What if I don't want to live until the bitter end?

Safeguarding the practice of Assisted Dying in the context of dementia

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Psychology, The University of Auckland, 2021.

ABSTRACT

Alongside increasing rates of dementia diagnoses worldwide, efforts to seek alternative end-of-life options are also increasing. While the ethical and legal dimensions surrounding the option of assisted dying (AD) remain controversial and deeply polarising, discussion around such provision for dementia raises even more controversy. Individuals with dementia can seek to extend their rights for autonomy and self-determination, to protect their preferences in a perceived incompetent future, through an advance directive. However, some clinicians and other commentators have found advance euthanasia directives (AEDs) to be unfeasible in practice. It is of interest and concern whether AEDs can be appropriately safeguarded to protect individuals' preferences when they may no longer possess decision-making capacity.

My research objective, therefore, is to explore whether a safeguard could be proposed which would provide guidance for individuals with dementia should they consider AD and for health professionals involved in their medical treatment/care. An in-depth literature review was conducted to explore the ethical validity and feasibility of such and how they may influence the practice of, and attitudes towards, AD in dementia.

Three empirical studies were undertaken: 1) Using the Delphi methodology, the perspectives of experts were sought to explore primary issues in this context as well as exploring a conceptual framework to safeguard practice and application; 2) the everyday challenges, experiences, and views of the public participating in online communities were explored through a Netnographic lens; and, 3) the synthesised findings of the Delphi and Netnography studies were put to the test by collecting data from an informed group.

Together, the conceptual and the empirical studies undertaken contribute to the research by: 1) illuminating the status quo of individuals whose personal/professional lives are affected by dementia and the current legislative provision, and their attitudes regarding such provision for dementia; 2) advancing our knowledge of some of the primary practical, moral, and legal challenges; and inconsistencies within current legislative provisions concerning AD and dementia; 3) addressing the potential impacts of permitting or prohibiting AEDs for individuals with dementia and their families/caregivers and healthcare providers; and, 4) proposing a number of potential safeguards to ensure its safe application.

DEDICATION

“There are only two days in our lives that are guaranteed shorter than 24hrs. If only we could ensure their dignity is guaranteed too” (Participant).

To the voiceless individuals with dementia and their loved ones and to the individuals who have fought and are still fighting to give them voices.

In memory of

Alireza Mojarad

My beloved cousin who lost his battle to blood cancer at the age of twenty-two.

ACKNOWLEDGMENTS

First and foremost, my deepest gratitude goes to the experts who generously contributed their time and invaluable thoughts and experience to this research. I would also like to acknowledge and thank the members of End-of-Life Choice Society who took part in my research and the EOLC committee members who took a chance on me and this research. A great part of this research has been built on hundreds of stories of people with dementia who are battling with their illness and suffering with much bravery and their families and caregivers who never give up on caring for their loved ones and patients. You have my admiration as well as my thanks.

I feel immeasurably indebted, grateful, and privileged to have been supervised by Dr Phillipa J Malpas. Phillipa, I truly appreciate all your contributions of time, thought-provoking comments, and support throughout the whole process to make my PhD experience productive. Your commitment and dedication to me and my work were beyond my expectation. You always read my work from a critical standpoint and provided excellent feedback on how to enhance the quality of my work and become a better researcher. I am also very grateful to my secondary supervisor, Professor Glynn R Owens, for guiding me on my journey especially at the very beginning. Glynn, thank you for supporting me and pointing me in the direction of ‘assisted dying’, and for bringing your always brilliant perspective into my research. With the help of you both, not only I have learned a great deal as a researcher, but I have also grown as a human being. Attending conferences is a part of an academic career, and without the support of my supervisors, I would not have been able to attend conferences in New Zealand, Canada, and Belgium and also present my work in the Leiden University in the Netherland. During these events, I met so many legends in my area of work and received valuable feedback and support.

My very special thanks go to my loving husband and friend. Farzan, I cannot begin express to you how much I appreciate your unwavering motivational support and love. You have always been understanding and encouraging no matter what. Thank you for all the ongoing discussions and criticism of my research to help me be a better thinker (hope that was the reason though!). You helped me meet all the challenges of conducting my research and thesis writing, generously offering your guidance and support even at times that you were most needed time and help for your PhD project. You are my true inspiration. I thank many other friends inside and outside the University of Auckland who have supported

and encouraged me and provided me advice. Mina Amir, thank you for being my number one friend to go to when things got emotionally tough during my PhD journey. You made being away from my loved ones much more tolerable and enjoyable. You were always there when I needed a time out from all the PhD dramas. Thank you for all your help and friendship. Thank you, Hamidreza Shahbaznejad for graciously offering your help and advice particularly on the methodology parts of my research and constantly reminding me and Farzan to have fun. I am so grateful to my dearest friends in the school of psychology. Nili Chowdhury, Maree Martinussen, Maria João Faustino, Maddy Manchi, Ashleigh Baker, Ties Coomber, and Emily Cross, thank you for all your input, though-provoking discussion, advice, support, energy, and friendship. Thank you for being interested and checking in, for all the good times and laughs, lunches in the student quad, chit chats in corridors, celebration drinks and so many other things that have sustained me. Thank you for simply being there for me and sharing this process with me. If I knew what I was missing, I would have moved to the city campus much earlier. Being a newbie in New Zealand and one of the two PhD students in psychology in the Tamaki campus, you Lucy Birrell, made life less scary by showing me how things work here in NZ and more importantly in academic life. I was so lucky to share the office with you Lucy and more importantly becoming your friend. I am also very grateful to Odette Groom, Kamalini Gnaniah, and Sue O’Shea for all the assistance they have provided in the School of Psychology. I also acknowledge the help of Nina Seja for proofreading my thesis.

And above all thanks to my Mum for reminding me constantly to be kind to myself and everyone else and do things that are best for everyone, and my Dad for believing in me. I am a better person because of you both. And finally, I am grateful to my beloved parents-in-law for their support and love along the way.

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Chapter Three: Conceptual framework for assisted dying for individuals with dementia: Views of experts not opposed in principle

Dehkhoda, A., Owens, R. G., & Malpas, P. J. (2020). Conceptual framework for assisted dying for individuals with dementia: Views of experts not opposed in principle. Dementia, https://doi.org/10.1177/1471301220922766

Nature of contribution by PhD candidate	Research planning and design, data collection, coding, analysis, manuscript preparation and submission.
Extent of contribution by PhD candidate (%)	80%

CO-AUTHORS

Name	**Nature of Contribution**
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Glynn Owens	Supervision of research, contribution to research planning and design, detailed feedback on manuscript drafts, advice regarding submission.

Certification by Co-Authors

The undersigned hereby certify that:

- the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and
- that the candidate wrote all or the majority of the text.

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Last updated: 28 November 2017

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Chapter Four: Views on asisted aying for individuals with dementia: A Netnographic approach

Dehkhoda, A., Owens, R. G., & Malpas, P. J. (2020a). A Netnographic Approach: Views on Assisted Dying for Individuals With Dementia. Qualitative Health Research, 30(13), 2077-2091.

Nature of contribution by PhD candidate	Research planning and design, data collection, coding, analysis, manuscript preparation and submission.
Extent of contribution by PhD candidate (%)	90%

CO-AUTHORS

Name	**Nature of Contribution**
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Chapter One

Chapter 1 – Introduction

PART I: Introducing the research and the researcher standpoint

We all die. What many of us hope for is a death that represents who we truly are and how we have lived our life; a death that sets free our soul and body in a most respectful way; and a death without unnecessary suffering. Many of us hope for a meaningful death that gives us a chance to conclude life's final chapter with respect and dignity. In parts of the world that recognise and embrace humans' rights, respect for autonomy, independence, and freedom of choice, this wish for a meaningful death is neither seemingly too much to ask for nor hard to grant.

The way that we die has changed over the years. Advances in modern medicine and technology have led to interventions that can improve life expectancy and expand the available options to sustain the lives of terminally ill patients. These advances have led to an increased medicalisation of death over the past century such that many healthcare institutions adopt strategies to provide extensive and high-quality end-of-life care (Teno et al., 2004). As modern medical practice has come to recognise personal end-of-life decision-making and the preferences of individuals, it is becoming apparent that the end-of-life healthcare strategies also have some challenges: health professionals can prolong life beyond an individual's ability to be involved in end-of-life decisions, or even sometimes beyond their desire to be kept alive. Although end-of-life care has developed significantly over the past several decades in many countries around the world, not all individuals have the opportunity to leave their life peacefully, and on their own terms. Some experience a gradual and painful dying and endure suffering until the very end. Some individuals have experienced a loved one requesting that life-sustaining treatment be withdrawn, or that eating and drinking be withheld to ensure death sooner rather than later. How many individuals have chosen options to hasten their death in the absence of alternatives that may better reflect what they want for themselves? How many individuals know a family member or friend who has been left traumatised watching a loved one through a long difficult dying? Although some individuals may view suffering at the end of life as a way to connect closer to their God, or for others to learn valuable lessons during the dying process, for many individuals, suffering at the end of life may need to be actively mitigated to preserve their psychological wellbeing.

We live in a time that regardless of differences in nations' ideologies, cultures and morals, many societies are moving towards a liberal culture that recognises their citizens' personal rights, autonomy and freedom of choice as long as they do not harm others. In some societies, an individual's right to choose how to live their life may also extend to choosing the manner and timing of their death. For instance, in November this year, New Zealanders overwhelmingly voted to allow legal assisted dying (AD) under certain eligibility criteria. What this means is that some terminally ill New Zealanders with less than six months left of life will have the option to request an assisted death.

1.1 How I came to this research

Having researched in the field of death and dying and worked with individuals suffering from incurable illnesses (primarily cancer) who were at the end stage of their life and watching their end-of-life experiences and challenges, I believed that it was crucial to accumulate my knowledge and experience in this field to understand the dying experiences of terminally ill patients and continue contributing to their end-of-life wellbeing. When I was intending to begin my PhD journey in this area, I came to know about people suffering from dementia through one of my supervisors, Professor Glynn Owens. I remember him coming back from a friend's funeral who had dementia. He was talking about his friend, of how brilliant and hardworking he was, who couldn't even recognise himself at the end of his life. Hearing his story and so many others like him, I kept wondering: what if I develop dementia? What would I do if there comes a time that I can't have a say about my life? How would I feel about someone else making decisions for me and my life? I think I would not want to live in a state of incompetency, not knowing myself and my loved ones and not being able to express my feelings and preferences. Or maybe I will! Although I still do not know whether I would want to live beyond my loss of mental and physical capacity, I know for sure that I fear dementia dreadfully, along with so many others around the world. Dementia is a complex disease and the number of people who are diagnosed with this disease is rising rapidly. Knowing that the issue of dementia and its related end-of-life decisions will become more and more relevant to the public and professional discussion, I chose to turn my focus to this end-of-life area, and as I was expanding my knowledge about this particular group of individuals, my interest in contributing to the community of people with dementia and their families through acknowledging the way they wished their lives to end began to grow.

I believe this unique group of individuals needs to take centre stage in the context of end-of-life care; there is an urgency to seek new ways to understand the psychological, existential, physical, and economic effects of dementia, both for individuals with dementia diagnosis and their community. There is also a need to explore and adopt optimal models of care tailored to their specific needs to enhance their end-of-life experiences irrespective of their end-of-life choices. One significant initiative would be the establishment of standards for best practice in the context of assisted dying and dementia that validates and prioritises individuals' values and preferences. Furthermore, a framework that encompasses procedural guidelines may be helpful to educate individuals with dementia and their families/caregivers, and health professional (HPs) provide standards for best practice to promote end-of-life care.

1.2 Research focus, contributions, and methodological approach

My investigation on the provision of assisted dying as one end-of-life options for people with dementia takes place at a particular moment in the history of assisted dying. Twenty years have passed since the Netherlands became the first country to legalise assisted dying after long societal debate on the matter (Jox, Horn, & Huxtable, 2013). Since then, several countries have succeeded in following the Dutch in legally providing access to assisted dying. This has brought about considerable political and societal change over the years. Arguments have been made that the legislation of assisted dying should be inclusive not only of competent individuals. In this respect, the Netherlands has the longest history of debate about assisted dying for incompetent patients with dementia. During the 1980s, with the transition of baby boomers into old age, related illnesses and associated comorbidities gradually dominated societal debates within assisted dying. As a result, the discussion shifted toward recognizing dementia as one of the most prevalent diseases among aging populations and growing acceptability of an assisted death for incompetent patients (Hertogh, de Boer, Dröes, & Eefsting, 2007a). This in turn, led to the Dutch law-based possibility of assisted dying for this targeted group of people by the means of Advance Euthanasia Directives (AEDs). The integration of law and dementia disease into the practice of assisted dying hasn't, however, been seamless despite the efforts on modifying the eligibility and assessment criteria to accommodate features of dementia (Mangino, Nicolini, De Vries, & Kim, 2020b).

Studies and case reports consistently report a number of complex ethical, legal, political, social, and clinical challenges within the context of assisted dying for individuals with dementia. At the heart of this issue, is whether it is ever ethically permissible to grant an individual with dementia an assisted death on the basis of an appropriate advance directive that instructs for such an option and whether any such directive has legal standing. At some point, the disease's progression will ensure that individuals with dementia are no longer able to determine their preferences or assent to their pre-expressed preference in their directive.

The practice of assisted dying is an inherently relational act that involves a HP and the relationship between them and the patient. Given dementia’s trajectory and the absence of patients’ voice in later stages of the disease, this relational view of autonomy and its implications on the patient’s network is particularly relevant as it implies the involvement of their representative and HPs who are responsible to advocate, interpret the instruction and perform an assisted death request accordingly. This interpretation requires some level of personal and/or professional judgment of the patient’s condition, which may at times appear in conflict with their pre-expressed wishes. This further calls into question whose judgment is valued more in these conflicting situations: the patient who may judge her future not worth living even if she became ‘happily demented’, or the HPs who may determine the patient’s best interest is in continuing living? Therefore, unless the involvement of HPs and other stakeholders are taken into account, there is a chance that the wishes of the patient may not be respected.

