Lockhart, L. K., & Zyzanski, S. (2001). Advance directives as acts of communication. *Archives of Internal Medicine*, *161*, 421-430.
- Docker, C. (1998). *Comments*. Scottish Voluntary Euthanasia Society [online]. Available: www.euthanasia.org/fastaccl.html.
- Docker, C. (2000). Values histories are more useful than advance directives. *British Medical Journal*, *320*, 54.
- Dolan, M. B. (1983). Another hospice nurse says. *Nursing*, *January*, 51.
- Dominion, T. (1999, 23 November). Poor response to euthanasia survey. *The Dominion*, p. 8.
- Douglas, C. D., Kerridge, I. H., Rainbird, K. J., McPhee, J. R., Hancock, L., & Spigelman, A. D. (2001). The intention to hasten death: a survey of attitudes and practices of surgeons in Australia. *Medical Journal of Australia*, *175*, 511-515.
- Doukas, D. J., & Gorenflo, D. W. (1999). Primary care physician attitudes and values toward end-of-life care and physician-assisted death. *Ethics & Behavior*, *9*(3), 219-230.
- Doukas, D. J., & McCullough, L. B. (1989). The values history. In W. Reichel (Ed.), *Clinical Aspects of Aging* (3rd ed., pp. 615-616). Baltimore: Williams and Wilkins.
- Downey, P. J. (1995). Euthanasia: Life death and the law. *New Zealand Law Journal*, *March*, 88-94.
- Doyle, D. (1991). Morphine: myths, morality and economics. *Postgraduate Medical Journal*, *67*(Suppl.2), S70-S73.
- Doyle, D. (1998a). Domiciliary palliative care. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed., pp. 957-973). Oxford: Oxford University Press.
- Doyle, D. (1998c). The provision of palliative care. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed., pp. 41-54). Oxford: Oxford University Press.
- Doyle, D., Hanks, G. W., & MacDonald, N. (Eds.). (1998). *Oxford textbook of palliative medicine* (2nd ed.). Oxford: Oxford University Press.
- Dryburgh, P. R. D. (1994). Euthanasia. *New Zealand Medical Journal*, *108*, 317.
- Duberstein, P. R., Conwell, Y., Cox, C., Podgorski, C. A., Glazer, R. S., & Caine, E. D. (1995). Attitudes towards self-determined death: A survey of primary care physicians. *Journal of the American Geriatric Society*, *43*, 395-400.
- Dugan, D. O. (1987). Death and Dying. Emotional, spiritual and ethical support for patients and families. *Journal of Psychosocial Nursing*, *25*(7), 21-29.

- Dunlop, R. J., Ellershaw, J. E., Baines, M. J., Sykes, N., & Saunders, C. M. (1995). On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply. *Journal of Medical Ethics*, 31(3), 141.
- Dutch policy on euthanasia. (2000). [online]. Available: http://www.minvws.nl/thema_actueel_cent...asp?Language=INTERNATIONAL&tekstid=4887
- Dworkin, R. (1993). *Life's dominion: an argument about abortion, euthanasia and individual freedom*. New York: Alfred Knopf.
- Dworkin, R. (1995). Individuals must choose for themselves whether euthanasia is ethical. In C. Wekesser (Ed.), *Euthanasia - Opposing viewpoints* (pp. 24-30). San Diego: Greenhaven Press.
- Dyer, C. (1993). Law lords rule that Tony Bland does not create precedent. *British Medical Journal*, 306(6875), 413-415.
- Dyer, C. (1999). Police investigate "euthanasia" deaths. *British Medical Journal*, 318, 143.
- Edelheit, J. (1995). Assisted suicide is not contrary to Judeo-Christian beliefs. In C. Wekesser (Ed.), *Euthanasia - Opposing viewpoints* (pp. 44-47). San Diego: Greenhaven Press Inc.
- Editorial. (1992). Advance directives. *The Lancet*, 340, 1321-1322.
- Editorial. (1997). The ethics industry. *The Lancet*, 350(9082), 897.
- Editorial. (1999, February 20-21). Little Liam's right to live. *New Zealand Herald*, p. 2.
- Edwards, M. J., & Conner, W. E. (1999). Legalized physician-assisted suicide in Oregon. (Letter to the Editor). *New England Journal of Medicine*, 341, 212-213.
- Emanuel, E. J. (1994a). Euthanasia: historical, ethical, and empiric perspectives. *Archives of Internal Medicine*, 154(7), 1890-1902.
- Emanuel, E. J., & Daniels, E. (1996). Oregon's physician-assisted suicide law: provisions and problems. *Archives of Internal Medicine*, 156(8), 825-830.
- Emanuel, E. J., Daniels, E. R., Fairclough, D. L., & Clarridge, B. R. (1998). The practice of euthanasia and physician-assisted suicide in the United States. *JAMA - The Journal of the American Medical Association*, 280(6), 507-513.
- Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *JAMA - The Journal of the American Medical Association*, 267(16), 2221-2226.
- Emanuel, E. J., & Emanuel, L. L. (1998). The promise of a good death (The promise of cancer research and treatment). *The Lancet*, 351(9114), S21-S30.
- Emanuel, E. J., Fairclough, D. L., Daniels, E. R., & Clarridge, B. R. (1996). Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *The Lancet*, 347, 1805-1810.
- Emanuel, E. J., Fairclough, D. L., & Emanuel, L. L. (2000). Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA - The Journal of the American Medical Association*, 284(19), 2460-2468.
- Emanuel, L. (1991). The health care directive: learning how to draft advance care documents. *Journal of the American Geriatric Society*, 39, 1221-1228.
- Emanuel, L. (1998). Facing requests for physician-assisted suicide: Toward a practical and principled clinical skill set. *Journal of the American Medical Association*, 280(7), 643-647.
- Emanuel, L. (2000). How living wills can help doctors and patients talk about dying. *British Medical Journal*, 320, 1618-1619.
- Emanuel, L. L. (1994b). What makes a directive valid? *Hastings Centre Report*, 24(6), S27-S29.
- Emanuel, L. L., Barry, M. J., Stoeckle, J. D., Ettelson, L. M., & Emanuel, E. J. (1991). Advance directives for medical care - A case for greater use. *The New England Journal of Medicine*, 324(13), 889-895.
- Emlar, N. P., & Hogan, R. (1981). Developing attitudes to law and justice: an integrative review. In S. S. Brehm, S. M. Kassin, & F. X. Gibbons (Eds.), *Developmental Social Psychology: Theory and Research* (pp. 298-314). New York: Oxford University Press.

- Erikson, E. H. (1963). *Childhood and society*. New York: Norton.
- Fainsinger, R. L. (1998). Use of sedation by a hospital palliative care support team. *Journal of Palliative Care, 14*(1), 51-54.
- Fainsinger, R. L., Tapper, M., & Bruera, E. (1993). A perspective on the management of delirium in terminally ill patients on a palliative care unit. *Journal of Palliative Care, 9*(Autumn), 4-8.
- Family not supported in Down's case. (1998, 21-22 November). *Weekend Herald*, p. A6.
- Family weep at cancer boy verdict. (2000, 24 August). *New Zealand Herald*, Front Page.
- Fazel, S., Hope, T., & Jacoby, R. (1999). Assessment of competence to complete advance directives. *British Medical Journal, 318*, 493-497.
- Feeding tube removal upheld. (1998, 1 October). *Associated Press*, APWire: 1:56 am eastern.
- Fenigsen, R. (1997). Dutch euthanasia revisited. *Issues in Law and Medicine, 13*(3), 301-311.
- Ferguson, P. R. (1997). Causing death or allowing to die? Developments in the law. *Journal of Medical Ethics, 23*, 368-372.
- Festinger, L. (1957). *A theory of cognitive dissonance*. Evanston, Ill: Row Peterson.
- Finlay, B. (1985). Right to life vs the right to die: Some correlates of euthanasia attitudes. *Sociology and Social Research, 69*, 548-560.
- Fins, J. J., & Bancroft, E. A. (1999). Letters: Legalised physician-assisted suicide in Oregon. *New England Journal of Medicine, 341*(3), 212.
- Fisher, J. (1999). Re-examining death: against a higher brain criterion. *Journal of Medical Ethics, 25*(6), 473-476.
- Flew, A. (1999). Advance directives are the solution to Dr Campbell's problem for voluntary euthanasia. *Journal of Medical Ethics, 25*(3), 245.
- Foley, K., & Hendin, H. (1999). The Oregon report. *Hastings Center Report, 29*(3), 37-42.
- Foley, K. M. (2000, 25th April). *H.R. 2260, Pain Relief Promotion Act*. Paper presented at the Hearing for Pain Relief Bill, Washington.
- For Casey's Sake. (1998, 19 July), *60 Minutes*. New Zealand Television One. Executive Producer, K. Taylor.
- Francke, A. L., & Kerkstra, A. (2000). Palliative care services in The Netherlands: a descriptive study. *Patient Education and Counseling, 41*, 23-33.
- Frankl, V. E. (1959). *Man's search for meaning*. New York: Simon & Schuster.
- Freud, S., (1952). *A general introduction to psychoanalysis*. (J. Riveire, Translator). New York: Washington Square Press. (Original work published in 1917).
- Fried, T. R., Stein, M. D., O'Sullivan, P. S., Brock, D. W., & Novack, D. H. (1993). The limits of patient autonomy: physician attitudes and practices regarding life-sustaining treatments and euthanasia. *Archives of Internal Medicine, 153*, 722-728.
- Friedman, Y., Franklin, C., Rackow, E. C., & Weil, M. H. (1989). Improved survival in patients with AIDS, Pneumocystis carinii pneumonia, and severe respiratory failure. *Chest, 96*, 862-866.
- Gamble, E. R., McDonald, P. J., & Lichstein, P. R. (1991). Knowledge, attitudes, and behavior of elderly persons regarding living wills. *Archives of Internal Medicine, 151*, 277-280.
- Ganzini, L., Johnston, W. S., McFarland, B. H., Tolle, S. W., & Lee, M. A. (1998). Attitudes of patients with amyotrophic lateral sclerosis and their care givers toward assisted suicide. *The New England Journal of Medicine, 339*(14), 967-973.
- Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A., & Lee, M. A. (2000). Physicians' experiences with the Oregon Death with Dignity Act. *New England Journal of Medicine, 342*, 557-563.
- Ganzini, L., Nelson, H. D., Schmidt, T. A., Kraemer, D. F., Delorit, M. A., & Lee, M. A. (2001). Oregon physicians' attitudes about and experiences with end of life care. *JAMA - The Journal of the American Medical Association, 285*(18), 2363-2369.
- Ganzini, L., & Sullivan, M. (1999). Responding to patient requests for physician-assisted suicide (Letter to the Editor). *JAMA - Journal of the American Medical Association, 281*, 227-228.