Conversely, an AED of a patient with dementia may represent a wish that is based on an unrealistic anticipation of future suffering. Where a patient appears happy and content, it may raise uncertainty as to whether the patient’s wishes remain the same. Following an assisted death wish of such a patient may result in harm to their current wellbeing. Having considered these various scenarios where both rejecting and following an AED may put incompetent individuals at harm, perhaps the question for me, was not “should assisted dying be legalised for individuals with dementia?” but “how should we legalise assisted dying for this particular group of people to ensure it is safe and practical?”

1.2.1 Research scope and objectives

The study of assisted dying for individuals with dementia has been primarily focused on either empirically investigating the perspectives and experiences of HPs’, families/caregivers, and the public on the matter and the complexities/challenges they experienced in healthcare settings, or on exploring its challenging moral and ethical underpinnings. Through these studies, it has been argued that AEDs as a particular tool for exercising an individual’s right to choose the moment and means of death has some limitations. These limitations are multi-layered with legal, ethical, and clinical aspects. There is a chasm between the expectations of patients, their families, and the public (non-specialists), regarding what AEDs can ideally do beyond the loss of competency and what specialists think they can actually do. This chasm along with the existing limitations has implications for the application of these directives in practice and should be further clarified as it provokes feelings of vulnerability on both sides. Despite the growth of dementia-specific research in the context of assisted dying and AEDs, research on frameworks/safeguards surrounding AEDs and their implementation in practice is yet to receive much attention in the literature.

In my research I wish to investigate some of these issues, highlighting some of the problems and exploring possible solutions. The primary focus of this research is to explore safeguarding the practice of assisted dying for individuals with dementia. A safeguard in this thesis means measures taken to protect against error and abuse and prevent harm. A robust safeguard in the practice of assisted dying would provide procedural guidance ensuring that the end-of-life wishes of an eligible individual are protected while ensuring that vulnerable individuals do not access assisted dying inappropriately. A robust safeguard must be developed having considered the potential risks and benefits of such practice to all stakeholders. It should also include specific guidelines for cases with specific situations.

I use a combination of primary and secondary studies which are all in a sense complementary. Reviewing the literature, I aim to arrive at a theoretical understanding of AEDs reflecting on their feasibility and role in the end-of-life care of a patient with dementia. To identify the gaps in this context, a variety of relevant topics are discussed including the status quo of AEDs with regards to patient with advanced dementia; legal, ethical, and practical aspects of low access to AEDs, and the role of fundamental ethical and philosophical theories around personhood, best interests, autonomy etc. in the views of all stakeholders and thereupon in maintaining the status quo. Within the scope of this research, I investigate the extent to which prior research have attempted to propose a solution and therefore to what extend my research as a whole would add to this body of knowledge. To add to this already existing information, I conducted three empirical studies. The first study explores the views of experts from a variety of disciplines relevant to dementia and assisted dying. The objective is to investigate the primary issues of, and concerns about, assisted dying for individuals with dementia as well as exploring a tentative conceptual framework to safeguard practice and application. My analyses are guided by the question whether it is possible to establish consensus views of experts on the challenges and possible ways forward.

Embedded within the online communication pertaining to assisted dying for individuals with dementia, the second study focuses on gaining an understanding of how this practice is conceptualized and understood by the public exploring their shared experiences, challenges, and their perspectives on this issue. My analyses are guided by the question, ‘how does the public’s experience (including formal and informal caregivers and some individuals with dementia) with dementia contribute to their views on assisted dying?

After completing these two studies, I had some ideas as to what the issues were and how to move forward. The logical next step was to assess whether the complex issues arising could be summarised enough to be comprehensible in survey form, and to get an idea about how many people would see these as worth pursuing? With two distinct yet complementary studies in my PhD, there wouldn’t have been time or resources to conduct the kind of large-scale survey that would ideally be desirable, but I had an opportunity to assess the feasibility of such a study and to gather some preliminary data. Therefore, intending to extend my understanding about the findings as well as areas of conflicts that need more investigation, the third study explores the views of an informed group of individuals with a stated position on assisted dying on the synthetised findings of the first two qualitative studies.

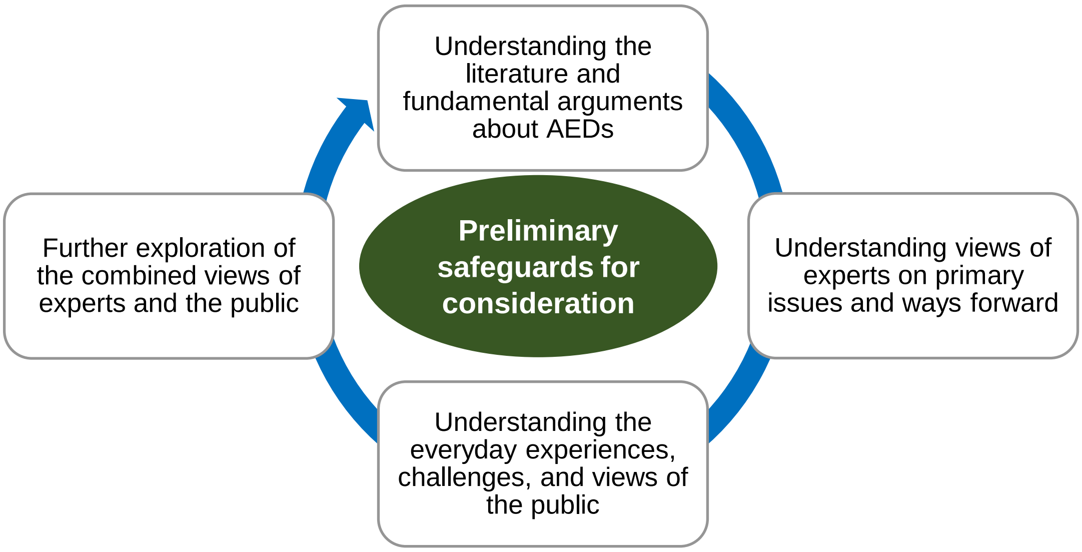
My research objectives were therefore threefold:

1. I wanted to explore whether experts see it is possible to devise safeguards that would provide access for assisted dying for individuals with dementia. If so, what form would they expect these safeguards to take? And based on their professional, clinical, and scholarly point of views, what challenges and issues need to be considered along the way?
2. I also intended to provide a more ‘grassroots’ view of the challenges and experiences regarding assisted dying in the context of dementia by including the views of the public whose personal, professional, and/or social lives are intertwined with dementia.
3. And lastly, I was inclined to explore what can we learn about the topic from an analysis of the combined views of experts and public on the matter and what this may mean for safeguarding the practice and its application?

In a nutshell, I explored theoretical perspectives as well as the lived and professional experiences and views of different stakeholders, seeking out an interpretive understanding of assisted dying for patients with dementia. Figure 1.1 shows in pictorial form the flow of the research.

I want to stress that in this thesis I do not pretend to solve all the ethical and practical issues at stake, nor do I intend to claim that my proposed safeguards are definitive. Rather, I aim to open the perspective to a more welcoming or open-minded approach to the possibility of safeguarding the practice of AD that respectfully deal with the end-of-life wish of a person with dementia.

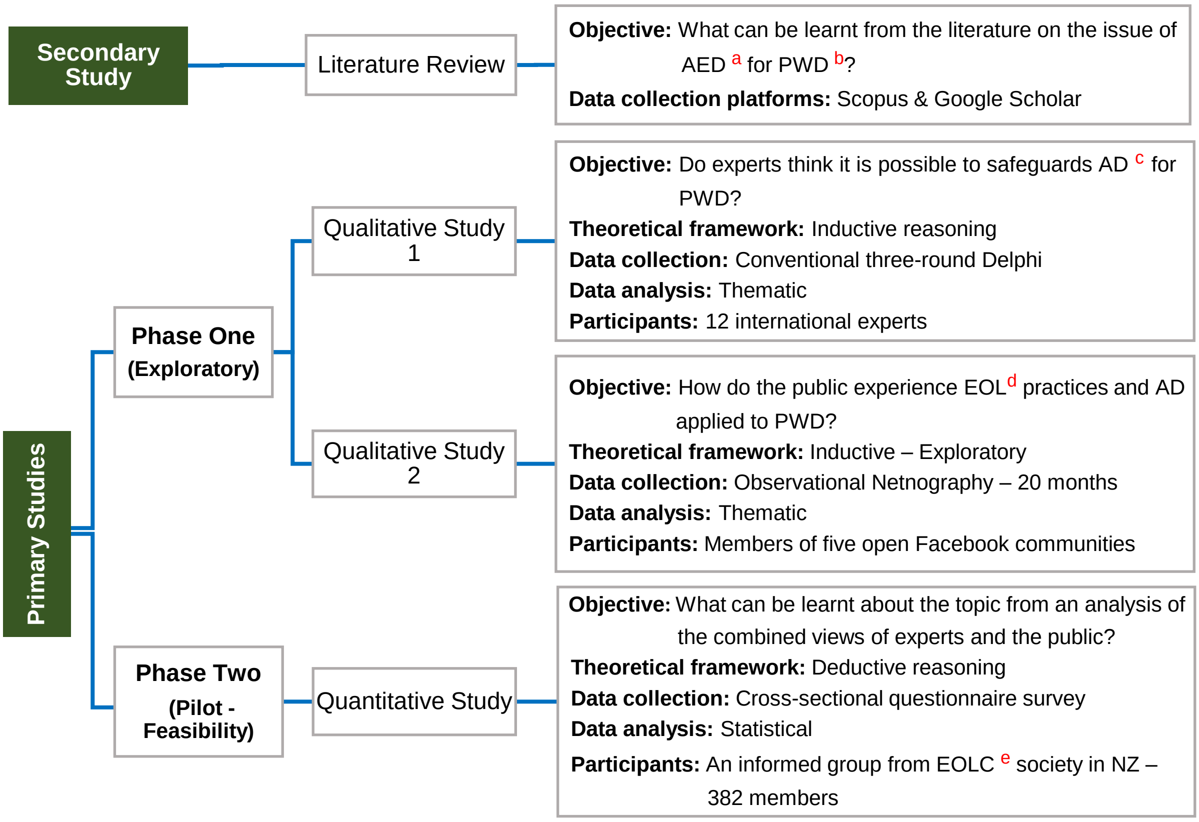
Figure 1.1 | Conceptual framework of the research flow



1.2.2 Research methodological approach

I designed a two-phase empirical research project consisting of two qualitative exploratory (Myers, 2013) and one quantitative pilot research to assess the feasibility and acceptability of the phase one's target outcomes (Duan, 2013). Figure 1.2 summarizes the methodological characteristics of the different phases of the study, with a summary of who was involved and how the data was gathered and analysed.

Figure 1.2 | Research layout, objectives, and methodological approach



[a] Advance Euthanasia Directives
[b] Patients with Dementia
[c] Assisted Dying
[d] End-of-Life
[e] End-of-Life Choice

Qualitative study 1: To explore the experts' view, a conventional three-round Delphi study was employed, and the results were analysed using a semantic–thematic approach. The sample of twelve international experts was drawn from experts working in both clinical practice and academia. These included dementia care, palliative care/medicine, gerontology and geriatric medicine, psychology, psychiatry, spiritual counselling, neuropsychology, epidemiology, ageing and mortality, ethics of care/health, health/end-of-life law, advance care planning, and end-of-life care/decision-making. Data collection took place between February and October 2017.

Qualitative study 2: A study on the public's views of five open Facebook communities was employed using an observational Netnography method for data gathering and thematic analysis for data analysis. The Facebook online communities focused on discussions around assisted dying, including topics relevant to assisted dying in the context of dementia. To conduct an in-depth analysis of online participants' different voices on the topic, the secondary data from online textual comments were observed and collected daily over 20 months from August 2016 to March 2018.

Quantitative study: A pilot feasibility study explored the synthesised findings of the two previous studies in phase one using a questionnaire. To provide a more nuanced understanding of assisted dying and dementia, an informed group of individuals rated their level of dis/agreements in the questionnaire between March and May 2019.

This methodological approach of triangulating three studies along with a literature review allowed me to contextualise my area of study in a more comprehensive way and advance our understanding of the status quo and how it is reinforced and maintained through current societal, practical, ethical and legal policies.

1.2.3 Thesis layout

This is a "thesis with publications"; this option for a Doctoral degree was instituted by the University of Auckland in recent years. It requires the candidate to include published or unpublished (submitted) journal articles in the thesis. There is no requirement as to the number of publications that can be included in a thesis. This thesis consists of three articles in total: edited versions of two published journal articles[1] (Chapters 3 and 4) and one article (Chapter 5) that will be submitted to a peer-reviewed journal. Following this first part of the introduction, in part II, I outline key end-of-life options that are available for individuals with dementia in current healthcare settings to set out the status quo. Completing an overview of the chapters, the thesis concludes with a discussion (Chapter 6) which addresses the significance and implications of the research as a whole. There are some overlapping areas referencing the same research. Given a certain amount of replication across the whole thesis this was inevitable. It is also important to note that the systematic literature search concluded in August 2020 and only highly relevant articles were reviewed beyond this point. To acknowledge the necessity of the researcher within qualitative studies, my voice has been presented whenever appropriate to give clarity to the research.