- Gawler, I. (1984). *You can conquer cancer*. Melbourne. Hill of Content Publishing Co. Pty. Ltd.
- Gawler, I. (1987). *Peace of Mind*. Melbourne. Hill of Content Publishing Co. Pty. Ltd.
- Gibson, J. (1990). Values history focuses on life and death decisions. *Medical Ethics*, 5, 17.
- Gill, C. J. (2000). Health professionals, disability, and assisted suicide - An examination of relevant empirical evidence and reply to Batavia. *Psychology Public Policy & Law*, 6(2), 526-545.
- Gillett, G. (1988). Euthanasia, letting die and the pause. *Journal of Medical Ethics*, 14, 61-68.
- Gillett, G., Bloore, S., & Ngata, P. (1996). *A New Zealand Medical Association report on euthanasia*. Christchurch, New Zealand: University of Otago, Bioethics Centre.
- Gillett, G. R. (1991). Intent in law and medicine. *New Zealand Law Journal*, April, 115-121.
- Gillick, M. R. (2000). Rethinking the role of tube feeding in patients with advanced dementia. *New England Journal of Medicine*, 342(3), 206-210.
- Gilligan, C. (1982). *In a different voice*. Cambridge: Harvard University Press.
- Gillon, R. (1999). Foreseeing is not necessarily the same as intending. *British Medical Journal*, 318, 1431-1432.
- Gjerdingen, D. K., Neff, J. A., Wang, M., & Chaloner, K. (1999). Older persons' opinions about life-sustaining procedures in the face of dementia. *Archives of Family Medicine*, 8(5), 421-425.
- Gleitman, H. (1991). *Psychology*. (3rd Edition). New York: W. W. Norton.
- Goethals, G. R., Cooper, J., & Naficy, A. (1979). Role of foreseen, foreseeable and unforeseeable behavioral consequences in the arousal of cognitive dissonance. *Journal of Personality and Social Psychology*, 37, 1179-1185.
- Goh, A. T., & Mok, Q. (2000). Most decisions are based on subjective appraisal. *British Medical Journal*, 320, 54.
- Goodwin, J. S. (1991). Mercy killing: Mercy for whom? *Journal of the American Medical Association*, 265, 326.
- Goodwin, P. (1997). Oregon's physician-assisted suicide law: an alternative positive viewpoint. *Archives of Internal Medicine*, 157(15), 1642-1645.
- Goold, S. D., Williams, B., & Arnold, R. M. (2000). Conflicts regarding decisions to limit treatment. *JAMA - The Journal of the American Medical Association*, 283(7), 909-912.
- Gordijn, B. (2001). Regulating moral dissent in an open society: The Dutch experience with pragmatic tolerance. *Journal of Medicine & Philosophy*, 26(3), 225-244.
- Gordijn, B., & Janssens, R. (2001). New developments in Dutch legislation concerning euthanasia and physician-assisted suicide. *Journal of Medicine & Philosophy*, 26(3), 299-309.
- Gordijn, B., & Janssens, R. (2000). The prevention of euthanasia through palliative care: New developments in The Netherlands. *Patient Education and Counseling*, 41, 35-46.
- Gostin, L. O. (1997). Deciding life and death in the courtroom: from Quinlan to Cruzan, Glucksberg and Vacco - a brief history and analysis of constitutional protection of the 'right to die'. *JAMA - The Journal of the American Medical Association*, 278(18), 1523-1529.
- Grassi, L., Magnani, K., & Ercolani, M. (1999). Attitudes towards euthanasia and physician-assisted suicide among Italian primary care physicians. *Journal of Pain and Symptom Management*, 17, 188-196.
- Gregory, A. (1997, September 19). 'Nobody wants to die'. *New Zealand Herald*, p. A1.
- Gregory, A. (2000a, 7 April). Ethics expert steps into 'starvation' row. *New Zealand Herald*, p. A7.
- Gregory, A. (2000b, 19 April). Family apologise for 'left-to-starve' claim. *New Zealand Herald*, p. A12.
- Gregory, D., & English, J. C. B. (1994). The myth of control: suffering in palliative care. *Journal of Palliative Care*, 10(2), 18-22.
- Griffiths, J., Bood, A., & Weyers, H. (1998). *Euthanasia & Law in the Netherlands*. Amsterdam: Amsterdam University Press.

- Groenewoud, J. H., van der Heide, A., Onwuteaka-Philipsen, B. D., Willems, D. L., van der Maas, P., & van der Wal, G. (2000). Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands. *New England Journal of Medicine*, 342(8), 551-556.
- Haas, J. S., Wiessman, J. S., Cleary, P. D., Goldberg, J., Gatsonis, C., Seage, G. R., Fowler, F. J., Massagli, M. P., Makadon, H. J., & Epstein, A. M. (1993). Discussion of preferences for life-sustaining care by persons with AIDS. *Archives of Internal Medicine*, 153, 1241-1248.
- Haley, K., Lee, M., (1998). *The Oregon Death with Dignity Act. A guidebook for health care providers*. Portland. Oregon Health Sciences University.
- Hamel, M. B., Teno, J. M., Goldman, L., Lynn, J., Davis, R. B., Galanos, A. N., Desbiens, N., Connors Jr, A. F., Wenger, N., Phillips, R. S., for the SUPPORT Investigators. (1999). Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. *Annals of Internal Medicine*, 130, 116-125.
- Hanson, L. C., Earp, J. A., Garrett, J., Menon, M., & Danis, M. (1999). Community physicians who provide terminal care. *Archives of Internal Medicine*, 159, 1133-1138.
- Hardy, J. (2000). Sedation in terminally ill patients. *The Lancet*, 356(9245), 1866
- Hassan, R. (1996). The euthanasia debate. *The Medical Journal of Australia*, 165, 535.
- Haverkate, I., van der Heide, A., Onwuteaka-Philipsen, B. D., van der Maas, P. J., & van der Wal, G. (2001). The emotional impact on physicians of hastening the death of a patient. *Medical Journal of Australia*, 175, 519-522.
- Haverkate, I., van der Wal, G., van der Maas, P. J., Onwuteaka-Philipsen, B. D., & Kostense, P. J. (1998). Guidelines on euthanasia and pain alleviation: compliance and opinions of physicians. *Health Policy*, 44, 44-45.
- Healthcare Otago Ltd v Williams-Holloway. (1999a). 04 March, NZFLR 798 .
- Healthcare Otago Ltd v Williams-Holloway. (1999b). 18 March NZFLR 804 .
- Helig, S., Brody, R., Marcus, F. S., Shavelson, L., & Sussman, P. C. (1997). Physician-Hastened Death Advisory Guidelines for the San Francisco Bay Area From the Bay Area Network of Ethics Committees. *Western Journal of Medicine*, 166(6), 370-378.
- Helme, T. (1993). "A special defence": A psychiatric approach to formalising euthanasia. *British Journal of Psychiatry*, 163, 456-466.
- Hendery, S. (1999, 10 April). Compassion may avert jail. *New Zealand Herald*, p. A4.
- Hendin, H. (1995). Selling death and dignity. *Hastings Center Report*, May-June, 19-23.
- Hendin, H. (1996). *Seduced by death: Doctors, patients and the Dutch cure*. New York: W W Norton Co.
- Hendin, H. (1999). Editorial: Euthanasia consultants or facilitators? *Medical Journal of Australia*, 170, 351-352.
- Hendin, H., & Klerman, G. (1993). Physician-assisted suicide: the dangers of legalization. *American Journal of Psychiatry*, 150(1), 143-145.
- Hendin, H., Rutenfrans, C., & Zylicz, Z. (1997). Physician-assisted suicide and euthanasia in the Netherlands. *JAMA - Journal of the American Medical Association*, 277(21), 1720-1722.
- Henneveld, L. (1994). Euthanasia. *New Zealand Medical Journal*, 107, 157-158.
- Heylen Poll. (1982). *Voluntary Euthanasia*. Auckland: Heylen Research Centre.
- Hippocratic Oath [online] <http://www.indiana.edu/~ancmed/oath.htm>
- Hofmann, J. C., Wenger, N. S., David, R. B., Teno, J., Connors Jr, A. F., Desbiens, N., Lynn, J., & Phillips, R. S. (1997). Patient preferences for communication with physicians about end-of-life decisions. *Annals of Internal Medicine*, 127, 1-12.
- Hofstede, G. (1991). Motivation, leadership, and organization: Do American theories apply abroad? In D. A. Kolb, I. M. Rubin, & J. S. Osland (Eds.), *The organizational behavior reader* (5th ed., pp. 347-368). New Jersey: Prentice Hall.
- Holley, J. L., Hines, S. C., Glover, J. J., Babrow, A. S., Badzek, L. A., & Moss, A. H. (1999). Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. *American Journal of Kidney Diseases*, 33(4), 688-693.