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[1] **Chapter 3**: Dehkhoda, A., Owens, R. G., & Malpas, P. J. (2020). Conceptual framework for assisted dying for individuals with dementia: Views of experts not opposed in principle. *Dementia.* https://doi.org/10.1177/1471301220922766
Chapter 4: Dehkhoda, A., Owens, R. G., & Malpas, P. J. (2020). A Netnographic Approach: Views on Assisted Dying for Individuals with Dementia. *Qualitative Health Research, 30*(13), 2077-2091. https://doi.org/10.1177/1049732320925795

Chapter Two provides an overview of the key literature and theoretical framework I have drawn on to contextualise my research. For this purpose, Scopus and Google Scholar searches were conducted to retrieve relevant articles on advance directives (with the focus on AEDs) for individuals with advanced dementia. In addition, the reference lists of identified articles were searched to include additional relevant articles. It engages with and explores the international literature to explore ethical arguments regarding AEDs for individuals with dementia, and their feasibility in practice, drawing on the arguments of Dworkin ("critical and experiential interests"), Dresser ("personal identity"), Jaworska ("new critical interest"), and others. This chapter discusses the primary challenges and moral tensions underpinning the application of AEDs in the advanced stage of dementia, including the attitudes towards such practices. It also focuses on the occurrence rates in the Netherlands and Belgium as well as outlining reasons for non-compliance with such AEDs in practice. Following a brief overview of the potential risks of non-compliance with such directives, I conclude the discussion by reflecting on the research data regarding assisted dying for individuals with dementia and how my research would potentially add to this existing body of knowledge.

Chapter Three is predicated on my understanding that if an AED is made in sound mind, a question still arises as to whether these directives can be appropriately framed and safeguarded to protect the wish of vulnerable individuals with dementia. I explore whether the development of a robust safeguard and procedural guidelines can be proposed. In this chapter, I explore the views of twelve international experts on the access barriers and their recommended solutions on the ways forward. Drawing on the consensus views of experts on the applicability of such practices, I close this chapter by suggesting that despite the issues surrounding the provision of assisted dying for individuals with dementia devising 'adequate' safeguards is achievable.

Chapter Four is a qualitative study exploring the everyday experiences, challenges, and perspectives of the public as well as their attitudes towards assisted dying and dementia. It uses online social communities in the public domain and the naturally occurring online communications of their members as a source of data. I begin this chapter by arguing the significant influence of social media on topical debates and their role in providing a medium that reflects public opinions on issues in a complex and nuanced way. Social media, as a chosen methodological platform, may best contribute to my research objective to fully comprehend public opinion on this matter. I then discuss how my immersion into the daily lived experiences of people online whose personal, professional, and/or social lives are intertwined with dementia has led me to conclude that the majority of contributors’ fear developing dementia. Their prior relevant experiences have resulted in them supporting the provision of AEDs – written by competent individuals – to prevent unnecessary suffering and protect their’ wishes and freedom of choice when decision-making competency is lost.

On a reflective note, I found reading and analysing hundreds of stories of people who are suffering very challenging. Online accounts of their suffering were often loaded with strong emotions. I learnt so much from the bravery of individuals in their battle with their diagnoses; of families who never gave up on caring for their loved ones; and of health professionals who support patients and their families. Although this experience made me determined represent their voices, I was very aware that I needed to be careful not let the emotions influence my objective judgement. My motivation to focus on generating and disseminating knowledge helped me to find the balance and to move forward.

In **Chapter Five** I present the research of a feasibility quantitative study that sets out to test the central findings of the two previous studies (Chapters 3 and 4) and articulates a more nuanced view of assisted dying for individuals with dementia. I illustrate the level of agreement and/or disagreement of a national, informed, and organised group of individuals in New Zealand. I conclude this chapter by outlining the findings in clusters that would serve the aim of developing a conceptual safeguard and, later, building a foundation for future research.

Chapter Six concludes the thesis by drawing the findings together into a coherent whole. This chapter plays a key structural role in connecting the narratives between chapters. Drawing on the findings and their relation to the literature, I highlight the potential impacts of allowing AEDs on individuals with dementia and their families/caregivers and healthcare provider team along with the potential safeguards that need to be implemented to ensure the safe application of AD in the context of dementia. Following a summary of my research and its contribution to the body of knowledge, I will point out the limitations of my studies and provide recommendations for future research.

1.2.4 Terminology and abbreviations

Ensuring the terminology used is clear and unambiguous is an essential part of any study. Any concept or phenomena can be defined in various ways and be interpreted and understood differently; this is especially so when the subject is deeply sensitive and contentious. Therefore, I have defined the terms I have used in my thesis. For convenience, the following Table 1.1 includes the terms I have used throughout my thesis, including a short definition. Abbreviations are also used. All other terms used within quotations reflect the common usage of that term in a particular region/country, organisation, or profession.

Table 1.1 | Definition and abbreviations of terms regarding end-of-life care and assisted dying practices

Terms	Abbreviations	Definitions
Assisted Dying	AD	Refers to the practices of euthanasia and physician-assisted dying.
Euthanasia (or voluntary euthanasia)	–	A competent patient asks for assistance to die and is administered a lethal dose of medication by a doctor or other authorised practitioner who also intended for the patient to die by their action (Government of Canada, 2019; 2016; Materstvedt et al., 2003; Onwuteaka-Philipsen et al., 2012).
Physician-Assisted Dying	PAD	A competent patient asks for assistance to die and is prescribed or supplied with a lethal dose of medication (by a doctor or other authorised practitioner) that they take at a time of their choosing (Government of Canada, 2019; Materstvedt et al., 2003; Onwuteaka-Philipsen et al., 2012).
Advance Care Planning	ACP	A process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others (Henry, Seymour, and Ryder., 2008).
Advance Directives	–	Generally instructional documents that specify the type of medical care a person wants to receive once he or she no longer has the capacity to make such decisions, and who should be in charge of making those decisions (Alzheimer's Association, 2018).
Advance Euthanasia Directives	AEDs	Generally instructional documents in which the author requests that a responsible healthcare provider (usually a physician) perform euthanasia in specified situations when they (the patient) are no longer competent (de Boer et al., 2010a). Note: In the Netherlands, patients in advanced stage of dementia, who are eligible, would be only administered euthanasia because they would be unable to take the lethal medication at the time of their choosing due to their incompetence.
Palliative Care	PC	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (WHO, 2020a).
Palliative Sedation	PS	Entails the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers (Cherny, Radburch, & Board of the European Association for Palliative Care, 2009).

Withhold and Withdraw Life-Sustaining Treatments	–	Involves either the decision not to start, or stopping treatments, that have the potential to sustain a person’s life (Downie & Lloyd-Smith, 2015).
Voluntary Stopping Eating and Drinking	VSED	The voluntary refusal of food and drink by mouth by a patient (Menzel & Chandler-Cramer, 2014).

PART II: End-of-life options – key concepts relevant to dementia

Before considering the issue of assisted dying for individuals with dementia, it is important that I first draw attention to the global importance and significance of dementia as a heath priority and its multidimensional impact on personal, familial, and societal wellbeing. I will also discuss information on the end-of-life options that are available for individuals with dementia, including assisted dying, and their associated challenges.

1.3 Dementia, a global health priority

With it now being the 7th leading cause of death (WHO, 2020b), dementia is one of the most prevalent diseases facing ageing populations worldwide. It is one of the leading causes of disability and dependency in older populations around the world. Old age is found to be the primary risk factor for Alzheimer's diseases and other dementias (Winblad et al., 2016; WHO, 2020b). As more people live longer as a result of profound advances in modern medicine and technology, it is predicted that many countries will witness a dramatic increase in the number of individuals who are diagnosed with dementia (Winblad et al., 2016; WHO, 2009b). According to the Lancet Neurology Commission report, “today, nearly 50 million people worldwide have dementia, with this figure projected to increase to 75 million by 2030 and to 132 million by 2050, largely driven by population ageing” (Frankish & Horton, 2017, p. 1), with the greatest increase expected in low-income and middle-income countries (WHO, 2020b; Winblad et al., 2016).

Dementia is an incurable, progressive, and debilitating disease, which occurs over time. According to the ICD-10[2] criteria presented by WHO (2009), dementia is

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[2] ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems, a medical classification list by the World Health Organization.

> A syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e., the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

Dementia also constitutes a number of behavioural and psychological changes – commonly known as “neuropsychiatric symptoms” – including “agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wondering, and a variety of socially inappropriate behaviours” (Kales, Gitlin, & LyKetsos, 2015, p. 1). Indeed, behavioural problems were found to be prevalent according to 89% of caregivers of people with dementia, while agitation, aggression, and personality changes were among the most problematic symptoms of care for 16% of individuals (Georges et al., 2008).

Alzheimer’s disease is known as the most common cause of dementia at around 60 to 70% of all cases (Mitchell et al., 2009; Winblad et al., 2016). Vascular dementia, dementia with Lewy bodies, and frontotemporal dementia are respectively the other most common types of dementia (Ames, Burns, & O’Brien, 2010; Husband & Worsley, 2006). Each type is characterised differently and accompanied by certain signs and symptoms; for instance, frontotemporal dementia typically affects behaviour and mood while vascular dementia frequently leads to depression, and Lewy body dementia can cause hallucinations (Husband & Worsley, 2006; Kales et al., 2015). Some of these symptoms are persistent across all stages of dementia and tend to worsen with the progression of the disease, including depression, anxiety, agitation, and apathy, whereas other symptoms such as delusion, hallucinations, and aggression tend to be more episodic (Kales et al., 2015).

Alongside these symptoms, cognitive and functional impairments seem to be inevitable trajectories in the dementia clinical course as the leading cause of difficulty for patients and their caregivers (Georges et al., 2008; Smits et al., 2015). Indeed, there is evidence that deterioration in cognition and activities of daily living is usually used to define dementia (Ames et al., 2010; Georges et al., 2008). These sources of difficulties may be followed by neuropsychiatric problems that are also extremely common across all stages and types of dementia; albeit their severity and prominence alter at different stages and in different types (Ames et al., 2010; Kales et al., 2015). Neuropsychiatric complications or behavioural and psychological challenges have a significant impact on patients and their families and are identified as the most problematic aspect of caring for and living with dementia (Georges et al., 2008).

With the progression of these multidimensional changes in cognition, function, behaviour, and changes in the personality of an individual with dementia, their physical and mental dependency increases; and thereupon the pressure on caregivers (Georges et al., 2008). Accompanied with other stressful aspects of living with dementia, these complications can lead to a poor quality of life for both patients and caregivers (Kales et al., 2015).

In this regard, studies show that dementia has a significant psychological, practical, and economic impact on family members as primary sources of care. Stress, anxiety, depression, reduced income, and lower quality of life for caregivers of people with dementia have been commonly reported (Ferri et al., 2006; Georges et al., 2008; Kales et al., 2015). Depression is also quite common for individuals suffering from dementia. Untreated depression at any stage of dementia could lead to higher functional impairment that could consequently cause more difficulties in performing activities of daily living (Kales, Chen, Blow, Welsh, & Mellow, 2005).

The challenges and problems above highlight the necessity of finding appropriate therapeutic approaches according to the unique needs of individuals with dementia.

1.4 End-of-life decisions and dementia

The increasing numbers of individuals affected by dementia has raised questions concerning decision-making at the end of life (Williams, Dunford, Knowles, & Warner, 2007). Sufficient end-of-life care that promotes patients' end-of-life preferences and wishes may enhance their quality of life throughout the dying process and provide comfort at the end of life when therapeutic approaches to dementia are limited with no prospect of cure.

1.4.1 Advance care planning (ACP)

End-of-life care that encompasses an advance care plan (ACP) respects patient-centred care. According to Henry et al. (2008):

> Advance care planning is a process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the

> process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. (p. 4)

Through an ACP, an individual discusses their personal goals, needs, concerns, and preferences in terms of their current and anticipated care and treatment. The goal of ACP is to ensure that patients receive the most appropriate care that accords with their set of values and preferences when they are no longer mentally capable of expressing those wishes themselves (Dening, Jones, & Sampson, 2011; Detering, Silveira, Arnold, & Savarese, 2016; Henry et al., 2008; Sinclair, Oyebode, & Owens, 2016). Regardless of individuals' medical conditions and severity, ACP should be proactive, continual, and integrated into the patients' care routine (Detering et al., 2016).

In general, ACP may lead to completion of one or more of the following directives, which come into effect once individuals lose capacity to make decisions: an Advance Statement (and/or Advance Directive/Living Wills) states patients' general preferences on matters such as life-sustaining treatments, resuscitation, etc. (these kinds of directives may not be legally binding); an Advance Decision to Refuse Treatment (ADRT), which are legally binding documents to inform decisions for refusing specific medical treatment and circumstances; and, Lasting Power of Attorney (LPA or Enduring Power of Attorney in New Zealand) for "health and welfare" and/or "property and finance", through which patients assign an elected person to make decisions on their behalf (Dening et al., 2011; Detering et al., 2016; Dixon, Karagiannidou, & Knapp, 2018; Henry et al., 2008; Sinclair et al., 2016).

When capacity is lost, ACP helps guide HPs and family/caregivers how and when to follow patients' preferences. Since cognitive impairment is an inevitable outcome of dementia, ACP is considered an important and effective strategy to ensure that end-of-life medical treatment and care is provided in the way the person prefers (Dening et al., 2011; Sinclair et al., 2016). Having the opportunity to consider the burdens and benefits of any medical treatment, individuals would likely avoid unwanted interventions, mitigating rushed decisions at the end of life (Dixon et al., 2018). ACP has also been found relatively effective in reducing inappropriate hospital admissions and care costs for people with dementia (Robinson et al., 2011).

Despite the presumed benefits of ACP for people with dementia, it faces some challenges in terms of documentation and implementation in healthcare settings (Dixon et al., 2018; Robinson et al., 2011).

Evidence shows difficulty in determining the right time to initiate ACP discussions that are neither too early when the disease trajectory is still unclear, nor too late for a cognitively able individual to be involved in the decision-making process (Dixon et al., 2018; Robinson et al., 2013). In addition, people with dementia tend to not formalise their wishes as much as they support an open discussion about ACP hoping that they would avoid “constraining the discretion of their caregivers and healthcare providers” (Dixon et al., 2018, p. 133).

Uncertainty about the roles and responsibilities of different HP groups, the general value of ACP, different types of ACP and their legal constraints, and the process of communication between patients, families and HPs all play a role in the low uptake of ACP among people with dementia (Robinson et al., 2013; Sinclair et al., 2016). These issues challenge the provision of optimal end-of-life care for people with dementia; what is needed is greater clarity around the ACP process, and improved communication between individuals and families near the end of life.

In Chapter Two, I will discuss ethical and practical implications of advance directives for an assisted death concerning individuals with advanced dementia.

1.4.2 Palliative care (PC)

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (WHO, 2020a). The focus of PC is to improve a patient’s quality of life throughout the illness experience while embracing the physical, social, emotional and spiritual elements of wellbeing (Ministry of Health, 2001).

Over the years, PC has broadened to cover not only terminal illnesses but also life-threatening illnesses that do not respond to curative treatments and do not necessarily have impending death prognostication (Birch & Draper, 2008). Thus, this understanding of PC encompasses diseases such as dementia, which often progress to a prolonged terminal phase in the advanced stages. Although PC has primarily provided services for advanced-stage cancer (Birch & Draper, 2008; Sampson, Ritchie, Lai, Raven, & Blanchard, 2005; van der Steen et al., 2014), there is growing recognition that patients with non-malignant disease would also benefit (Ministry of Health, 2001). In cases of dementia, some studies suggested PC to be an adequate model of care as it focuses on controlling symptoms and pain, and on improving the quality of patients' lives in a person-centred environment (Ames et al., 2010; van der Steen, 2010).

As dementia and cancer disease characteristics are different, so too should be the care approaches available to patients and their families. Principles of PC stipulate that “all dying people should be informed of their entitlement to palliative care and have access to quality health and supportive services appropriate to, and consistent with, their needs” (Ministry of Health, 2001). As to this principle, people with dementia are also entitled to receive dementia-specific palliative care services. Nonetheless, it is still not clear exactly what dementia-specific PC entails or how it may contribute to dementia care (Mclnerney, Doherty, Bindoff, Robinson, & Vickers, 2018; van der Steen et al., 2014); meaning that an accepted standard of PC that is specific to dementia for clinical practice is yet to be explored (van der Steen et al., 2014). Despite some attempts to provide more specific guidelines and recommendations regarding PC for people with dementia (van der Steen et al., 2014), this has neither been adequate (Mitchell, Morris, Park, & Fries, 2004; Parsons, Hughes, Passmore, & Lapane, 2010; Sampson et al., 2005) nor provided to all patients in need (Birch & Draper, 2008) or discussed with them and their families (Volicer & Simard, 2015). There are some plausible explanations for this limited access of PC services for people with dementia particularly in the advanced stages.

While it is believed that PC is applicable to all stages of dementia, it is unclear which stage best responds to PC (van der Steen et al., 2014). The different disease trajectories and deterioration in each stage of dementia requires specific care strategies in terms of appropriate assessment, and in treating and managing skills to control behavioural, physical, and cognitive problems (van der Steen et al., 2014). This task becomes more challenging in the absence of communication in more advanced stages of dementia (Birch & Draper, 2008; van der Steen et al., 2014; Volicer & Simard, 2015). Without meaningful communication with such patients, it is also difficult to achieve one of the central roles of PC, which is to manage and relieve physical pain. Not having a particular pattern for pain perception based on the dementia type may also contribute to the difficulty in assessing the pain (Ames, 2010).

The other challenge in delivering an effective palliative care service to older people with a protracted dying process is associated with an inability to predict the onset of terminal phases and the time of death of such patients (Parsons et al., 2010). Prognostication in dementia in that regard is highly uncertain (Birch & Draper, 2008; Mclnerney, et al., 2018; Parsons et al., 2010; Sampson et al., 2005; van der Steen, 2010).

All these complications may be associated with highly reported risks of suboptimal pain control, undertreatment of symptoms, overtreatment or even occasionally aggressive treatments with burdensome intervention, and unnecessary investigations during the last stage of dementia (Birch & Draper, 2008; Sampson et al., 2005; van der Steen, 2010).

1.4.2.1 Palliative sedation (PS)

The European Association of Palliative Care (EAPC) defines palliative sedation as "the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and healthcare providers." (Cherny et al., 2009, p. 581). PS is a treatment of last resort and an essential part of palliative care at the end-of-life of selected patients with otherwise refractory distress (Cherny et al., 2009). By definition, refractory distress is generally associated with excessive unbearable distress that cannot be relieved within a tolerable time frame (Juth, Lindblad, Lynöe, Sjöstrand, & Helgesson, 2010). Palliative sedation – ranging from mild to deep and intermittent or continuous – is potentially beneficial for some patients who are undergoing unpleasant treatment procedures and are unresponsive to conventional treatments and optimal palliative care (Anquinet et al., 2013; Cherny et al., 2009).

The application of PS in the care of cognitively impaired patients may face some difficulties given the inability of these patients to efficiently communicate and help care providers assess the cause and level of their distress (Cherny et al., 2009). Patients with dementia who are dying reportedly experience burdensome symptoms of pain, shortness of breath and agitation at some point in the disease process, with an increase as death approaches. Other common symptoms include restlessness and difficulty swallowing (Hendriks, Smalbrugge, Hertogh, & van der Steen, 2014; van der Steen, 2010). There is evidence that during dying, some patients with dementia experience a range of symptoms despite the use of continuous deep sedation until death[3] (Anquinet et al., 2013). Research suggests room for further improvements in palliative care and sedation in the context of dementia (Birch & Draper, 2008; Fox et al., 2018).

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[3] Continuous deep sedation until death is considered the most controversial type of palliative sedation due to its potential double effect of hastening death; it is often debated within the context of other end-of-life practices that shorten life such as euthanasia (Anquinet et al., 2013; Cherny et al., 2009; Claessens, Menten, Schotsmans, & Broeckaert, 2008; Engström, Bruno, Holm, & Hellzen, 2007).

Palliative sedation may unintentionally hasten death when the ultimate end is to alleviate unbearable suffering and NOT to bring an end to the patient's life. Such actions have been defended by the principle of double effect. The principle permits palliative sedation when the bad effect (the patient's death) is not directly intended, but merely tolerated or foreseen (Juth et al., 2010).

When a sedative drug is used to intentionally hasten the death of a patient based on their explicit request, such practices are not considered part of PS practice. In thinking about intentional actions that hasten death, I now turn my focus to assisted dying.

1.4.3 Assisted dying (AD)

Two practices, known as euthanasia or physician-assisted dying, bring an intended end to the life of a competent patient at her/his explicit request. As opponents and proponents use "highly charged rhetoric and emotive language" to influence the debate (Wai-Poi, 2009, p. 4), and to avoid confusion, it is important to clarify how the terms will be used in this thesis (for definitions see table 1.1). We use the term *Assisted Dying* as a generic term that encompass the administration (euthanasia), or the supply (physician-assisted dying) of a lethal medication, where the intention of both the patient and physician is to hasten death.

Globally, the practice of assisted dying is a contentious, divisive, and controversial social and personal issue in which politicians and professionals in law, medicine, and religion as well as the public all claim a compelling role in the decision-making process. Public policy and legal issues are tightly bound with ethical issues associated, and societies share some common problems posed by the practice of assisted dying. However, different historical, political and cultural factors in jurisdictions result in different legislative responses with regards to the treatment of assisted dying. In other words, how assisted dying legislation translates into practice is influenced by these factors as well as the manner in which legislation is implemented (Dierickx et al., 2020).

Using the definitions, I proposed earlier in Table 1.1, both practices of euthanasia and physician-assisted dying are legal in the Netherlands, Belgium[4], Luxembourg, Canada, Victoria State of Australia,

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[4] Physician-assisted dying is not explicitly legalised; however, the cases are treated the same as euthanasia (Emanuel et al., 2016).

Western Australia[5], and New Zealand[6]. While Switzerland[7] and some states of America[8] only allow physician-assisted dying, Colombia permits only euthanasia (Dyer, White, & Rada, 2015; Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016; White et al., 2019). As I mentioned above, the regulatory schemes and characteristics governing the practice vary considerably in these jurisdictions (see Table 1.2 for detailed information). Regardless of differences, as a general principle, all regulations require that an assisted death request be made by a mentally competent individual who has made the request voluntarily and free from any pressure or coercion. In addition to the competency eligibility requirement at the time of drafting an assisted death request, the majority of policies also require the presence of competency immediately before assisted death is carried out. In other words, only a limited number of these regulations have provided the opportunity to waive the requirement that one provide final consent in the time of assisted dying procedures. These regulations allow that assisted death requests be made in advance of losing decision-making competency. This competency requirement is the focus of this study as it would typically limit the provision of assisted dying for individuals suffering from illnesses that deteriorate their competency, including dementia.

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[5] Western Australia has passed legislation which enables voluntary assisted dying to become a choice available to people in mid-2021 (Government of Western Australia, 2020).

[6] In a binding referendum that was held on whether the End-of-Life Choice Act 2019 should come into force, majority of New Zealander voted in favour of the Act. The Act will come into force on 7 November 2021, 12 months after the official results was declared (Ministry of Health, 2020).

[7] Article 115 of the Swiss Penal Code decriminalised the act of “assisted suicide” as long as there is no selfish motive by the person assisting. The Act does not require a doctor to be involved and the practice is not restricted to individuals with terminal illnesses. From 1980s onward, some organisations have been established to facilitate an assisted suicide, including for Swiss non-residence (Emanuel et al., 2016; Dyer et al., 2015).

[8] In the United States, the practice of physician-assisted dying and not euthanasia has been legally permitted in ten jurisdictions including Oregon (1997), Washington (2009), Montana (2009), Vermont (2013), California (2016), Colorado (2016), the District of Colombia (2016), Hawaii (2019), New Jersey (2019), and Maine (2019) (Death with Dignity, 2020; Emanuel et al., 2016). Montana does not have a statute safeguarding physician aid-in-dying; however, the act is legal in the state through a Supreme Court ruling (Death with Dignity, 2019).

Table 1.2 | Eligibility requirements in states and countries with legalised assisted dying laws

Jurisdictions	Year allowed	Commonly used terminology	Primary eligibility requirements						
			Age (Year)	**Competency required**	**Diagnosis**	**Life expectancy (Months)**	**Suffering**	**Residency**	**AED** [a]
The Netherlands	2002	Euthanasia and (Physician) Assisted Suicide [b]	• Competent minor 12 -17 • ≥ 18	No [c]	• Incurable illness • No prospect of improvement	• None [d]	• Unbearable (physical or mental) • No prospect of relief • Patient must be conscious of suffering [e]	No [f]	Yes
Belgium	2002	Euthanasia	• Minor with discernment capacity • Emancipated minor • ≥ 18	No [g]	• Serious & incurable condition caused by illness or accident • Medically futile condition	• None (adult) • Terminal phase (minor)	• Unbearable (physical or mental) • Only physical for competent minor	No [f]	Yes
Luxembourg	2009	Euthanasia and Assisted Suicide	≥ 18	No [h]	• Hopeless medical condition • Severe and incurable accidental or pathological disorder	• None	• Constant & unbearable (physical or psychological) • No prospect of relief	No [f]	Yes
USA States	1997 – 2019	Physician Assisted Death or Physician Assisted Suicide [i]	≥ 18	Yes	• Terminal illness	• < 6 months	• None specified	Yes	No
Quebec, CAN Canada	2014 2016	Medical Assistance in Dying	≥ 18	Yes	• Grievous & irremediable medical condition • Serious and incurable illness, disease or disability • Advanced state of irreversible decline in capability	• Natural death must be reasonably foreseeable [j]	• Constant & unbearable (physical or psychological) • No prospect of relief	Yes [k]	No
Colombia	2015 (1997)	The Fundamental Right to Die with Dignity	• Minors with discernment capacity • Emancipated minor • ≥ 18	No [l]	• Terminal disease or pathological condition • In clear & irreversible progression	• Terminal phase • Imminent or short-term death	• Acute and intense • No prospect of relief	-	Yes

Table 1.2 | Eligibility requirements in states and countries with legalised assisted dying laws

Jurisdictions	Year allowed	Commonly used terminology	Primary eligibility requirements						
			Age (Year)	Competency required	Diagnosis	Life expectancy (Months)	Suffering	Residency	AED [a]
Victoria, AUS	2019	Voluntary Assisted Dying [m]	≥ 18	Yes	• Incurable, advanced & progressive illness, disease, or condition • It must cause death	• < 6 (terminal) • < 12 (Neuro-degenerative)	• Unbearable • No prospect of relief	Yes	No
New Zealand	2021	Assisted Dying	≥ 18	Yes	• Terminal illness	• < 6 (terminal)	• Unbearable • No prospect of relief	Yes	No
Switzerland	1942	Assisted Suicide	None specified	Yes	• None	• None	• Not Specified	No	No

[a] Advance Euthanasia Directive

[b] This is “physician-assisted dying” under my proposed definition.

[c] AED written in sound mind can be acted upon in the state of incompetency of individuals with dementia.

[d] The Act does not stipulate that euthanasia or assisted suicide must only be performed in the terminal stage, or the condition should be life-threatening. The patient’s life expectancy plays no role in the Act in cases where the statutory due care criteria have been fulfilled (RTE, 2018).

[e] The patient’s consciousness of suffering may be apparent through words or from utterances or physical symptoms. If the patient can no longer express the level of suffering in words, other signals may reveal the patient’s burden of suffering (RTE, 2018).

[f] Non-residents can request an assisted death; however, the law requires a close doctor-patient relationship.