- Hooper, S. C., Vaughan, K. J., Tennant, C. C., & Perz, J. M. (1996). Major depression and refusal of life-sustaining medical treatment in the elderly. *Medical Journal of Australia*, 165, 416-419.
- Hopper, D. (1998, 21 September). 300 people protest woman's plan to pull husband's feeding tubes. *Associated Press*, APWire: 1.55 am eastern.
- Horwood, A. (1998, September 21). Judge to decide on baby's life. *New Zealand Herald*, p. A3.
- Crossfire Election Special. (1999, 21 November). Television New Zealand One. Executive Producer: Mike Hosking.
- Hospital promises changes. (1998, 28-29 November). *Weekend Herald*, p. A5.
- Hughes, D. L., & Singer, P. A. (1992). Family physicians' attitudes towards advance directives. *Canadian Medical Association Journal*, 146, 1937-1944.
- Humphrey, D. (1997). *Final Exit*. Melbourne: Penguin Books.
- Hyde, H. (1999). *House Resolution 2260*. Washington: Federal Government.
- In re Karen Quinlan. (1976). 70 New Jersey 10 355 A.2d .
- Independent London. (1999, 20 - 21 February). Arrogance has no place in modern medicine. *New Zealand Herald*, p. A2.
- International Narcotics Control Board. (1998). *Morphine consumption: Latin America and the World, 1996* [online]. Available: <http://www.medsch.wise.edu/painpolicy/publicat/monograph/98mclaw.htm>.
- Jackson, A. (2000). Observations on the first year - A commentary. *Psychology, Public Policy, & Law*, 6(2), 322-330.
- Janssens, R. J. P. A., ten Have, H. A. M. J., & Zylicz, Z. (1999). Hospice and euthanasia in the Netherlands: an ethical point of view. *Journal of Medical Ethics*, 25, 408-412.
- Jarmulowicz, M. (1995). *Neuropathological findings in cases of persistent vegetative state*. Catholic Medical Quarterly. Available: http://www.catholicdoctors.org.uk/CMQ/Indiv%20Articles/neuropath_tony_bland.htm [2001, 27 November].
- Jecker, N., & Pearlman, R. A. (1992). Medical futility: Who decides? *Archives of Internal Medicine*, 152(June), 1140-1144.
- Jennett, B. (1999). Editorial: Should cases of permanent vegetative state still go to court? *British Medical Journal*, 319, 796-797.
- Jennett, B., & Plum, F. (1972). Persistent vegetative state after brain damage: a syndrom looking for a name. *Lancet*, 734-737.
- Jochemsen, H. (1998). Dutch court decisions on nonvoluntary euthanasia critically reviewed. *Issues in Law & Medicine*, 13(4), 447-458.
- Johnston, M. (1999, 13 July). Give more power to parents say rights advocates. *New Zealand Herald*, p. A4.
- Johnston, M. (2000, 25 August). Cancer boy dies after lack of care. *New Zealand Herald*, p. A2.
- Johnston, S. C., Pfeifer, M. P., & McNutt, R. (1995). The discussion about advance directives. *Archives of Internal Medicine*, 155, 1025-30.
- Judge upholds right to die decision. (1998, 21 September). *Associated Press*, APWire: 7.07 pm eastern.
- Justice, C. (1995). The "natural" death while not eating: A type of palliative care in Banaras, India. *Journal of Palliative Care*, 11(1), 38-42.
- Kade, W. J. (2000). Death with dignity: A case study. *Annals of Internal Medicine*, 132(6), 504-506.
- Kashiwagi, T. (1991). Hospice care in Japan. *Postgraduate Medical Journal*, 67(Suppl.2), S95-S99.
- Kastenbaum, R. (1978). In Control. In C. A. Garfield (Ed.), *Psychosocial care of the dying patient* (pp. 227-240). New York: McGraw Hill.
- Keizer, B. (1997a). *Dancing with Mister D*. Auckland: Black Swan.
- Keizer, B. (1997b, Wednesday 9 April). In search of a decent death. *The Guardian*, p. 021.

- Kelly, P. M. (1999). *Prof Gillon crystal clear (as usual)*. eBMJ [online]. Available: <http://www.bmj.com/cgi/eletters/318/7196/1431#EL9>.
- Kemmelmeier, M., & Burnsten, E. (1999). Individualism and authoritarianism shape attitudes towards physician-assisted suicide. *Journal of Applied Social Psychology, 29*(12), 2613-2631.
- Kenny, N. P., & Frager, G. (1996). Refractory symptoms and terminal sedation of children: Ethical issues and practical management. *Journal of Palliative Care, 12*(3), 40-45.
- Kent, B., & Owens, R. G. (1995). Conflicting attitudes to corneal and organ donation: a study of nurses' attitudes to organ donation. *International Journal of Nursing Studies, 32*(5), 484-492.
- Keown, J. (1995). Euthanasia in the Netherlands: sliding down the slippery slope? In J. Keown (Ed.), *Euthanasia Examined* (pp. 261-296). Cambridge: Cambridge University Press.
- Keown, J. (1993). Courting euthanasia: Tony Bland and the law lords. *Ethics and Medicine, 9*, 37.
- Keown, J., & Jochemsen, H. (1999). Voluntary euthanasia under control? Further empirical evidence from the Netherlands. *Journal of Medical Ethics, 25*, 16-21.
- Key, P. (1989). Euthanasia: Law and morality. *Auckland University Law Review, 6*(2), 224-244.
- Kimsma, G. K., & Leeuwen, E. V. (1993). Dutch euthanasia: background, practice, and present justifications. *Cambridge Quarterly of Healthcare, 2*, 19-31.
- Kirk, K. (1998). How Oregon's Death with Dignity Act affects practice. *American Journal of Nursing, 98*(8), 54-55.
- Kissane, D. W., & Kelly, B. J. (2000). Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia for the mentally ill. *Australian and New Zealand Journal of Psychiatry, 34*, 325-333.
- Kissane, D. W., Spruyt, O., & Aranda, S. (2000). Palliative care - new approaches to the problem of suffering. *Australian & New Zealand Journal of Medicine, 30*, 377-384.
- Kissane, D. W., Street, A., & Nitschke, P. (1998). Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *The Lancet, 352*, 1097-1102.
- Klotzko, A. J. (1997). What kind of life? What kind of death? An interview with Dr Henk Prins. *Bioethics, 11*(1), 24-42.
- Kmietowicz, Z. (1997). Woman dies two months after food withdrawal. *British Medical Journal, 314*(24 May), 314.
- Koenig, H. G., Wildman-Hanlon, D., & Schmader, K. (1996). Attitudes of elderly patients and their families toward physician-assisted suicide. *Archives of Internal Medicine, 156*(19), 2240-2249.
- Kohlberg, L. (1967). Moral and religious education and the public schools: A developmental view. In T. R. Sizer (Ed.), *Religion and public education*. NY: Houghton Mifflin Company.
- Kohlberg, L. (1968). The child as a moral philosopher. *Psychology Today, September*, 25-30.
- Kohlwes, R. J., Koepsell, T. D., Rhodes, L. A., & Pearlman, R. A. (2001). Physicians' responses to patients' requests for physician-assisted suicide. *Archives of Internal Medicine, 161*, 657-663.
- Kuhse, H., & Singer, P. (1988). Doctors' practices and attitudes regarding voluntary euthanasia. *The Medical Journal of Australia, 148*(June 20), 623-627.
- Kuhse, H., & Singer, P. (1993). Voluntary euthanasia and the nurse: an Australian survey. *International Journal of Nursing Studies, 30*(4), 311-322.
- Kuhse, H., Singer, P., Baume, P., Clark, M., & Rickard, M. (1997). End-of-life decisions in Australian medical practice. *Medical Journal of Australia, 166*, 191-196.
- Kumar, A. (2000, February 7). When the light goes out. *St Petersburg Times*, p. 1B.
- Kutner, L. (1969). Due process of euthanasia: the living will, a proposal. *Indiana Law Journal, 44*, 539-554.
- La Puma, J., Orentlicher, D., & Moss, R. J. (1991). Advance directives on admission. *JAMA - Journal of the American Medical Association, 266*, 402-405.

- Laghi, B. (2001, 19 January). Former juror in Latimer case calls for mercy. *The Globe and Mail*, p. A4.
- Lantos, J. D., Singer, P. A., Walker, R. M., Gramelspacher, G. P., Shapiro, G. R., Sanchez-Gonzalez, M. A., Stocking, C. B., Miles, S. H., & Siegler, M. (1989). The illusion of futility in clinical practice. *JAMA - The American Journal of Medicine*, 87, 81-84.
- Larkin, N. (2000, 25 August). Parents' agony over son they loved to death. *New Zealand Herald*, p. A11.
- Lavery, J. V., Boyle, J., Dickens, B. M., Maclean, H., & Singer, P. A. (2001). Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study. *The Lancet*, 358(9279), 362-367.
- Leenaars, A., & Conolly, J. (2001). Suicide, assisted suicide and euthanasia: International perspectives. *Irish Journal of Psychiatric Medicine*, 18(1), 33-37.
- Lester, D. (1996). Psychological issues in euthanasia, suicide and assisted suicide. *Journal of Social Issues*, 52(2), 51-62.
- Lewis, K. (1999, 13 July). Rau Williams ruling upsets all concerned. *New Zealand Herald*, p. A10.
- Ley, P., & Spelman, M. S. (1967). *Communicating with the patient*. London: Trinity Press.
- Linsky, A. S. (1975). Stimulating response to mailed questionnaires: A review. *Public Opinion Quarterly*, 39, 82-101.
- Littlejohn, T., & Burrows-Johnson, J. (1996). An attitudinal survey of euthanasia in Windward Oahu. *Hawaii Medical Journal*, 55(December), 265-269.
- Loewy, E. H. (2001). Terminal starvation, self-starvation and orchestrating the end of life. *Archives of Internal Medicine*, 161, 329-332.
- Lupton, D. (1997). Foucault and the medicalization critique. In A. R. Peterson & R. Bunton (Eds.), *Foucault, health and medicine*. New York: Routledge.
- MacDonald, W. L. (1998a). The difference between blacks' and whites' attitudes toward voluntary euthanasia. *The Journal for the Scientific Study of Religion*, 37(3), 411-427.
- MacDonald, W. L. (1998b). Situational factors and attitudes toward voluntary euthanasia. *Social Science and Medicine*, 46(1), 73-81.
- MacLennan, C. (1998, 4 August). Diminished responsibility law needs to be codified. *New Zealand Herald*, p. A11.
- Madorsky, J. G. (1997). Is the slippery slope steeper for people with disabilities? *Western Journal of Medicine*, 166, 410-411.
- Mager, D. (1997, 24 October). Dialysis details unclear. *New Zealand Herald*, p. A3.
- Mahoney, J. (2001, 18 April). Most support cut in Latimer's term for mercy killing. *The Globe and Mail*, p. A3.
- Mangus, R. S., Dipiero, A., & Hawkins, C. E. (1999). Medical students' attitudes toward physician-assisted suicide. *JAMA - Journal of the American Medical Association*, 281(21), 2080-2081.
- Martin, D. K., Emanuel, L. L., & Singer, P. (2000). Planning for the end of life. *The Lancet*, 356(November 11), 1672-1676.
- Masters, B. A. (1998, 10 October). The battle outlives Hugh Finn. *Washington Post*, p. A01.
- Masters, C. (1999, 30 April). More mercy killings tipped as NZ ages. *New Zealand Herald*, Front Page.
- Matthews, H. (1998). Better palliative care could cut euthanasia. *British Medical Journal*, 317(7173), 1613.
- Maynard, F. M., & Muth, A. S. (1987). The choice to end life as a ventilator-dependent quadriplegic. *Archives of Physical Medical Rehabilitation*, 68(December), 862-864.
- McCann, R. M., Hall, W. J., & Groth-Juncker, A. (1994). Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA - Journal of the American Medical Association*, 272, 1263-1266.

- McHaffie, H. E., Lyon, A. J., & Fowlie, P. W. (2001). Linger death after treatment withdrawal in the neonatal intensive care unit. [Special Issue]. *Archives of Disease in Childhood*, 85(1), F8-F12.
- McNeill, R. & Schug, S. (2002) [Physician attitude to pain]. Unpublished raw data
- Medical Council of New Zealand. (1999). *The New Zealand Medical Workforce 1998*. Wellington: Medical Council of New Zealand.
- Meier, D. E., Emmons, C., Wallenstein, S., Quill, T., Morrison, R. S., & Cassel, C. K. (1998). A national survey of physician-assisted suicide and euthanasia in the United States. *The New England Journal of Medicine*, 338(17), 1193-1201.
- Meilaender, G. (1995). Euthanasia cannot be an ethical individual choice. In C. Wekesser (Ed.), *Euthanasia - Opposing viewpoints* (pp. 31-38). San Diego: Greenhaven Press Inc.
- Meisel, A., Snyder, L., & Quill, T. (2000). Seven legal barriers to end-of-life care: Myths, realities and grains of truth. *Journal of the American Medical Association*, 284(19), 2495-2501.
- Melia, K. M. (2001). Ethical issues and the importance of consensus for the intensive care team. *Social Science & Medicine*, 53(6), 707-719.
- Micetich, K. C., Steinecker, P. H., & Thomasma, D. C. (1983). Are intravenous fluids morally required for a dying patient. *Archives of Internal Medicine*, 143, 975-978.
- Mill, J. S. (1910). *Utilitarianism, on liberty, considerations on representative government*. London: Orion Publishing Group.
- Miller, F. G., & Meier, D. E. (1998). Voluntary death: a comparison of terminal dehydration and physician-assisted suicide. *Annals of Internal Medicine*, 128, 559-562.
- Mitchell, K. (1995). Laypersons' attitudes to euthanasia. Unpublished research manuscript: University of Auckland, Auckland.
- Mitchell, K., & Owens, R. G. (2000). Euthanasia and palliative psychology in end of life care. *Australian Psychologist*, 35(3), 193-200.
- Morrison, R. S., & Meier, D. E. (1994). Physician-assisted dying: fashioning public policy with an absence of data. *Generations*, 18(4), 48-53.
- Morrison, R. S., Morrison, E. W., & Glickman, D. F. (1994). Physician reluctance to discuss advance directives. An empiric investigation of potential barriers. *Archives of Internal Medicine*, 154, 2311-2318.
- Mount, B. (1996). Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes. *Journal of Palliative Care*, 12(4), 31-37.
- Mount, B. M., & Hamilton, P. (1994). When palliative care fails to control suffering. *Journal of Palliative Care*, 10(2), 24-26.
- Muller, M. T., van der Wal, G., van Eijk, J. T. M., & Ribbe, M. W. (1995). Active euthanasia and physician-assisted suicide in Dutch nursing homes: patients' characteristics. *Age and Ageing*, 24(5), 429-434.
- Murphy, C. (2001,). What to do about suicide websites? *Agence France-Presse*, Wire: April 17.
- Murphy, D. J., & Santilli, S. (1998). Elderly patients' preferences for long-term life support. *Archives of Family Medicine*, 7(484-488), 484-488.
- Muskin, P. R. (1998). The request to die: role for a psychodynamic perspective on physician-assisted suicide. *JAMA - The Journal of the American Medical Association*, 279(4), 323-328.
- Narratives from the Netherlands. (1996). *Cambridge Quarterly of Health Care*, 5, 77-92.
- Neeson, B. (1998, 13 August). Why we need to have law to set degrees of murder. *New Zealand Herald*, pp. A15.
- Nel, E., Helmreich, R., & Aronson, R. (1969). Opinion change in the advocate as a function of the persuasibility of his audience: A clarification of the meaning of dissonance. *Journal of Personality and Social Psychology*, 12, 117-124.
- Neuberger, J. (1998). Cultural issues in palliative care. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford Textbook of Palliative Medicine* (pp. 777-785). Oxford: Oxford Unity Press.

- New Zealand Bill of Rights Act. (1990). http://www.uni-wuerzburg.de/law/nz01000_.html
- New Zealand Crimes Act 1961. [online]. Available: <http://rangi.knowledge-basket.co.nz/gpacts/reprint/text/1961/an/043.html>.
- Nichols, M. (1997). Sympathy and anger: some disabled people feel 'endangered' in Canadian society. *Maclean's* (November 17), 16-17.
- Nuland, S. B. (2000). Physician-assisted suicide and euthanasia in practice. *New England Journal of Medicine*, 342(8), 583-584.
- NZPA. (2000, November 16). Death of a patient who begged to die. *The Dominion*, p. 19.
- NZPD 549. (1995). *Death with Dignity Bill*. Wellington.
- Oddie, G. (1998). The moral case for the legalisation of voluntary euthanasia. *Victorian University of Wellington Law Review*, 28, 207-224.
- Ogden, R. (1994). Palliative care and euthanasia: A continuum of care? *Journal of Palliative Care*, 10(2), 82-85.
- O'Keefe, M., & Hogan, D. (1999, 20 October). After five years, Oregon's law faces house vote. *The Oregonian*, Front Page.
- Oliver, D. (1984). Terminal dehydration. *Lancet*, 2, 631.
- Onwuteaka-Philipsen, B. D., Kriegsman, D. M. W., van der Wal, G., Dillmann, R. J. M., & van Eijk, J. T. (1999). General practitioners' opinions on consultation of another physician in case of euthanasia. *European Journal of General Practice*, 5, 137-142.
- Onwuteaka-Philipsen, B. D., Muller, M. T., & van der Wal, G. (1997a). Euthanasia and old age. *Age and Ageing*, 26(6), 487-493.
- Onwuteaka-Philipsen, B. D., Muller, M. T., & van der Wal, G. (1997b). Euthanatics: implementation of a protocol to standardise euthanatics among pharmacists and GPs. *Patient Education and Counseling*, 31, 131-137.
- Onwuteaka-Philipsen, B. D., van der Wal, G., J Kostense, P., & van der Maas, P. J. (1999). Consultants in cases of intended euthanasia or assisted suicide in the Netherlands. *Medical Journal of Australia*, 170, 360-363.
- Oregon Death with Dignity Act. (1997). *Oregon Revised Statute 127 800-127 897*.
- Oregon Health Division. (1997). *Oregon's death with dignity act* [online]. Available: <http://www.ohd.hr.state.or.us/chs/pas/pas.htm>.
- Oregon Health Division. (2000). *Oregon's Death with Dignity Act: The second year's experience* [online]. Available: <http://www.ohd.hr.state.or.us/chs/pas/pas.htm>.
- Oregon Health Division. (2001a). *Oregon's Death with Dignity Act: The first year's experience* [online]. Available: <http://www.ohd.hr.state.or.us/chs/pas/pas.htm>.
- Oregon Health Division. (2001b). *Oregon's Death with Dignity Act: Three years of legalized physician-assisted suicide* [online]. Available: <http://www.ohd.hr.state.or.us/chs/pas/pas.htm>
- Oregon Public Health Services. (2000). *Oregon's Death with Dignity Act: Three years of legalized physician-assisted suicide* [online]. Available: <http://www.ohd.hr.state.or.us/chs/pas/ar-index.htm>.
- Orentlicher, D. (1992). The illusion of patient choice in end-of-life decisions. *JAMA - Journal of the American Medical Association*, 267, 2101-2104.
- Orentlicher, D. (1997). The Supreme Court and physician-assisted suicide - rejecting assisted suicide but embracing euthanasia. *The New England Journal of Medicine*, 337, 1236-1239.
- Orentlicher, D., & Caplan, A. (2000). The Pain Relief Promotion Act of 1999: A serious threat to palliative care. *JAMA - Journal of the American Medical Association*, 283(2), 255-258.
- Ostheimer, J. M. (1980). The Polls: Changing attitudes toward euthanasia. *Public Opinion Quarterly*, 44, 123-128.
- Ouslander, J. G., Tymchuk, A. J., & Rahbar, B. (1989). Health care decisions among elderly long-term care residents and their potential proxies. *Archives of Internal Medicine*, 149, 1367-1372.