[g] The euthanasia request can be based on a written advance directive for euthanasia in cases of unconsciousness. Although legally ineligible, people with dementia may voice a formal request for euthanasia and physician-assisted dying and receive the assistance to be helped to die while still competent (Chambaere, Cohen, Robijn, Bailey, & Deliens, 2015; Downie & Lloyd-Smith, 2015).

[h] Similar to Belgium, competent adults can make written advance directives for euthanasia should they lose capacity to express it in the future; the act is however limited to unconscious people such as in an irreversible coma (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2010a).

[i] Although a variety of terminologies is used in each state’s regulatory act, including ‘medical aid in dying’, ‘physician aid in dying’, ‘death with dignity’, etc. (CCA, 2018), their eligibility requirements are mostly similar with regards to the age, diagnosis, and life expectancy criteria (Emanuel et al., 2016).

[j] On February 24, 2020, the Minister of Justice and Attorney General of Canada introduced a bill, which proposes changes to the *Criminal Code’s* provisions on MAiD to allow MAID for eligible persons who wish to pursue a medically assisted death, whether their natural death is reasonably foreseeable or not (Government of Canada, 2019).

[k] An individual requesting MAiD must be eligible for health services funded by the federal government, or a province or territory (or during the minimum period of residence or waiting period for eligibility (CCA, 2018).

[l] AED can be written by any capable, healthy or sick person, in full use of their legal and mental faculties and with full knowledge of the implications of that statement (Colombian Ministry of Health and Social Protection [MINSALUD], 2018). They are, however, only allowed in the context of imminent death (CCA, 2018).

[m] VAD Act consists of 68 safeguards, most of which relate to the assessment process, and is described by the Victorian Government as the safest and most conservative model worldwide (White,

1.4.3.1 Assisted dying and dementia

As dementia is a complex fast-growing health problem, it must be regarded as a health priority globally. Growing numbers of individuals with dementia, coupled with the fact that increasing advances in medicine and medical health have led to an extended life beyond an individual's ability to be involved in treatment decisions, highlights the necessity of protecting individuals' will when their capacity is lost. Not surprisingly, against the physical and psychological difficulties mentioned earlier, some people diagnosed with dementia may not want to continue living if their disease advances to the stage where they lose their sense of self, autonomy, independency, and control, or when their mental faculties have diminished to a level that they find unacceptable. Some may desire to choose the time and manner of their dying and by doing so maintain their sense of self-determination and control. Some individuals may decide to request an assisted death because they do not want to become a burden on their family, or when they are no longer capable of recognising loved ones (Gastmans & Denier, 2010; Hertogh et al., 2007a; Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, Mahtani-Chugani, & Balaguer, 2012; Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016; Schroepfer, 2006; van Tol, Rietjens, & van der Heide, 2010). To these people, maintaining a good quality of life outweighs its length. Some individuals who do not have dementia, may desire access to assisted dying should they developed dementia. The findings of an international systematic literature review of "the attitudes of health professionals, patients, caregivers and the public" in 2014 concludes that people in some jurisdictions desire to have the option of assisted dying available for themselves or for others in the case of dementia (Tomlinson & Stott, 2015).

It is important to distinguish between individuals with dementia with and without decisional competency. An assisted dying request from a person who is at the earlier stages of their disease and who retains competence to make an informed decision would be treated and assessed in the same way as others with other (non-competency eroding) illnesses. For example, in Belgium, patients at the early stage of dementia may be legally assisted to die if they are still fully competent to make a well-considered and repeated request and are in unbearable physical or mental suffering that cannot be relieved (Downie & Lloyd-Smith, 2015). Similarly, in the Netherlands, a competent person (even if diagnosed with dementia) who is capable of assessing the scope of their assisted dying request, of understanding the information on their prognosis and alternatives, and of coming to an independent decision on the matter may be granted an assisted death if all other requirements are met (Regional Euthanasia Review Committees

[RTE], 2018b). Assisted dying for a person at more advanced stages of dementia whose decisional competency is impaired may, however, be only available through AEDs in these two countries. This particular advance directive can only be operative in jurisdictions where assisted dying is permitted. Not all permissive jurisdictions, however, include the provision of AEDs in their assisted dying laws. Some forms of AEDs are legally allowed in four countries: the Netherlands, Belgium, Luxembourg, and Colombia. Nonetheless, because of the specific legislative provisions of these directives in each of these countries, their implications vary in cases of dementia.

In the Netherlands, Section 2 (1) of the Dutch Termination of Life on Request and Assisted Suicide Act (2002) stipulates six “due care” criteria to be followed by physicians for the application of lawful assisted dying practice. Section 2 (2) of the act concerns written AEDs by patients who are no longer capable of expressing their end-of-life decisions (Janssen, 2002; Legemaate & Bolt, 2013). According to Section 2 (2), an AED of an individual aged 16 or over would be considered a legal replacement for an oral request (first due care criteria) in the case of mental incompetency provided that the directive was drawn up when the person was still decisionaly competent. (RTE, 2018b). The AED has the same status as an oral request for euthanasia and will be granted if other due care criteria are met to the greatest extent possible in the given situation (RTE, 2018b).

The criteria for AEDs in Belgium and Luxembourg are largely the same. In these two countries, AED are effective only if (a) the patient is afflicted by a serious and incurable accidental or pathological condition; (b) the patient is *unconscious*; and (c) the condition is irreversible according to the state of medical science at the time (Downie & Lloyd-Smith, 2015; Government of Luxembourg, 2009; Lewis & Black, 2013; van Zeebroeck, 2018). Accordingly, assisted dying requests may be granted only if the person with dementia is in a state of irreversible unconsciousness. An advance request for euthanasia is also available under the Colombian right to die with dignity act, but it is allowed only in the context of imminent death (Council of Canadian Academies [CCA], 2018). The implications of assisted dying laws in these four countries with regard to dementia and AEDs, their feasibilities in practice, and relevant challenges will be further discussed in Chapter Two.

Of these four countries, Colombia and Luxembourg lack implementation experience of AEDs. Of the other two with more substantial practical experience, Belgium lacks detailed data or case descriptions from either biannual reports or academic studies on AEDs (CCA, 2018). Therefore, the Netherlands is the only jurisdiction that provides summary documents of reported cases of medically assisted deaths based on the instruction in an AED and that is why most information about AEDs discussed in this thesis is from the Netherlands. Data from the oversight bodies that produce these reports suggest an overall increase in the number of requests for assistance to die by people with dementia in the Netherlands and Belgium (Dierickx, Deliens, Cohen, & Chambaere, 2017; Picard et al., 2019; RTE, 2020). Where there is no information provided on the degree of cognitive impairments in Belgian dementia cases (Dierickx et al., 2017; Picard et al., 2019), the Dutch reports show that the vast majority of requests were in the early stage of dementia, when individuals were still aware of their situation, the prognosis of their disease, and the related behavioral and cognitive changes that may result as the disease progressed (RTE, 2020). This increase in numbers may be an indication of the new aging generation who "challenge the stereotyping of old age as a state of resignation. They want to remain in control of their life and future, and specifically reject the perspective of a disease that causes their identity to unravel and brings with it a loss of competence and independence" (Hertogh et al., 2007a, p. 49). Fear of developing dementia and the inevitable decline that follows the diagnosis, alongside a wish to retain control, autonomy, choice, and competency in aging may have increased the potential of requests for assisted dying in people with dementia (Tomlinson & Stott, 2015).

An individual with dementia may fear the unfolding deterioration of their bodily and mental functioning, loneliness, confusion, adverse changes in their personality and behaviours, and the inability to recognise loved ones. Such fears may provoke unbearable suffering and contribute to a person desiring to request an assisted death in the earlier stages of the disease in order to ensure their fears do not become a reality (de Beaufort & van de Vathorst, 2016; Legemaate & Bolt, 2013). The fear of disability, losing independence, and becoming a burden on others among other factors are also felt by some independent healthy older people who support an assisted death (Malpas, Mitchell, & Johnson, 2012). The prior experiences of these older people, who may have nursed or looked after patients and/or loved ones with dementia, may be a strong contributing factor of their support of an assisted death (Malpas et al., 2012).

The desire for an assisted death in early-stage dementia, as opposed to an advanced stage, as well as low records of AEDs' implementation in advanced stage of dementia (from the Netherlands) may suggest concerns regarding its application later due to patients' inability to make informed decisions rendering AEDs ineffective and impractical. In practice, HPs may be reluctant to perform an assisted death on a person with no understanding of her/his surroundings (Bolt, Snijdewind, Willems, van der

Heide, & Onwuteaka-Philipsen, 2015). The reason for this reluctance may be inferred from the controversial case of euthanasia in the Netherlands in 2015. The case centred on an elderly woman with advanced dementia who had drawn up a living will some years before her admission to the nursing home and had regularly stated that she wanted to die. The doctor who euthanised her said she had spoken three times to the patient about her wish to die, but not about her living will because that was long forgotten. Being convinced that the patient was suffering unbearably, the doctor decided that euthanasia was appropriate. While euthanasia was being performed, the patient started to resist to the point that her present family members had to hold her down so that the process could be carried out. Although the Dutch review committee believed that the doctor acted in good faith, the case was taken to the court because coercion was involved (Asscher and Van de Vathorst, 2020). This case may explain the lack of HPs' inclination to adhere to an AED of a patient who is no longer capable of communicating their wishes.

Individuals, on the other hand, may wish to die earlier than they would otherwise prefer to in order to avoid the risk of becoming incompetent and losing the opportunity of requesting a death on their own terms (de Beaufort & van de Vathorst, 2016). One example would be the case of Seales v Attorney General, who brought the assisted dying debate to the fore in New Zealand in 2015. Lawyer Lecretia Seales, who was terminally ill from a brain cancer at the time, sought from the High Court a declaration that her general practitioner would not risk conviction in administering or prescribing a lethal drug to assist her to die. Part of her claim was that if she was denied an assisted death, she may have to end her life earlier than she wanted, thus violating her right to life. These two very human stories show what is at stake for individuals at either side of this matter and capture the essence of the complexities involved. More empirical research is needed to better understand, and to inform the debate.

Before I conclude this chapter, it is important to discuss the status of assisted dying law in New Zealand. Although my research has an international focus, it has been conducted in New Zealand where assisted dying has recently been regulated with some implications for people with dementia.

1.4.3.2 Assisted dying, and dementia in New Zealand

In New Zealand, currently almost 70,000 people are living with dementia. Women are affected by more than 30 percent compared to men, and the number is estimated to increase to more than 170,000, including both men and women, by 2050 (Alzheimers New Zealand, 2020). Reports show an increase in the number of people with dementia in the last five years by 29 percent; from almost 50,000 in 2011 to over 60,000 in 2016 (Alzheimers New Zealand, 2018).

Assisted dying is not legal under current New Zealand law. In 2017, member of Parliament David Seymour introduced the End-of-Life Choice Act, which was drawn from the Member's Bill Ballot in Parliament. This Act gives competent people with a terminal illness or grievous and irremediable medical condition the option of requesting assisted dying (New Zealand Legislation, 2020). At the 2020 General Election, New Zealanders had the opportunity to vote in a referendum on whether the End-of-Life Choice Act should come into force, in which a majority of voters supported the Act. The Act come into force on 7 November 2021 (Ministry of Health, 2020).

The Act, however, excludes the provision of advance directives to request an assisted death, which limits its access for New Zealanders with dementia. According to the eligibility criteria of this Act, a *competent* person with dementia who is suffering from "grievous and irremediable medical condition" could be eligible for assisted dying only if they a) are in an advanced state of irreversible decline in capability, b) experience unbearable suffering that cannot be relieved in a manner that he or she considers tolerable, c) have the ability to understand the nature and consequences of assisted dying, and more importantly, d) have life expectancy of less than 6 months (New Zealand Legislation, 2020). As individuals with dementia usually lose decision-making competence more than six months before their expected death, they most probably will be excluded from the Act.

The use of advance directives in New Zealand is encouraged and aims to improve care at the end of life (Malpas, 2011). In New Zealand, the Code of Health and Disability Services Consumers' Right (the Code) recognises the right of a patients to use an advance directive to "refuse services and to withdraw consent to services" (Health & Disability Commissioner [HDC], 1996). New Zealanders predominantly use advance directives to request the withholding or withdrawal of medical treatment at the end of life (Malpas, 2011). The legal provision of advance directives to allow assisted death has been supported by the majority of New Zealanders in cases of future incompetency caused by conditions such as brain injury (66% support, 19% oppose) and advanced dementia (65% support, 20% oppose) (Horizon Research, 2019). Support to allow a competent adult to write such a directive, should they develop dementia, was higher in New Zealanders aged 55-64 (71%) than those over 65 years with 65% in support (Horizon Research, 2019). This supportive perspective with regard to dementia dropped among general practitioners (n=78) to around 40% (Havill, 2015). Another research into the perspectives of doctors (n=155) and nurses (n=356) revealed that 37% of doctors and 67% of nurses supported legalising assisted dying in NZ, assuming provision of appropriate guidelines and protocols (Oliver, Wilson, & Malpas, 2017). A sub-sample of those supporting shows that 76% of doctors and 87% of nurses agreed to legalising assisted dying where the patient has advanced dementia and irremediable condition rendering life unbearable in their view and had made a clear advance directive that instructs assisted dying in certain circumstances. Support for dementia cases was lowest compared to other medical conditions due to ethical complexity of medical decision-making for incompetent cases (Oliver, Wilson, & Malpas, 2017).

1.5 Summary

Part I of this introductory chapter introduced the main purposes of this thesis and presented the motivation for studying assisted dying in the context of dementia. It also presented my methodological approach and the conceptual framework which connects the three original articles and the research questions. Part II provided information about the condition of dementia and the end-of-life care and options that are available to those diagnosed with dementia. This second section aimed to provide a backdrop to the understanding of life with dementia and its impact on patients and their families. Additionally, it draws attention to the importance of challenging our views on end-of-life care of a patient with dementia to provide quality individualised care. This chapter finishes by providing an overview of the practice of assisted dying (including assisted dying for dementia), laws, and regulations set out the baseline for the discussions that follow in the next chapter.