- Owens, R. G. (1995). Radical behaviourism and life-death decisions. *Clinical Psychology Forum*, 80, 12-16.
- Owens, R. G. (1999). Ethics, aesthetics and empiricism. In *Business ethics in theory and practice*, P. H. Werhane & A. E. Singer (Eds). Dordrecht: Kluwer Academic Publications
- Padmanabhan, N. (1999). *When doctors might kill their patients*. eBMJ [online]. Available: <http://www.bmj.com/cgi/eletters/318/7196/1431#EL9>.
- Palmer, L. D. (1998, 9 October). Quietly, Virginia battle ends over comatose man. *Boston Globe*, p. A03.
- Paris, J. J. (1986). When burdens of feeding outweigh benefits. *Hastings Center Report*, 18, 30-32.
- Paris, J. J. (1998, 31 October). Hugh Finn's "right to die". *America*, p.13.
- Parker, I. (1992). *Discourse dynamics: Critical analysis for social and individual psychology*. London & New York: Routledge.
- Parkes, C. M. (1972). Accuracy of predictions of survival in later dates of cancer. *British Medical Journal*, ii, 29-31.
- Parkes, C. M. (2000). Commentary: Prognoses should be based on proved indices not intuition. *British Medical Journal*, 320, 473.
- Patrick, D. L., Pearlman, R. A., Starks, H. E., Cain, K. C., Cole, W. G., & Uhlmann, R. F. (1997). Validation of preferences for life-sustaining treatment: Implications for advance care planning. *Annals of Internal Medicine*, 127, 509-517.
- Patterson, D. R., Miller-Perrin, C., McCormick, T. R., & Hudson, L. D. (1993). When life support is questioned early in the care of patients with cervical-level quadriplegia. *New England Journal of Medicine*, 328, 506-509.
- Paul, J. (1999). Withholding food and fluids is justifiable only for terminally ill. *British Medical Journal*, 318, 1415.
- Pereira, J., Hanson, J., & Bruera, E. (1997). The frequency and clinical course of cognitive impairment in patients with terminal cancer. *Cancer*, 79, 835-842.
- Perry, A., Rivlin, M. M., & Goldstone, A. H. (1999). Bone marrow transplant patients with life-threatening organ failure: when should treatment stop. *Journal of Clinical Oncology*, 17(1), 298-303.
- Peruzzi, W. T., Skoutelis, A., Shapiro, B. A., et al., (1991). Intensive care unit patients with acquired immunodeficiency syndrome and Pneumocystis carinii pneumonia: suggested predictors of hospital outcome. *Critical Care Medicine*, 19, 892-900.
- Pijnenborg, L., van Delden, J. M. M., Kardaun, J. W. P. F., Glerum, J. J., & van der Maas, P. J. (1994). Nationwide study of decisions concerning the end of life in general practice in the Netherlands. *British Medical Journal*, 309(6963), 1209-1213.
- Pijnenborg, L., van der Maas, P. J., Kardaun, J. W. P. F., Glerum, J. J., van Delden, J. J. M., & Looman, C. W. N. (1995). Withdrawal or withholding of treatment at the end of life: results from a nationwide study. *Archives of Internal Medicine*, 155(3), 286-292.
- Pijnenborg, L., van der Maas, P. J., van Delden, J. J. M., & Looman, C. W. N. (1993). Life-terminating acts without explicit request of patient. *The Lancet*, 341, 1196-1199.
- Pochard, F., Azoulay, E., Chevret, S., Lemaire, F., Hubert, P., Canoui, P., Grassin, M., Zittoun, R., Le Gall, J. R., Dhainaut, J. F., & Schlemmer, B. (2001). Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision-making capacity. *Critical Care Medicine*, 29(10), 1893-1897.
- Portney, R. K. (1996). Letter to the Editor. *Journal of Palliative Care*, 13(2), 56.
- Potok, C. (1972). *My name is Asher Lev*. N.Y: Ballantine Books.
- Potter, J. (1997). Discourse analysis and constructionist approaches: theoretical background. In J. T. E. Richardson (Ed.), *Handbook of Qualitative Research Methods*. Leicester: British Psychological Society.
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London: Sage Publications.

- Printz, L. A. (1992). Terminal dehydration, a compassionate treatment. *Archives of Internal Medicine*, 152(April), 697-700.
- Publicity 'stopped' hospital taking legal action for boy. (2000, 16 August). *New Zealand Herald*, p. A3.
- Quill, T., Dresser, R., & Brock, D. W. (1997a). The rule of double effect: A critique of its role in end-of-life decision-making. *New England Journal of Medicine*, 337(24).
- Quill, T., Lo, B., & Brock, D. W. (1997b). Palliative options of last resort: A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA - The Journal of the American Medical Association*, 278(23), 2099-2105.
- Quill, T. E. (1993). Doctor, I want to die. will you help me? *JAMA - The Journal of the American Medical Association*, 270(7), 870-874.
- Quill, T. E. (2000). Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". *JAMA - Journal of the American Medical Association*, 284(17), 2502-2507.
- Quill, T. E., & Byock, I. R. (2000). Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. *Annals of Internal Medicine*, 132(5), 408-414.
- Quill, T. E., Lee, B. C., & Nunn, S. (2000). Palliative treatments of last resort: Choosing the least harmful alternative. *Annals of Internal Medicine*, 132, 488-493.
- Quirk, P. (1998). Euthanasia in the Commonwealth of Australia. *Issues in Law & Medicine*, 13(4), 425-446.
- R v Novis* (HC Hamilton, T42/87, 1988)
- R v Ruscoe* (8 CRNZ 68, 1992)
- R v Stead* (7 CRNZ 2 91, 1991)
- Rachels, J. (1975). Active and passive euthanasia. *New England Journal of Medicine*, 292, 78-80.
- Rachels, J. (1993). *The elements of moral philosophy*. (2nd ed.). New York: McGraw-Hill Inc.
- Rasmussen, P. A. (2000). Physician-assisted suicide and euthanasia. *New England Journal of Medicine*, 343(2).
- Rebagliato, M., Cuttini, M., Broggin, L., Berbig, I., de Vonderwied, U., Hansen, G., Kaminski, M., Kollee, L. A. A., Kucinkas, A., Lenoir, S., Levin, A., Persson, J., Reid, M., & Saracci, R. (2000). Neonatal end-of-life decision-making. *JAMA - Journal of the American Medical Association*, 284(19), 2451-2459.
- Regnard, C. (1999). *The desperate actions of compassionate doctors*. eBMJ [online]. Available: <http://www.bmj.com/cgi/eletters/318/7196/1431#EL9>.
- Reuters. (2001, March 21). *UK right-to-die woman renews death plea* [online]. Available: http://dailynews.yahoo.com/h/nm/20011128/hl/ukdie_1.html.
- 'Right to die' subject dies. (1998, 10 October). *Associated Press*, APWire: Domestic 1009.237.
- Rights of the Terminally Ill Act 1995, Northern Territory of Australia [online]. Available: <http://www.nt.gov.au/lant/parliament/committees/rotti/parldebate.shtml>. Darwin: Legislative Assembly
- Rights of the Terminally Ill Regulations 1996, Northern Territory of Australia [online]. Available: <http://www.nt.gov.au/lant/parliament/committees/rotti/parldebate.shtml>. Darwin: Legislative Assembly
- Roberts, D. (1998, November 24). Latimer gets life, vows to appeal. *The Globe and Mail*, Front page.
- Robertson, S. (1995). Making an advance directive. *British Medical Journal*, 310, 236-238.
- Ross, L. (1977). The intuitive psychologist and his shortcomings: Distortions in the attribution process. In L. Berkowitz (Ed.), *Advances in experimental social psychology* (Vol. 10). New York: Academic Press.
- Rousseau, P. (1996). Terminal sedation in the care of dying patients. *Archives of Internal Medicine*, 156, 1785-1786.

- Rousseau, P. (2000). The ethical validity and clinical experience of palliative sedation. *Mayo Clinic Proceedings, October 1*, 1064-1066.
- Roy, D. J. (1996). On the ethics of euthanasia discourse. *Journal of Palliative Care, 12*(4), 3-5.
- Roy Morgan Poll. (1992, May 25). Finding No. 2250. Auckland: Roy Morgan Research Centre.
- Ryan, C. J. (1996). Betting your life: an argument against certain advance directives. *Journal of Medical Ethics, 22*, 95-99.
- Sabini, J. (1995). *Social psychology*. (2nd ed.). New York: W. W. Norton & Company Inc.
- Sam, M., & Singer, P. A. (1993). Canadian outpatients and advance directives: poor knowledge, little experience but positive attitudes. *Canadian Medical Association Journal, 148*, 1497-1502.
- Sanson, A., Dickens, E., Melita, B., Nixon, M., Rowe, J., Tudor, A., & Tyrrell, M. (1998). Psychological perspectives on euthanasia and the terminally ill: An Australian Psychological Society discussion paper. *Australian Psychologist, 33*(1), 1-11.
- Saunders, C. (1994). The dying patient. In R. Gillon (Ed.), *Principles of health care ethics* (pp. 775-782). Chichester: John Wiley & Sons Ltd.
- Saunders, C. (2000). The evolution of palliative care. *Patient Education and Counseling, 41*, 7-13.
- Scher, S. J., & Cooper, J. (1989). Motivational basis of dissonance: The singular role of behavioral consequences. *Journal of Personality and Social Psychology, 56*, 899-906.
- Schiff, R., Rajkumar, C., & Bulpitt, C. (2000). Views of elderly people on living wills: interview study. *British Medical Journal, 320*, 1640-41.
- Schneiderman, I. J., Kaplan, R. M., Pearlman, R. A., & Teetzel, H. (1993). Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences? *Journal of Clinical Ethics, 1993*(4), 28-33.
- Schneiderman, L. J., Jecker, N. S., & Jonsen, A. R. (1990). Medical futility: Its meaning and ethical implications. *Annals of Internal Medicine, 112*(12), 949-954.
- Schneiderman, L. J., Kronick, R., Kaplan, R. M., Anderson, J. P., & Langer, R. D. (1992a). Effects of offering advance directives on medical treatments and costs. *Annals of Internal Medicine, 117*, 599-606.
- Schneiderman, L. J., Kronick, R., Kaplan, R. M., Anderson, J. P., & Langer, R. D. (1994). Attitudes of seriously ill patients toward treatment that involves high costs and burdens on others. *The Journal of Clinical Ethics, 5*(2), 109-112.
- Schneiderman, L. J., Pearlman, R. A., Kaplan, R. M., Anderson, J. P., & Rosenberg, E. M. (1992b). Relationship of general advance directive instructions to specific life-sustaining treatment preferences in patients with serious illness. *Archives of Internal Medicine, 152*, 2114-2122.
- Seale, C., & Addington-Hall, J. (1994). Euthanasia: why people want to die earlier. *Social Science and Medicine, 39*(5), 647-654.
- Seedhouse, D. (1998). *Ethics - The heart of health care*. New York: John Wiley & Sons Ltd.
- Seidlitz, L., Duberstein, P. R., Cox, C., & Conwell, Y. (1995). Attitudes of older people toward suicide and assisted suicide: An analysis of Gallup Poll findings. *Journal of the American Geriatrics Society, 43*, 993-998.
- Seymour, J. E. (2000). Negotiating natural death in intensive care. *Social Science & Medicine, 51*, 1241-1252.
- Shapiro, J. P. (1997). Euthanasia's home: what the Dutch experience can teach Americans about assisted suicide. *U.S. News and World Report, 122*(1), 24-28.
- Sheldon, T. (1993). Euthanasia law does not end debate in the Netherlands. *British Medical Journal, 307*(6918), 1511-1512.
- Sheldon, T. (1996). Dutch patients complain about poor access to euthanasia. *British Medical Journal, 313*, 961.
- Shetter, W.Z. (1997). *The Netherlands in perspective*. Utrecht: Nederlands Centrum Buitenlanders.
- Shortland v Northland Health Ltd* (M75/97, 1997)

- Siegel, S. (1956). *Nonparametric statistics for the behavioral sciences*. New York: McGraw-Hill.
- Siegler, M. (1985). The progression of medicine. From physician paternalism to patient autonomy to bureaucratic parsimony. *Archives of Internal Medicine*, 145(April), 713-715.
- Silveira, M. J., Di Piero, A., Gerrity, M. S., & Feudtner, C. (2000). Patients' knowledge of options at the end of life. *Journal of the American Medical Association*, 284(19), 2483-2488.
- Simcock, K. (1990). The helpless dying. *New Zealand Medical Journal*, 103, 541-542.
- Singer, E., Hans-Juergen, H., & Schwarz, N. (1992). Confidentiality assurances in surveys: reassurance or threat. *International Journal of Public Opinion Research*, 4, 256-268.
- Singer, E., Thurn, D. R. V., & Miller, E. R. (1995). Confidentiality assurances and response: a quantitative review of the experimental literature. *Public Opinion Quarterly*, 59(1), 65-77.
- Singer, P. (1990). *Animal Liberation*. (2nd ed.). New York: Random House.
- Singer, P. (1996). *Rethinking life and death: the collapse of our traditional ethics*. New York: St. Martin's Press.
- Singer, P. A. (1994a). Advance directives in palliative care. *Journal of Palliative Care*, 10(3), 111-116.
- Singer, P. A. (1994b). Disease-specific advance directives. *Lancet*, 344, 594-596.
- Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end of life care: Patients' perspectives. *JAMA - Journal of the American Medical Association*, 281(2), 163-168.
- Singer, P. A., Pellegrino, E. D., & Siegler, M. (2001). *Clinical ethics revisited [online]*. Available: <http://www.biomedcentral.com/1472-6939/2/1>.
- Singer, P. A., Thiel, E. C., Salit, I., Flanagan, W., & Naylor, C. D. (1997). The HIV-specific advance directive. *Journal General Internal Medicine*, 12, 729-735.
- Singh, B. K. (1979). Correlates of attitudes toward euthanasia. *Social Biology*, 26(3), 247-254.
- Skegg, P. D. G. (1994). Omissions to provide life-prolonging treatment. *Otago Law Review*, 8(2), 205-238.
- Skinner, B. F. (1974). *About Behaviorism*. London: Jonathon Cape Ltd.
- Slome, L. R., Mitchell, T. F., Charlebois, E., Benevedes, J. M., & Abrams, D. I. (1997). Physician-assisted suicide and patients with human immunodeficiency virus disease. *New England Journal of Medicine*, 336, 417-421.
- Smedira, N. G., Evans, B. H., Grais, L. S., Cohen, N. H., Lo, B., Cooke, M., Schechter, W. P., Fink, C., Epstein-Jaffe, E., May, C., & Luce, J. M. (1990). Withholding and withdrawal of life support from the critically ill. *New England Journal of Medicine*, 322, 309-315.
- Smith, C. (2001, March 6). Former Sonoma County woman ends life on her own terms as cancer spreads. *The Press Democrat*, Front Page.
- Smith, G. P. (1995). Restructuring the principle of medical futility. *Journal of Palliative Care*, 11(3), 9-16.
- Smith, J. L. (2000). Commentary: Why do doctors overestimate? *British Medical Journal*, 320, 472-473.
- Solomon, M. (2000). *Editorial: Why are advance directives a non-issue outside the United States [online]*. Available: <http://www2.edc.org/lastacts/archives/archivesJan99/editorial.asp>.
- Spanjer, M. (1995). Assisted suicide for mental distress. *The Lancet*, 345(8944), 246-248.
- Speck, P. (1998). Spiritual issues in palliative care. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (pp. 805-814). Oxford: Oxford University Press.
- Speden, G. (1995, October 17). Champion tried to take charge of his fate. *The Dominion*, p. 6.
- Spreeuwenberg, C. (1999). Euthanasia in perspective of palliative care: impossible or inevitable? *European Journal of General Practice*, 5, 132-133.
- SPSS Inc. (1998). *SPSS Base 8.0 User's Guide*. Chicago: SPSS.
- Staats, P. S. (1998). The pain-mortality link: Unraveling the mysteries. In R. Payne, R. B. Patt, & C. S. Hill (Eds.), *Assessment and treatment of cancer pain* (Vol. 12, pp. 145-158). Seattle: IASP Press.
- Stevens, C. A., & Hassan, R. (1994). Nurses and the management of death, dying and euthanasia. *Medicine & Law*, 13, 541-554.

- Storr, A. (1989). *Freud*. Oxford: Oxford University Press.
- Suarez-Alamazor, M. E., Belzile, M., & Bruera, E. (1997). Euthanasia and physician-assisted suicide: A comparative survey of physicians, terminally ill cancer patients and the general population. *Journal of Clinical Oncology*, *15*, 418-427.
- Sullivan, A. D., Hedberg, K., & Fleming, D. W. (2000). Legalized physician-assisted suicide in Oregon - The second year. *New England Journal of Medicine*, *342*(8), 598-604.
- Sullivan, M., Ormel, J., Kempen, G. I. J. M., & Tymstra, T. (1998). Beliefs concerning death, dying, and hastening death among older, functionally impaired Dutch adults: A one-year longitudinal study. *Journal of the American Geriatrics Society*, *46*(10), 1251-1257.
- Sullivan, M., Rapp, S., Fitzgibbon, D., & Chapman, C. R. (1997). Pain and the choice to hasten death in patients with painful metastatic cancer. *Journal of Palliative Care*, *13*(3), 18-28.
- Sullivan, R. (1993). Accepting death without artificial nutrition or hydration. *Journal of General Internal Medicine*, *8*(April), 220-224.
- Sulmasy, D. (1999). The rule of double effect. *Archives of Internal Medicine*, *159*, 545-549.
- Sulmasy, D. P., Linas, B. P., Gold, K. F., & Schulman, K. A. (1998). Physician resource use and willingness to participate in assisted suicide. *Archives of Internal Medicine*, *158*(9), 974-978.
- SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognosis and preferences for outcomes and risks of treatments (SUPPORT). *JAMA - Journal of the American Medical Association (JAMA)*, *274*, 1591-1598.
- Szasc, T. S., & Hollender, M. H. (1956). The basic models of the doctor-patient relationship. *Archives of Internal Medicine*, *97*, 585-592.
- Szlosarek, P. W. (2001). Recent advances in palliative care: Letter. *British Medical Journal*, *322*, 234.
- ten Have, H. A. M. J., & Welie, J. V. M. (1992). Euthanasia: Normal Medical Practice? *Hastings Center Report*, *22*(2), 34-38.
- ten Have, H. A. M. J., & Welie, J. V. M. (1996). Euthanasia in the Netherlands. *Critical Care Clinics*, *12*(1), 97-108.
- The assisted-suicide ban. (1999, 1 November). *Washington Post*, p. A26.
- The withdrawal of food and fluids in persistent vegetative state. (1994). A policy paper. New Zealand Medical Association.
- Thomas, D. R. (2000). *Qualitative data analysis: Using a general inductive approach* [online]. Health Research Methods Advisory Service. Available: www2.auckland.ac.nz/mch/hrmas/qualdatanalysis.htm.
- Auckland Area Health Board v Attorney-General* (M853/92, 1992, Thomas J)
- Thorns, A., & Sykes, N. (2000). Opioid use in last week of life and implications for end-of-life decision-making. *The Lancet*, *356*(9227), 398.
- Tilden, V. P., Tolle, S. W., Nelson, C. A., Fields, J., & Tilden, V. P. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research*, *50*(2), 105-115.
- Tindall, B., Forde, S., Carr, A., Barker, S., & Cooper, D. A. (1993). Attitudes to euthanasia and assisted suicide in a group of homosexual men with advanced HIV disease. *Journal of Acquired Immune Deficiency Syndrome*, *6*(9), 1069-1070.
- Tobin, R. (1993). The incompetent patient's right to die: time for legislation allowing advance directives? *NZ Recent Law Review*, 80-98.
- Treloar, A. J. (1999). Advance directives: limitations upon their applicability in elderly care. *International Journal of Geriatric Psychiatry*, *14*, 1039-1043.
- Triandis, H. C., Brislin, R., & Hui, C. H. (1988). Cross-cultural training across the individualism-collectivism divide. *International Journal of Intercultural Relations*, *12*, 269-289.
- Tulp Jr, D. R., Hoy, C. E., Kusch, G. L., & Cole, S. J. (1991). *Nonresponse under mandatory vs voluntary reporting in the 1989 survey of pollution abatement costs and expenditures*.