Chapter Two

Chapter 2 – Literature review

From advance euthanasia directives legislation to practice: A review of ethical validity and feasibility in cases of advanced dementia

This chapter conducts a review of the literature relating to assisted dying in the advanced stages of dementia. It discusses the role, validity, and feasibility of an advance euthanasia directive, a key concept driving this study/practice. To identify the gaps, it discusses relevant ethical theories and their role in reinforcing current societal, practical, and ethical attitudes and policies. It then introduces the inconsistencies within current legislative provisions concerning AD and dementia along with other underlying reasons and challenges associated with access to assisted dying. Each of the individual articles/chapters (chapters 3, 4, and 5) in this thesis contains its own literature review section, which draws on or extends the literature presented in this chapter.

2.1 Introduction

In jurisdictions where assisted dying is legally permitted, people with terminal or irreversible conditions can request an assisted death under certain circumstances, provided they retain their competency through to the point where their request is actioned. People suffering from dementia however, who request an assisted death, will be unable to receive it if they lose competency. Currently, 50 million individuals globally have developed dementia (WHO, 2020). From the diagnosis, median survival rates vary from 3 to 12 years with individuals spending most of that time in the advanced stages of the disease (Mitchell, 2015). The severest stage of dementia (stage 7), also known as advanced dementia, includes clinical features of “profound memory deficits (e.g., inability to recognize family members), minimal verbal abilities, inability to ambulate independently, inability to perform any activities of daily living, and urinary and faecal incontinence” (Mitchell, 2015: page 2633). Thus, individuals with advanced dementia are arguably those, who are most in need of an advance directive to make their wishes known, grounding the necessity of having documented their directive when their mental faculties are intact. In Germany, lack of knowledge and information about advance directives, particularly in the context of dementia, was found to be the main reason for not having completed one, whereas the opportunity for ensuring self-determination at the end of life and avoiding undesired treatments were the main reasons for completing one (Schmidhuber, Haeupler, Marinova-Schmidt, Frewer, & Kolominsky-Rabas, 2017).

Advance directives are generally instructional documents that "specify the type of medical care a person wants to receive once he or she no longer has the capacity to make such decisions, and who should be in charge of making those decisions" (Alzheimer's Association, 2018). Advance directives only come into effect when individuals have lost the capacity to make decisions for themselves. Adults whose capacity to make decisions is impaired have the right to designate an enduring power of attorney for their healthcare and state their wishes in advance of their incompetency. This would also encompass matters of end-of-life care such as to limit, refuse or stop medical treatments, and day-to-day acts of care and support (Alzheimer's Association, 2018; Samsi, Manthorpe, Nagendran, & Heath, 2012). Such instructions are also a way to preserve the autonomy of individuals (de Boer, Hertogh, Dröes, Jonker, & Eefsting, 2010b; Schmidhuber, et al., 2017) speaking for the individual when they can no longer make their preferences known. The legal status and regulation of advance directives are however, based on the social-cultural context and thus differ by country.

Despite the variation in legislative approaches, a number of studies have acknowledged the important role of advance directives in guiding both health professionals (HPs) and family members increasing the concordance between patients' preferences and the care delivered in practice, as well as greater satisfaction with care (Dixon, Karagiannidou, & Knapp, 2018; Porteri, 2018). Without the guidance of advance directives, the risk of a burden on proxies to make decisions on behalf of their loved ones is increased as well as the risk of undue and/or burdensome care for these individuals (Tjia, Dharmawardene, & Givens, 2018). The feasibility of advance directives that instruct for assisted dying is, however, subject to rigorous moral and ethical criticism. Scholars have questioned the validity and applicability of advance euthanasia directives (AEDs) when individuals are no longer competent (Cholbi, 2015; Dresser, 1995; Dworkin, 1993; Harvey, 2006; Hertogh, de Boer, Dröes, & Eefsting, 2007a; Gastmans & De Lepeleire, 2010; Jaworska, 1999; Menzel & Steinbock, 2013; Parfit, 1986; Porteri, 2018; Post, 1997). At the heart of this issue, is whether it is ever ethically permissible to grant an individual with advanced dementia an assisted death on the basis of a relevant advance directive, and whether such a directive has legal standing.

To understand better how the practice of assisted dying for individuals with dementia in the context of advance directives has been understood and experienced, this review chapter engages with the international literature to explore the validity and feasibility of AEDs as well as their scope and application regarding cases of individuals with marginal or complete lack of competence. Ethical arguments around the use and moral validity of AEDs for individuals with advanced dementia are therefore being discussed as one of the key factors influencing the uptake and adherence to these directives and attitudes of end-users. The discussion around the ethical arguments is followed by the analysis of other important factors that influence the practice, including legal aspects of AEDs, psychological aspects of advocating and following AEDs, and organizational policies around AEDs.

2.2 Foundational ethical perspectives of the self and advanced dementia

Dementia gradually makes it more difficult for a person to retain relationships with others and make autonomous choices. Eventually, an individual may lose their sense of self, or what has been called “personal identity”. Derek Parfit argues that personal identity “consists in overlapping chains of psychological continuity and connectedness” (Parfit, 1986, p. 199). Any permanent disruption in the relationship between these physical and psychological entities may result in loss of personal identity. The neurological damage that occurs as dementia advances may disrupt personal identity to the degree that the competent person with dementia and the incompetent person they become, are no longer the same person; the “new” person has no fundamental connection to the earlier self. In this situation, an advance directive, arguably, no longer stands as an authority in determining future action, as it belongs to a different person.

Dworkin (1993) rejects the theory of personal identity loss due to gradual cognitive decline, arguing that the previous competent self and the “new” incompetent self are one and the same person. His argument is based on two primary kinds of interests that drive our lives: experiential and critical interests. Experiential interests are those that individuals possess that include daily activities such as cooking, watching a game of cricket, or walking along a beach – the kinds of things which bring us pleasure. Although these are, as Dworkin states, essential to a good life, they come second in importance to critical interests. Activities such as raising children, establishing close friendships, and accomplishing one’s goals are examples of critical interests that give meaning to life; without them, we may view our lives as deficient, or see ourselves as worse off in important and significant ways.

Our experiential and critical interests are important in understanding our lives holistically. Could death be in the best interests of an individual with dementia? Dworkin argues we must look at what was important to the individual and how they lived their life, not just at the stage of their life dominated by dementia. According to Dworkin, most people perceive that death has a “special, symbolic importance:

they want their deaths, if possible, to express and in that way vividly to confirm the values they believe most important to their lives" (1993, p. 211). Advance directives, in this sense, become the voice of individuals when their ability to express their values has gone and thus must be honoured to maintain one's integrity and authority. Dworkin argues we must take their former critical interests into account when we consider their advance directive request to die; not to do so would be unjustified paternalism.

Dresser (1995) objects to Dworkin's view and argues that the now incompetent person is likely to have new desires, abilities, beliefs, and values that might make their life worth living, even if they had formally rejected such a life when they were competent. Under such a view it would be morally justified to override the advance directive of the person with dementia who now appears happy, contented, and to be enjoying life. Hence, she justifies placing limitations on individuals' precedent autonomy if their contemporaneous experiential interests are in clear conflict with former choices. For Dresser, a person's critical interests become less important and their experiential interests more important as they become incompetent. She worries that individuals with dementia who appear to be content, happy and comfortable would be harmed if their critical interests were advanced, when it is possible the individual no longer valued or cared about them.

A further consideration addresses the relevance of psychological adaptation, especially by drawing attention to how it is conceptualised in the context of dementia. Some attribute the conflicting preferences of patients in the later stages of their dementia to psychological adjustment and adaptation strategies that help them come to terms with their progressive decline (de Boer et al., 2007; Hertogh, de Boer, Dröes, & Eefsting, 2007b). To explain the contradictory preferences of individuals with dementia, an analogy has been repeatedly drawn between individuals with early and advanced dementia, and individuals with disabilities or chronic illnesses using the concept of 'response shift' (Byrne-Davis, Bennett, & Wilcock, 2006; Schwartz, Andresen, Nosek, Krahn, & RRTC Expert Panel on Health Status Measurement, 2007; Sprangers & Schwartz, 1999). A response shift in this context defines as the change in the meaning of one's self-evaluation of quality of life resulting from changes in internal standards, values, or conceptualisation (Sprangers & Schwartz, 1999).

As Jongsma et al., (2016) explain, "changes in patient's health may prompt behavioural, cognitive and affective processes necessary for accommodating the illness" resulting in a response shift and thus changes in one's preferences (Jongsma, Sprangers, & van de Vathorst, 2016, p. 598). It is argued that people with dementia undergo the same process of accommodating the illness as people with other serious illnesses, including disabilities (Hertogh et al., 2007a). This suggests that individuals with dementia may come to enjoy a different quality of life during the illness trajectory (Byrne-Davis et al., 2006; Schölzel-Dorenbos, Olde Rikkert, Adang, & Krabbe, 2009), rendering their advance directive meaningless, calling into question whether a person who now appears to be happy and contented, should be bound by a document written many years ago in ignorance of what their future may hold or how they may respond to a life-changing event?

A similar thread of thought can be found in the work of Jaworska (1999), who develops an alternative to Dworkin and Dresser’s analyses. She gives priority to the current interests of individuals with dementia, as Dresser does, but for very different reasons. Jaworska believes that individuals with dementia retain their capacity to value and therefore are still capable of generating new critical interests. As individuals with dementia gradually lose their earlier critical interests their new simpler configuration of interests gains an increasing importance. Her argument is, unlike those of Dworkin and Dresser, focused on the earlier stages of dementia when patients can provide some degree of rationale to value their current experiences and activities. Patients with dementia continue, it is argued, to possess the capacity to value their lives; thus, respecting patients’ immediate interests is not contrary to their autonomy (Jaworska, 1999).

Individuals with dementia who still possess this capacity are rightfully and legally entitled to change their end-of-life preferences. They are still active agents and in that sense are no different from competent individuals with any other illness. Advance directives are plausibly more practical if written in acknowledgment of the fact that the response shift may occur, and critical interests may change through the dementia process; of course, these directives only come into effect when an individual is no longer competent to make decisions requiring consideration of the options available. Once that point is reached, it remains unclear how an advance directive should be understood in accordance with the response shift. Jongsma et al., (2016) argue that individuals with dementia, especially those in advanced stages of the disease, are cognitively unable to self-evaluate and provide self-report of their quality of life, which are the key components of measuring a response shift. Hence, they conclude that the response shift is an implausible explanation for patients’ altered preferences. Regardless, this may create uncertainty for those held responsible for following the preferences of an AED. This uncertainty increases when a patient appears indifferent to receiving assisted dying, shows expressions that counter what is written in their AEDs, expresses a desire to continue living, or even in some cases physically or verbally resists the assisted dying procedure (Council of Canadian Academies [CCA], 2018). In such conflicting situations, it becomes unclear how to balance the moral forces of autonomy of the patient's past self against the preferences of the contemporaneous self.

When capacity is lost, the decisions on whether and when to enact an AED inevitably involve a third person. The autonomy of the incompetent patient is, therefore, embodied in the decisions made by their proxies. As Holm (2001) argues, even decisions that are considered in accord with the 'best interest' of the patient, according to the assessment of others, also constitute *interference* with the autonomy of that patient (whichever autonomy that might be). The principle of respecting autonomy in healthcare ethics is, however, predominantly about the individual's rights to make treatment decisions that accord with their personal values and desires with the emphasis on self-determination and *non-interference* (CCA, 2018). This model of respecting autonomy aligns more closely with the individualistic conception of autonomy with less attention to the relational aspects of decision-making in cases of incompetent patients. Over the years, these viewpoints on the ethical challenges of advance directives concerning incompetent patients have been widely discussed in the literature (Cholbi, 2015; Gastmans & De Lepeleire, 2010; Harvey, 2006; Hertogh et al., 2007a; Holm, 2001; Menzel & Steinbock, 2013; Porteri, 2018; Post, 1997; Tsinorema, 2015). Their positions, however, have remained contentious in regard to practice (de Boer et al., 2010b).

2.3 Ethical perspectives at the edge of practice

Some scholars accept Dworkin's view that patients' advance directives should remain valid in order to respect their autonomously made choices and preserve their right of self-determination (Davis, 2014; Menzel & Steinbock, 2013; Porteri, 2018; Tjia et al., 2018). Porteri (2018) argues that while Dresser's theory of the emergence of a "new" person in the stage of advanced dementia is an interesting perspective from a theoretical standpoint, it has no grounding in real life. What an individual with dementia fears most is the potential negative changes to their personality, interests, dependency, and values, not that their existence, as they currently know it, would end and a new self would arise (Porteri, 2018). In this view, an individual's desire for an assisted death may be grounded in their attempt to protect their future integrity and to be remembered in that way (Gastmans & De Lepeleire, 2010; Wolff, 2012). Some physicians have, indeed, come to recognise the mental and psychological suffering that individuals with dementia may experience due to their future decline and loss of independence and dignity (Gastmans & De Lepeleire, 2010; Kouwenhoven, van Thiel, van der Heide, Rietjens, & van Delden, 2019). An indication of emphasis on an individuals' subjective experience of suffering can also be found in the Dutch Code of Practice[9]. Here the endorsement of suffering to be the result of 'anxiety about future deterioration' and/or 'summation of mental and physical aspect' is a broad interpretation that yields a major role for subjective elements. This in turn gives priority to the patient's autonomous choice (Kouwenhoven et al., 2019). The issues of physical/psychological suffering, autonomy and self-determination may all be given different emphasis by those involved in the decision to end life. It is of course also worth noting that, typically, legislation permitting assisted dying permits individuals to make a request; it may not necessarily give the individual the right to insist that their request (or those of a proxy under AED) be actioned. At its most simple level, any autonomy granted to request assistance in dying is likely to be paralleled by a similar autonomy granted to practitioners to decline to provide it.