- Paper presented at the Proceedings of the Section on Survey Research Methods, Alexandria, VA.
- Tulsky, J. A., Fischer, G. S., Rose, M. R., & Arnold, R. M. (1998). Opening the black box: How do physicians communicate about advance directives? *Annals of Internal Medicine*, 129(6), 441-449.
- Twycross, R., & Lichter, I. (1998). The terminal phase. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (pp. 977-992). Oxford: Oxford University Press.
- Twycross, R. (1999). When doctors might kill their patients. *eBMJ*.
<http://www.bmj.com/cgi/eletters/318/7196/1431#EL9>
- Uhlmann, R. F., & Pearlman, R. A. (1991). Perceived quality of life and preferences for life-sustaining treatment in older adults. *Archives of Internal Medicine*, 151, 495-497.
- Uhlmann, R. F., Pearlman, R. A., & Cain, K. C. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology*, 43(5), M115-M121.
- Undoing Oregon's Law. (2001, 10 November). *Washington Post*, p. A26.
- Upper House of the States General, Netherlands. (2000). Review procedures of termination of life on request and assisted suicide and amendment to the Penal Code (Wetboek van Strafrecht) and the Burial and Cremation Act (Wet op de Iijkbezorging) (Termination of life on request and assisted suicide (Review Procedures) Act). (26 691, no 137, 2000-2001).
- Vachon, M. L. S. (1995). Staff stress in hospice/palliative care: a review. *Palliative Medicine*, 9, 91-122.
- Vachon, M. L. S. (1998). The stress of professional caregivers. In D. Doyle, G. W. C. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed, pp. 919-929). Oxford: Oxford University Press.
- van Deldon, J. J. M., Pijnenborg, L., & van der Maas, P. J. (1993). The Rummelink study: two years later. *The Hastings Centre Report*, 23(6), 24-27.
- van der Leij, L. (1998, 6 April). *Euthanasia row looms large in Dutch election*. Reuters [online]. Available:
http://www.reuters.com/home.jhtml;jsessionid=HNUS22OYJIGACRBAEZZSFYKKEA TIIWD?action=check&_requestid=787996
- van der Maas, P. J., Pijnenborg, L., & van Delden, J. J. M. (1995). Changes in Dutch opinions on active euthanasia: 1966 through 1991. *JAMA - Journal of the American Medical Association*, 273(18), 1411-1414.
- van der Maas, P. J., van Delden, J. J. M., & Pijnenborg, L. (1992). Euthanasia and other medical decisions concerning the end of life. [Special Issue]. *Health Policy*, 22/1+2.
- van der Maas, P. J., van Delden, J. J. M., Pijnenborg, L., & Looman, C. W. M. (1991). Euthanasia and other medical decisions concerning the end of life. *The Lancet*, 338(8768), 669-675.
- van der Maas, P. J., van der Wal, G., Haverkate, I., de Graaff, C. L. M., Kester, J. G. C., Onwuteaka-Philipsen, B. D., van der Heide, A., Bosma, J. M., & Willems, D. L. (1996). Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in The Netherlands, 1990-1995. *The New England Journal of Medicine*, 335(22), 1699-1705.
- van der Wal, G., & Onwuteaka-Philipsen, B. D. (1996). Cases of euthanasia and assisted suicide reported to the public prosecutor in North Holland over 10 years. *British Medical Journal*, 312, 612-613.
- van der Wal, G., van der Maas, P. J., Bosma, J. M., Onwuteaka-Philipsen, B. D., Willems, D. L., Haverkate, I., & Kostense, P. J. (1996). Evaluation of the notification procedure for physician-assisted death in the Netherlands. *The New England Journal of Medicine*, 335(22), 1706-1711.
- van Thiel, G. J. M. W., van Deldon, J. J. M., de Haan, K., & Huibers, A. K. (1997). Retrospective study of doctors' "end of life decisions" in caring for mentally handicapped people in institutions in the Netherlands. *British Medical Journal*, 315, 88-91.

- Waddell, C., Clarnette, R., Smith, M., & Oldham, L. (1997). Advance directives affecting medical choices. *Journal Palliative Care*, 13, 5-8.
- Waddell, C., Clarnette, R. M., Smith, M., Oldham, L., & Kellehear, A. (1996). Treatment decision-making at the end of life: a survey of Australian doctors' attitudes towards patients' wishes and euthanasia. *Medical Journal of Australia*, 165, 540-544.
- Wake, B. (2001, 17 May). Supporter urge leniency for Latimer. *Ottawa Citizen*, p. A7.
- Wall, T. (1999a, 30 April). Karnon: I'll take those last legs out when I'm ready. *New Zealand Herald*, p. A4.
- Wall, T. (1999b, 10 April). Suicide pact husband has suffered enough. *New Zealand Herald*, p. A3.
- Wan, C. (1999, 9 May). Mercy killing: Gauging support. *South China Morning Post*, p. 3.
- Wellman, R. J., & Sugarman, D. B. (1999). Elder and young adults' perceptions of the decision to withdraw from medical treatment: A replication and extension. *Journal of Social Behavior and Personality*, 14(2), 287-298.
- Wenger, N. S., Kanouse, D. E., Collins, R. L., Liu, H. H., Schuster, M. A., Gifford, A. L., Bozzette, S. A., & Shapiro, M. F. (2001). End-of-life discussions and preferences among persons with HIV. *JAMA - Journal of the American Medical Association*, 285(22), 2880-2887.
- Wetherell, M., Stiven, H., & Potter, J. (1987). Unequal egalitarianism: A preliminary study of discourses concerning gender and employment opportunities. *British Journal of Social Psychology*, 26, 59-71.
- White, M., & Callahan, D. (2000). Oregon's first year - the medicalization of control. *Psychology, Public Policy, & Law*, 6(2), 331-341.
- Whitney, S. N., Brown, B. W., Brody, H., Aloser, K. H., Bachman, J. G., & Greely, H. T. (2001). Views of United States physicians and members of the American Medical Association House of Delegates on physician-assisted suicide. *Journal of General Internal Medicine*, 16(5), 290-296.
- Wicklund, R. A., & Brehm, J. W. (1976). *Perspectives on cognitive dissonance*. New Jersey: Lawrence Erlbaum Associates.
- Williams, G. (1983) *Textbook on Criminal Law*. (2nd ed) London, Stevens
- Williams, L. (1999, 19 July). Patients' rights [Letter to the Editor]. *New Zealand Herald*, p. A12.
- Wilson, J. K., Fox, E., & Kamakahi, J. J. (1998). Who is fighting for the right to die? Older women's participation in the Hemlock Society. *Health Care for Women International*, 19(5), 365-380.
- Wilson, K. G., & Chochinov, H. M. (1996). Physician-assisted death. *New England Journal of Medicine*, 335(7), 518-519.
- Wilson, K. G., Scott, J. F., Graham, I. D., Kozak, J. F., Chater, S., Viola, R. A., de Faye, B. J., Weaver, L. A., & Curran, D. (2000). Attitudes of terminally ill patients towards euthanasia and physician-assisted suicide. *Archives of Internal Medicine*, 160(16), 2454-2460.
- Winkler, E. R. (1987). The morality of withholding food and fluid. *Journal of Palliative Care*, 3, 26-30.
- Winter, B., & Cohen, S. (1999). ABC of intensive care: Withdrawal of treatment. *British Medical Journal*, 319, 306-308.
- Wise, J. (2001). Netherlands first country to legalise euthanasia. *Bulletin of the World Health Organisation*, 79, 580.
- Wolfe, J., Fairclough, D. L., Clarridge, B. R., Daniels, E. R., & Emanuel, E. J. (1999). Stability of attitudes regarding physician-assisted suicide and euthanasia among oncology patients, physicians, and the general public. *Journal of Clinical Oncology*, 17(4), 1274-1279.
- Woolfrey, J., & Campbell, C. S. (1998). What happens now? Oregon and physician-assisted suicide. *The Hastings Center Report*, 28(3), 9-18.
- Worthen, L. T., & Yeatts, D. E. (2000). Assisted suicide: Factors affecting public attitudes. *Omega Journal of Death and Dying*, 42(2), 115-135.
- Yandall, P. (1999, 17 November). Battler urges disabled to fight. *New Zealand Herald*, p. H9.

- Young, A. (1997a, 21 October). Doctors vexed by death issue. *New Zealand Herald*, p. A3.
- Young, A. (1997b, 12 May). Life support hard issue for families. *New Zealand Herald*, p. A16.
- Zanna, M. P., & Cooper, J. (1974). Dissonance and the pill: An attribution approach to studying the arousal properties of dissonance. *Journal of Personality and Social Psychology*, 29, 703-709.
- Zenz, M. (1991). Morphine myths: sedation, tolerance, addiction. *Postgraduate Journal of Medicine*, 67(Supplement 5), S100-S102.
- Zerwekh, J. V. (1983). The dehydration question. *Nursing*, January, 47-49.
- Zylicz, Z., & Janssens, M. J. P. A. (1998). Options in palliative care: dealing with those who want to die. *Bailliere's Clinical Anaesthesiology*, 12(1), 121-131.

Table 9.3: Table showing summary statistics for Young and Older Laypersons and Doctors on justifiability and legality of actions as a function of age and consent of patient.

JUDGEMENT ON JUSTIFICATION OF END OF LIFE DECISION		YOUNG LAYPERSONS (N = 205)			OLDER LAYPERSONS (N = 595)			DOCTORS (N = 120)		
		% Y RESPONSE	SIGN	% Y RESPONSE	SIGN	% Y RESPONSE	SIGN	% Y RESPONSE	SIGN	
(1) Being adult/baby affecting judgement on justification withdrawing LS	AD	86	p = .405*	97	p = 664*	96	p = 664*	96	p = 219*	
	BB	83 (n = 200, $\chi^2 = .694$, df1)	NS	98 (n = 538, $\chi^2 = .188$, df1)	NS	99 (n = 117, $\chi^2 = 1.511$, df1)	NS	NS		
(2) Being adult/baby affecting judgement on justification withholding N&H	AD	40	n = .154*	81	p = 377*	81	p = 377*	81	p = .134*	
	BB	34 (n = 197, $\chi^2 = 2.028$, df1)	NS	83 (n = 511, $\chi^2 = .779$, df1)	NS	74 (n = 114, $\chi^2 = 2.246$, df1)	NS	NS		
(3) Being adult/baby affecting judgement on justification for increasing pain medication at the risk of hastened death, with consent	AD	88	p = .002*	98	p = 503*	96	p = 503*	96	p = 1.0*	
	BB	76 (n = 201, $\chi^2 = 9.878$, df1)		97 (n = 532, $\chi^2 = .448$, df1)	NS	94 (n = 117, $\chi^2 = .000$, df1)	NS	NS		
(4) Consent/No consent affecting judgement on justification of increasing pain medication at the risk of hastened death for adult	C	88		98		96		96		
	NC	8 (n = 202, $\chi^2 = 154.152$, df1)	p < .001*	59 (n = 541, $\chi^2 = 202.227$, df1)	p < .001*	36 (n = 117, $\chi^2 = 64.338$, df1)	p < .001*	p < .001*		
(5) Consent/No consent affecting judgement on justification of increasing pain medication at the risk of hastened death for child	C	75		97		94		94		
	NC	7 (n = 202, $\chi^2 = 130.340$, df1)	p < .001*	54 (n = 527, $\chi^2 = 228.004$, df1)	p < .001*	39 (n = 115, $\chi^2 = 62.016$, df1)	p < .001*	p < .001*		
(6) Decision (Withdrawing LS/withholding N&H) affecting judgement on justification of Action for baby	LS	83		98		99		99		
	N&H	34 (n = 201, $\chi^2 = 88.480$, df1)	p < .001*	83 (n = 532, $\chi^2 = 74.557$, df1)	p < .001*	74 (n = 115, $\chi^2 = 28.033$, df1)	p < .001*	p < .001*		
JUDGEMENT ON LEGALITY OF END OF LIFE DECISION		Y	Uns (%)	N (%)	SIGN	Y	Uns (%)	N (%)	SIGN	
(7) Being adult/baby affecting judgement on legality withdrawing LS	AD	48	40	12	p = 021**	58	31	11	p = 015**	
	BB	34	51	11	NS	46	45	9	NS	
(8) Being adult/baby affecting judgement on legality withholding N&H	AD	15	53	32	p = 01**	33	51	17	p = 058**	
	BB	13	68	19		30	56	14	NS	
(9) Being adult/baby affecting judgement on legality increasing medication (consent)	AD	42	50	7	p < .001*	50	40	9	p < .001*	
	BB	22	64	14		38	51	11	p < .001*	
(10) Consent/No consent affecting judgement on legality of increasing pain medication at the risk of hastened death for adult	C	43	49	7		49	41	9		
	NC	5	42	52	p < .001*	21	51	28	p < .001*	
(11) Consent/No consent affecting judgement on legality of increasing pain medication at the risk of hastened death for child	C	22	64	14		39	51	10		
	NC	4	47	50	p < .001*	14	56	30	p < .001*	

NB % may not equal 100 due to rounding. *p = .01 **p = .008 Key: AD = Adult, BB = Baby, C = Consent, NC = No Consent, LS = Life Support, N&H = Nutrition and Hydration

Table 7.3: Table showing summary statistics for Young and Older Laypersons and Doctors on level of tolerance and judgements on legality for physician-assisted death and terminal sedation. (NB % may not equal 100 due to rounding. Key: * $p = .01$ ** $p = .006$)

JUDGEMENT ON JUSTIFICATION OF HASTENING DEATH DECISION	YOUNG LAYPERSONS (N = 205)		OLDER LAYPERSONS (N = 595)		DOCTORS (N = 120)		EURO-PAK (EP)/OTHER ETHNIC (OE) YOUNG LP		18-35/70-80 YEARS AGE COMPARISON	
	% Y RESPONSE	Y Uns N (%)	% Y RESPONSE	Y Uns N (%)	% Y RESPONSE	Y Uns N (%)	% Y RESPONSE (EP) (n = 137)	% Y RESPONSE (OE) (n = 68)	% Y RESPONSE (18/35) (n = 151)	% Y RESPONSE (70/80) (n = 255)
(1) Doctor supplying information on how to hasten death to a terminally ill patient, on request	65	(n = 203, $\chi^2 = 12$, $p < .001^*$, df 1)	80	(n = 559, $\chi^2 = 9.818$, $p = < .002^*$, df 1)	50	(n = 113, $\chi^2 = 10.827$, $p < .001^*$, df 1)	71	51	72	83
	56	(n = 201, $\chi^2 = .031$, $p = .003^{**}$, df 1)	77	(n = 557, $\chi^2 = .078$, $p = .790$, ** df 1) NS	41	(n = 113, $\chi^2 = 3.405$, $p = .065^{**}$, df 1) NS	63	41	64	81
	64	(n = 201, $\chi^2 = .45$, $p = .503^{**}$, df 1) NS	77	(n = 561, $\chi^2 = 1.065$, $p = .302^{**}$, df 1) NS	34	(n = 112, $\chi^2 = 1.510$, $p = .219^*$, df 1) NS	68	56	69	83
	62	(n = 199, $\chi^2 = 4.516$, $p = .034^{**}$, df 1)	76	(n = 527, $\chi^2 = 101.731$, $p < .001^{**}$, df 1)	30	(n = 115, $\chi^2 = 72.014$, $p < .001^{**}$, df 1)	70	47	70	83
	71		97		96					
(2) Doctor supplying drugs to hasten death to a terminally ill patient, on request										
(3) Doctor assisting a terminally ill patient to take drugs to hasten death, on request										
(4) Doctor administering a lethal injection to a terminally ill patient, on request										
(5) Terminally sedating a dying patient and stopping all nutrition and hydration, until death										
JUDGEMENT ON LEGALITY OF HASTENING DEATH DECISION	Y Uns N (%)		Y Uns N (%)		Y Uns N (%)		Y Uns N (%)		Y Uns N (%)	
	11	40 50 (n = 204, $z = -5.115$, $p < .001^*$ df 1)	9	43 48 (n = 568, $z = 4.846$, $p < .001^*$, df 1)	18	26 56 (n = 117, $z = 4.032$, $p < .001^*$, df 1)	11	35 54 (n = 136, $z = 4.719$, $p < .001^*$, df 1)	10	50 40 (n = 68, $z = 1.886$, $p = .059^*$, df 1) NS
	2	36 62 (n = 204, $z = -.469$, $p = .639^*$ df 1)	4	41 55 (n = 566, $z = -1.81$, $p = .856^*$, df 4) NS	4	25 71 (n = 118, $z = -4.003$, $p < .001^*$, df 1)	1	28 71 (n = 136, $z = -1.213$, $p = .225^*$ df 1)	3	53 44 (n = 68, $z = -1.633$, $p = .102^*$ df 1) NS
	4	33 63 (n = 205, $z = 1.414$, $p = .157^*$ df 1) NS	4	38 57 (n = 568, $z = -4.287$, $p < .001^*$, df 1)	0	12 88 (n = 118, $z = -2.646$, $p = .008^*$ df 1)	2	23 75 (n = 137, $z = -.905$, $p = .366^*$ df 1)	9	53 38 (n = 68, $z = 1.091$, $p = .275^*$ df 1)
	2	32 65 (n = 203, $z = -9.944$, $p < .001^*$ df 1)	3	33 64 (n = 534, $z = -17.318$, $p < .001^*$ df 1)	0	6 94 (n = 117, $z = -10.233$, $p < .001^*$ df 1)	1	21 77 (n = 137, $z = -9.237$, $p < .001^*$ df 1)	4	54 41 (n = 68, $z = -3.683$, $p < .001^*$ df 1)
	26	66 8 (n = 203, $z = -9.944$, $p < .001^*$ df 1)	47	44 9 (n = 534, $z = -17.318$, $p < .001^*$ df 1)	81	15 4 (n = 117, $z = -10.233$, $p < .001^*$ df 1)	33	62 5 (n = 137, $z = -9.237$, $p < .001^*$ df 1)	12	72 15 (n = 68, $z = -3.683$, $p < .001^*$ df 1)

Table 8.2: Table showing summary statistics for Young and Older Laypersons and Doctors on judgements on justifiability and legality of actions with and without a living will.

JUDGEMENT ON JUSTIFICATION OF END OF LIFE DECISION	YOUNG LAYPERSONS (N = 205)		OLDER LAYPERSONS (N = 595)		DOCTORS (N = 120)	
	% Y RESPONSE	SIGN	% Y RESPONSE	SIGN	% Y RESPONSE	SIGN
(1) Judgement on justification of withdrawing life support with/without a living will	LW	$p = 1.0^*$	97	$p = .824$	97	$p = 1.0^*$
	NLW	NS	97 (n = 570, $\chi^2 = .049, df1$)	*NS	96 (n = 118, $\chi^2 = 4.34E-14, df1$)	NS
(2) Judgement on justification of withdrawing N&H with/without a living will	LW	$p < .001^{**}$	95	$p = .006^{**}$	89	$p = .125^{**}$
	NLW	$p < .001^{**}$	63 (n = 202, $\chi^2 = 14.7, df1$)	NS	85 (n = 115, $\chi^2 = 2.354, df1$)	NS
(3) Judgement on justification of withholding N&H with/without a living will	LW	$p < .001^*$	89	$p < .001^*$	89	$p = .004^*$
	NLW	$p < .001^{**}$	40 (n = 200, $\chi^2 = 19.149, df1$)	$p < .001^{**}$	81 (n = 116, $\chi^2 = 8.284, df1$)	$p = .001^{**}$
(4) Judgement on justification of withdrawing LS or withholding N&H (NLW)	LS	$p < .001^{**}$	97	$p = .001^{**}$	97	$p = .001^{**}$
	N&H	$p < .001^{**}$	64 (n = 200, $\chi^2 = 28.891, df1$)	$p = .001^{**}$	84 (n = 116, $\chi^2 = 10.827, df1$)	$p = .001^{**}$
(5) Judgement on justification of withdrawing N&H or withholding N&H (NLW)	W/d	$p < .001^{**}$	93	$p < .001^{**}$	84	$p = .388^{**}$
	W/h	$p < .001^{**}$	40 (n = 198, $\chi^2 = 30.730, df1$)	$p < .001^{**}$	81 (n = 116, $\chi^2 = .745, df1$)	NS
JUDGEMENT ON LEGALITY OF END OF LIFE DECISION	Y	SIGN	Y	SIGN	Y	SIGN
(6) Living Will/No Living Will affecting judgement on legality of withdrawing life support	Uns (%)		Uns (%)		Uns (%)	
	No (%)		No (%)		No (%)	
(7) Living Will/No Living Will affecting judgement on legality of withdrawing N&H	38	$p = .159^*$	43	$p < .001^*$	79	$p = .009^*$
	52 (n = 204, NS)	NS	15 (n = 574, NS)	$p < .001^*$	14 (n = 118, NS)	$p = .009^*$
(8) Living Will/No Living Will affecting judgement on legality of withholding N&H	47	$p = .901^{**}$	56	$p = .028^{*NS}$	86	$p = .549^{**}$
	41 (n = 203, NS)	NS	32 (n = 539, NS)	$p = .622^*$	12 (n = 118, NS)	$p = .549^{**}$
(9) Judgement on legality of withdrawing LS and withdrawing N&H (NLW)	21	$p = .001^{**}$	37	$p < .001^{**}$	65	$p < .001^{**}$
	57 (n = 203, NS)	NS	46 (n = 542, NS)	$p < .001^{**}$	21 (n = 118, NS)	$p < .001^{**}$
(10) Judgement on legality of withdrawing N&H and withholding N&H (NLW)	16	$p = .001^{**}$	29	$p = .001^{**}$	61	$p = .178^{**}$
	60 (n = 203, NS)	NS	53 (n = 554, NS)	$p < .001^{**}$	21 (n = 118, NS)	$p = .178^{**}$

NB % may not equal 100 due to rounding.

* $p = .008$ ** $p = .005$

Key: LW = Living Will, NLW = No Living Will, LS = Life Support, N&H = Nutrition and Hydration, W/d = withdraw, W/h = withhold