Regardless, there seems to be a shift from the Dutch compassion-driven framework for assisted dying – to relieve unbearable suffering – towards a practice prioritising the patient's autonomous choice (Kouwenhoven et al., 2019). This is consistent with Dutch practice where the autonomy of an individual with dementia and loss of dignity is increasingly playing a significant role in granting assisted dying requests (Evenblij et al., 2019). Over the years, Dutch physicians have gradually come to endorse an individual's right of self-determination about one's life and death resulting in an increase in the number of assisted death requests being granted (Koopman, 2019). Regardless, the pivotal role of physicians in practice seems evident. This role is even greater in cases of incompetent patients whose conditions may appear in conflict with the content of their advance directives. In these conflicting situations, the role of treating HPs is being challenged raising questions about the right approach to individuals requesting an assisted death. There are no easy answers to that question, with strong arguments for both respecting the AED of patients and providing an assisted death as previously instructed irrespective of potential conflict (respect for their precedent autonomy); or overriding a patients' AED on the grounds that that decision perhaps recognises their current autonomy which may not be clear or obvious. Furthermore, a decision may also be motivated by compassion, or not wanting the guilt of making a decision in the current context of the patient expressing any views on hastening their death.

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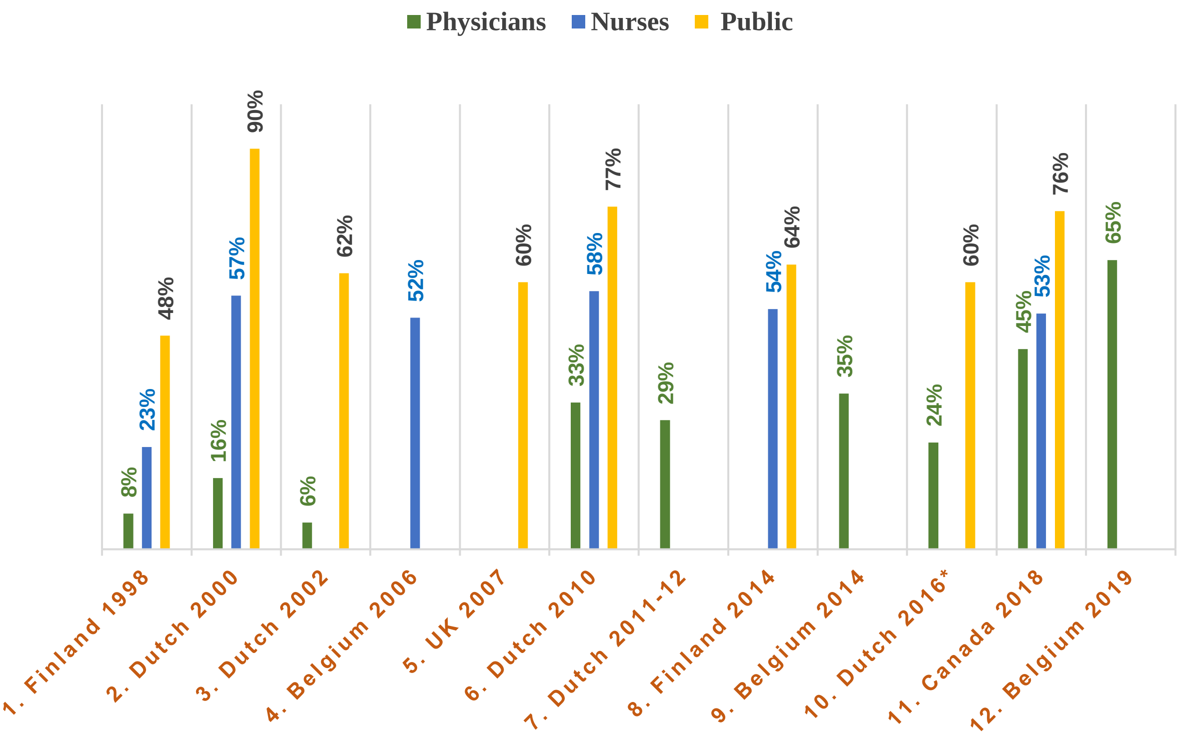
[9] The Code of Practice of the Regional Euthanasia Review Committees "gives an impression of how the committees apply and interpret the statutory due care criteria for euthanasia as set out in the Termination of Life on Request and Assisted Suicide Act. The Code outlines the issues that the committees regard as relevant in performing their statutory tasks [...]. More importantly, the Code provide stakeholder guidance to deal with euthanasia requests in a manner that complies with the Act (RTE, 2015).

This issue also touches on concepts of identity and personhood, complex issues which go well beyond the scope of this thesis. It can be argued that the person with dementia is no longer the same person who prepared the original AD (indeed, this perspective is often reflected in the comments of loved ones, for instance, 'that's not my mum anymore'). If the individual is indeed 'no longer the same person' then arguably the AD may no longer apply.

2.4 Attitudes towards assisted dying in advanced dementia

There is a divergence of opinions on this subject among physicians, nurses, and the general public (Brinkman-Stoppelenburg et al., 2020; Tomlinson & Stott, 2015). The stage of dementia and the presence or not of an AED play a role in the attitudes towards assisted dying in these individuals (Bravo et al., 2019; Tomlinson & Stott, 2015). With regard to advanced dementia, different levels of acceptance of assisted dying are demonstrated in Figure 2.1 below.

Figure 2.1 | Level of acceptance of assisted dying in advanced dementia



1. Ryynanen et al., 2002; 2. Rurup et al., 2006; 3. Rietjens et al., 2005; 4. Gielen et al., 2009; 5. Williams et al., 2007; 6. Kouwenhoven et al., 2013; 7. Bolt et al., 2015; 8. Terkamo-Moisio et al., 2017; 9. Picard et al., 2019; 10. Brinkman-Stoppelenburg et al., 2020; 11. Bravo et al., 2019; 12. Cleemput & Schoenmakers, 2019

* This level of acceptance among gps decreases to 23% for clinical specialist and 8% for nursing home physicians.

Note: wherever possible, x-axis represents studies in the year in which they were conducted.

Together publicly growing recognition of an ‘individual right of self-determination about one’s life and death’ and the ‘right to die’ among the Dutch population over the years (Koopman, 2019; Kouwenhoven et al., 2019) accommodated the inclusion of dementia as another acceptable reason for an assisted death. The public has come to regard such an option as an acceptable personal choice to make regardless of the individuals’ state of competence. The extent of discrimination between competent and incompetent is less among the public relative to physicians (Rietjens, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2005). In cases of incompetency, it appears that the public value the expressed wishes of the formerly competent patient more than physicians and nurses (Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2006) retaining the highest degree of acceptance of assisted dying when there is an AED that is written prior to losing competency (Bravo et al., 2019; Diehl-Schmid et al., 2017; Kouwenhoven et al., 2013; Rietjens et al., 2005; Tomlinson & Stott, 2015). It has been noted that public acceptance of assisted dying is strongly associated with tolerance towards freedom of personal choices (Cohen, van Landghem, Carpentier, & Deliens, 2014) and with other factors including younger age and higher educational level. A plausible explanation may be that younger people are more educated and probably less religious, and education positively increases the level of value felt for personal autonomy and individualism (Brinkman-Stoppelenburg et al., 2020).

On the other side of the spectrum, physicians, by comparison with nurses and the general public, continue to be least in favour of acting upon an assisted death request of a patient with advanced dementia (Bolt et al., 2015; Bravo et al., 2019; Kouwenhoven et al., 2013; Kouwenhoven et al., 2015; Rietjens et al., 2005; Tomlinson & Stott, 2015) stating the problems concerned with the evaluation of the Dutch due care criteria[10] as primarily underlying reasons (Bolt et al., 2015; Schuurmans et al., 2019). Among physicians with different specialties, the willingness to consider performing euthanasia based on the AEDs in the advanced stages are lowest among nursing home physicians. This reticence could be due to them being most likely to be involved in end-of-life care of patients with dementia and performing assisted death and therefore being more aware of the difficulties involved in the process

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[10] The six requirements of “due care” are stipulated in section 2 (1) of the Termination of Life on Request and Assisted Suicide Act and requires that the physician must: a) be satisfied that the patient’s request is voluntary and well-considered, b) be satisfied that the patient’s suffering is unbearable, with no prospect of relief or improvement, c) have informed the patient about their situation and prognosis, d) have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient’s situation, e) have consulted at least one other, independent physician, who must see the patient and give a written evaluation on whether due care criteria stated above have been fulfilled, and, f) have exercised due medical care and attention in termination of the patient’s life or assisting in his death.

(Bolt et al., 2015; Brinkman-Stoppelenburg et al., 2020; de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2010a; Schuurmans et al., 2019). An AED is regarded impractical for physicians who require, in addition, to establish the voluntary and persistent nature of the patient's assisted dying request and the presence of unbearable suffering at the time of its application (Evenblij et al., 2019; Kouwenhoven et al., 2015). Nurses are more in favour of assisted dying for individuals with advanced dementia than physicians, and less in favour of it than the public (Kouwenhoven et al., 2013; Rietjens et al., 2005; Rurup et al., 2006; Ryynänen, Myllykangas, Viren, & Heino, 2002; Terkamo-Moisio, Pietilä, Lehto, & Ryynänen, 2019). Nurses are involved daily with the end-of-life care of patients and their families and more often are confronted with the complexity of their care. They are often the first health professional to whom a patient expresses a desire to be helped to die regardless of the legal status (De Bal, Gastmans, & Dierckx de Casterle, 2008; Bravo et al., 2018a). Nurses serve as a liaison between physicians and patients or families often assisting and counselling patients and their larger health care team of their assessment of patients' needs and end-of-life requests (De Bal et al., 2008). Although nurses' feelings about assisted dying and their involvement with the care of a patient requesting such assistance are complex, their actions are driven by their concerns and compassion about patients suffering (De Bal et al., 2008). Furthermore, despite their essential role as informants, liaisons, and consultants in the assisted dying decision-making process, physicians often have the ultimate responsibility of carrying out the request (De Bal et al., 2008). These factors may explain their middle-ground position.

The differences in views of HPs and the public seem to be associated with HPs' work experience in the healthcare setting including their knowledge of the care options available and complexities of the situation (Bolt et al., 2015; Terkamo-Moisio et al., 2019). While it appears that informing the public of the ethical and practical complexities in AEDs may decrease their supportive attitudes towards assisted dying legalisation in dementia (Mangino, Bernbard, Wakim, & Kim, 2020a), different roles and responsibilities of HPs in the process of decision-making and the delivery of care could be attributed to their less permissive opinion relative to the public (Rietjens et al., 2005; Terkamo-Moisio et al., 2019). While "people who can express their wishes in the form of advance directives want them to be followed, physicians who have to carry out the wishes of these people are responsible and will usually only consider following an advance directive if this is consistent with the law" (Rurup et al., 2006, p. 379). Patients and families often have high expectations of the feasibility of AEDs (Brinkman-Stoppelenburg et al., 2020) while they are, at points, poorly informed about what current assisted dying laws entail with regards to incompetent cases (Picard et al., 2019). Ambiguous AEDs and people being unaware of the procedure were among the reasons that complicated assessing and granting euthanasia requests that were published by the Regional Euthanasia Review Committee [RTE] between 2011 and 2018 (Mangino, Nicolini, De Vries, & Kim, 2020b). It is hard to infer a trend on attitudes towards assisted dying for advanced dementia because of the differences in studies' populations and questions/vignette presented to participants. Reported findings, however, show that support for the use of AED for an incompetent patient with dementia would be greater in the presence of suffering and distress. Recent findings also show that people contemplate the expansion of assisted dying laws to include individuals with dementia particularly in jurisdictions where assisted dying is already legal (Chambaere, Cohen, Robijn, Bailey, & Deliens, 2015; Cohen-Almagor, 2015; Dehkhoda, Owens, & Malpas, 2020a; Dening, Jones, & Sampson, 2013).

2.5 Assisted dying for individuals with dementia based on AEDs: laws and occurrence rate

Some forms of AED are legally included in the assisted dying laws of the Netherlands, Belgium, Luxembourg, and Colombia (CCA, 2018; Dierickx, Deliens, Cohen, & Chambaere, 2017; Dyer, White, & Garcia Rada, 2015). However, only the Netherlands and Belgium have publicly provided some information, mainly in forms of statistics or case reports, on how AEDs are working in practice.

The Dutch Act – Section 2 (2) of the Dutch euthanasia legislation stipulates that a decisionaly competent patient aged sixteen or over may draw up an advance directive setting out a request for euthanasia. If at some point the patient is no longer capable of expressing their assisted dying wish, the physician may accept their AED as a request pursuant to section 2 (1) (a) of the Act. Therefore, AEDs have the same status as an oral request for euthanasia. In the events of AED, due care criteria apply to the greatest extent possible in the given situation ("mutatis mutandis") (RTE, 2018b).

One key aspects of the Act concerns individuals with dementia. While there is no provision that euthanasia may only be performed in the 'terminal stage', the Act implies that assisted dying can only be performed while some level of consciousness is retained as it requires the physician to confirm the unbearable nature of patient's suffering and according to the Code of Practice, "suffering assumes a conscious state" (RTE, 2015, p. 29). The latter has an implication for AEDs: they may only be adhered to in cases of patients with reduced consciousness only if signs of suffering can be established from their behaviour and utterances (RTE, 2015). This appears in direct contrast to the assisted dying legislation in Belgium and Luxemburg where AEDs may only be followed for patients at an unconscious level (CCA, 2018).

The first reported case of euthanasia of an individual with *early* dementia was in 2004 (RTE, 2005). From 2009, the RTE began to clearly state the numbers of cases of individuals with dementia who died as a result of an assisted death. The annual reports show that the RTE received 871 dementia-related assisted dying cases between 2009 and 2018. Even though, dementia is negatively associated with both requesting and receiving euthanasia compared to other conditions (Evenblij et al., 2019), since the enactment of the Dutch euthanasia law in 2002, the rate of requests involving individuals with dementia has continued to increase (Figure 2.2). In 2012, the policy of the euthanasia review committee faced a radical change; that is, “the initial reluctance to consider requests for termination of life from certain groups of patients (such as those with mental illness or dementia) appears to be making way for a more liberal position” (RTE, 2013, p. 3). This shift in opinion led to an increase in the number of assisted dying cases involving individuals with dementia from 42 cases in 2012 to 97 cases the following year. After a 0.48% decrease in the number of dementia cases in 2014 (81 out of 5,306) – despite the 10% increase in the total number of assisted death cases compared to 2013 (97 out of 4,829) – the rate of assisted dying in cases of dementia continued to increase to 169 cases (out of 6,585) reported in 2017. As in 2017, there was a slight decrease of 0.18% in the number of patients with dementia who were assisted to die to 146 cases out of 6,126 assisted deaths in 2018. The majority of patients were, however, in the early stages of the disease, defined as a phase of dementia in which patients are deemed competent with regards to their request since they could still oversee the consequences of their request (Brinkman-Stoppelenburg et al., 2020).

The RTE reported the first case of an assisted death with a patient with *advanced* dementia in 2011, with three cases reported in 2017 where AEDs were used. Concurrently, Dutch physicians published a manifesto arguing against the use of AED for patients in the very advanced stages of dementia believing that an assisted death is only morally justified for those who are able to orally confirm their request (RTE, 2018a). As this debate continued in 2018, the number of granted euthanasia cases based on the AED of a patient with advanced dementia remained very low with only 2 reported cases in 2018 (RTE, 2019). It appears that despite legislation in the Netherlands, compliance with AEDs in practice remains low and assisted dying for people with dementia is limited to mainly competent patients in early-stage dementia. In 2015, a mortality follow-up study was performed in the Netherlands to estimate the frequency of requesting and receiving assisted dying. Results show that out of 5361 deceased patients aged $\geq$ 17 years and whose death was non-sudden,_803 (15.0%) had dementia. Among those with dementia 2.1% had requested an assisted death where only 43% (0.9/2.1) of these requests were granted (Evenblij et al. 2019). This study, however, does not specify whether these requests were concurrent or documented in a form of an AED.

The Belgian Act – AEDs are legally effective in Belgium only if (a) the patient is afflicted by a serious and incurable accidental or pathological condition; (b) the patient is *unconscious*; and (c) the condition is irreversible according to the state of medical science at the time (Downie & Lloyd-Smith, 2015; Lewis & Black, 2013; van Zeebroeck, 2018). Furthermore, the Act also stipulates that advance directives must have been made at least five years prior to the start of incapacity (Downie & Lloyd-Smith, 2015). These requirements limit the provision of euthanasia to only those patients with dementia in an unconscious state, as states (a) and (c) are present in cases of dementia.

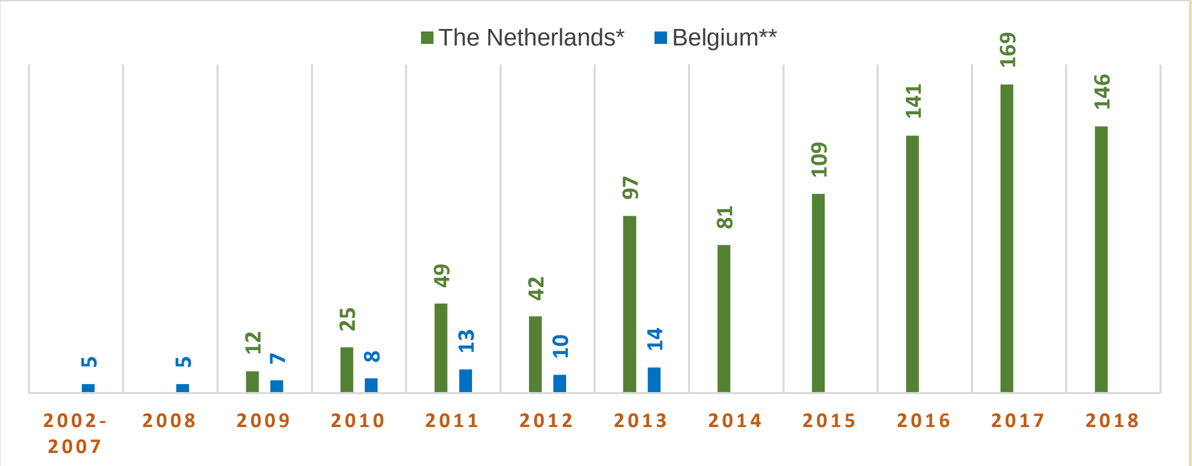
The Belgian criteria of unconsciousness resulting from serious and incurable disorders is more susceptible to a HPs' objective evaluation than a Dutch subjective criterion of suffering (Rurup et al., 2012). Meaning that it is easier to assess whether or not a patient with dementia is in an irreversible unconsciousness state than to assess the level of suffering of an incompetent yet conscious patient. Furthermore, respecting AEDs in the state of irreversible unconsciousness could be argued to be of less moral concern than respecting them for patients who are conscious but lack decision-making competency. At the time that an AED is meant to take effect in an unconscious state, there is no active agent whose preferences need to be taken into account (Menzel & Steinbock, 2013; Tsinorema, 2015). This rather straightforward requirement of the Belgian Act may explain the greater willingness of Belgian HPs – unlike the Dutch ones – to perform euthanasia based on AED (Lewis & Black, 2013; Rurup et al., 2012). A recent study on the views of 113 Flemish GPs on euthanasia in the case of dementia shows that as the progression of dementia increases, so too does the acceptability of performing euthanasia (Cleemput & Schoenmakers, 2019). In contrast, among Dutch physicians the willingness to consider performing euthanasia, where an AED is available, decreases with the progression of dementia (Bolt et al., 2015; Cleemput & Schoenmakers, 2019; Kouwenhoven et al., 2015) because of need to establish suffering before assisted dying can occur. The differences between Dutch and Belgian regulations on the use of AEDs and the state of consciousness could explain this apparent contradiction.

While the practice of assisted dying for individuals with dementia remains comparatively limited in Belgium, people with dementia are increasingly desiring access to the law (Dierickx et al., 2017; Cleemput & Schoenmakers, 2019). This desire has been primarily centred on amending the law to extend AEDs for patients who lack decision-making competency but are still conscious. Reports show a gradual increase in the prevalence of euthanasia for conscious individuals with dementia from 2008 onwards (Figure 2.2). Euthanasia was performed on a total number of 62 patients with dementia during the period of 2002-2013, (Dierickx et al., 2017) and on 60 cases during 2014-2017 (Picard et al., 2019). There is no information provided on the degree of cognitive impairments in these cases and whether the dementia itself or another underlying medical condition, has triggered the assisted death request (Dierickx et al., 2017; Picard et al., 2019). Reports, however, indicate that the majority of cases were at earlier stages as previously discussed.

Luxembourg Act – The Euthanasia and Assisted Suicide Law allows assisted death for a competent patient with a terminal medical condition in the same way as the Belgian Act. However, unlike Belgium, patients can create an AED at any stage of the disease as long as they are competent to do so. These directives are, nonetheless, required to be confirmed at least once every five years from the date of registration (Downie & Lloyd-Smith, 2015). This specific requirement stipulates that if a patient with dementia has been incompetent for more than five years and is still conscious, their advance directive will no longer be valid for the purpose of assisted dying. The National Commission of Control and Evaluation (CNCE) in Luxembourg has reported only one death following an AED in 2012 (CCA, 2018). It is, however, unclear whether this was a case of dementia.

Colombia Act – Under Resolution 2665 on Colombia right to die with dignity, advance directives enable the formulation of various instructions for end of life, including the request for euthanasia (Colombian Ministry of Health and Social Protection [MINSALUD], 2018). In the presence of an advance directive, a patient’s substitute decision-maker can either make the request for euthanasia on the patient’s behalf or even withdraw the existing request and choose other alternatives (CCA, 2018). At this time no statistics on the practice in Colombia have been identified (CCA, 2018). Of the four countries that allow AEDs, Colombia limit their application only to the context of imminent death (CCA, 2018).

Figure 2.2 | Cases of euthanasia involving individuals with early and advanced dementia



* Dutch regional euthanasia review committee (RTE)

** Dierickx et al., 2017

Note 2: numbers of cases that involved patients with advanced dementia in the Netherlands are 1 case in 2011, 3 cases in 2017, and 2 cases in 2018.

2.6 Reasons for not following AEDs in individuals with advanced dementia: current practice

Many factors underpin the low rate of following AEDs in advanced dementia. These include a) the law is inconsistent with regard to incompetent cases, b) initiating the process of assisted death based upon AEDs causes moral and emotional distress for those involved such as caregivers and HPs, c) caregivers may be reluctant to condone an assisted death when a caregiver is responsible for making the final decision to act upon an AED, and d) nursing home policies are not always in alignment with assisted dying laws.

2.6.1 Inconsistency between the Dutch assisted dying laws and practice

Unlike section 2 (1) of the Act, presented in section 2.4 above, there are some inconsistencies in section 2 (2) with regard to AEDs for incompetent patients. As to the first criterion, it is presumed difficult for physicians to assess either the voluntariness of the directives that may have been made years ago or the decision-making process that led to directives being executed (Evenblij et al., 2019; Schuurmans et al., 2019; van Delden, 2004). A physician may not know the patient or have had any long-term involvement in their medical care.

Regarding the second criterion of suffering assessment, the inconsistencies between law and practice are twofold. The first problem is associated with evaluating unbearable suffering, which is still required to be established immediately prior to the termination of life on advance request (RTE, 2015). The due care criteria allow for a framework through which HPs are permitted to assess both physical and psychological suffering (Mondragón, Salame, Kraus, & De Deyn, 2019). The suffering assessment should incorporate verbal and nonverbal manifestations of suffering through patients' behaviour and utterances. When verbal communication is no longer possible, nonverbal communication becomes the essence of this evaluation. Over the years 2007-2012, the Dutch Regional Review Committee elaborated on and interpreted the due care criteria in many ways including in cases of dementia. In the advanced stages of dementia, the committee proposed combining different sources of information provided by patients from their previously written directives, their current behavioural clues and body language, and their contemporaneous oral statements (Legemaate and Bolt, 2013). Despite this, difficulties in determining the unbearableness of the suffering of incompetent patients because of lost communication skills continue to be the primary reason for non-compliance with AEDs (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2011; Evenblij et al., 2019; Kouwenhoven et al., 2015; Mangino et al., 2020b; Mevis, Postma, Habets, Rietjens, & van der Heide, 2016; Rietjens, van der Maas, Onwuteaka-Philipsen, van Delden, & van der Heide, 2009). As interpreted by the Code of Practice, unbearable suffering is about the suffering of a specific patient with regards to their life history, personality, stamina and values, and their awareness of the suffering (RTE, 2015), all of which could be influenced by the patient's lack of insight (anosognosia).

The second problem, as van Delden (2004) notes, is related to the clause "no prospect of relief", which refers to the relief of symptoms (such as pain, distress, nausea, etc.) – not the relief of the underlying disease. As he claims, "in line with this, a diagnosis of a dementia syndrome alone cannot be enough. The associated distress, disorientation, or emotional instability could be enough, but these are often relieved – at least to some extent – by the admission to a nursing home, which provides structure and protection to an individual with dementia" (van Delden, 2004, p. 448).

Loss of communication would also interfere in the effectiveness of the third and fourth criteria, which require shared decision-making and reflection on the patient's situation. Full compliance with the due care criteria rests upon communication, mutual understanding, and joint decision-making, which is in conflict with the primary intention of AEDs: to speak for the individual when they can no longer communicate or share in decision-making.

The Dutch euthanasia law requires physicians to fulfil the due care criteria “in a corresponding way”, not in the same way as euthanasia in the absence of dementia, to allow some interpretation and adjustment to the rules in specific circumstances (de Boer et al., 2011; Mevis et al., 2016; van Delden, 2004). Despite this, emerging studies indicate the inadequacy of Article 2.2 in practice to comply with AEDs of an incompetent patient who is rendered incompetent as a result of dementia (de Boer at al., 2010a; Hertogh, 2009; Mangino et al., 2020; van Delden, 2004).

2.6.2 Moral and emotional distress of initiating assisted dying based on AEDs

Acting upon AEDs in the stage of advanced dementia may entail the personal and professional views of others. Family members/caregivers and physicians faced with the responsibility of making the decision of whether or when to act upon an AED, may cause ‘moral distress’ (Hertogh, 2009). There is a responsibility, particularly on families/caregivers to present the directive, thus initiating the implementation process (Hertogh, 2009). Research affirms that families/caregivers “often underestimate the gravity of the moral obligation they engage in when accepting the responsibility of seeing an AED complied with. Many of them eventually shy away from this responsibility […]” (Hertogh, 2009, p. 103).

Any specifications about the chosen moment of performing the AED requires interpretation by someone else other than the author of an AED. The issue of irreversibility of dementia makes it difficult (if not impossible) for the patient to reconsider the decision made in advance. Where the patient seems to resist the course of action that had been expressed in their advance directive, this may result in understandable caution and even doubt about progressing (Gastmans & de Lepeleire, 2010). How is such resistance to be interpreted? When the precedent and current wishes of patients with dementia appear to be in conflict, some families and HPs may find it morally distressing to initiate the process of assisted dying and watch their loved ones or patients die despite knowing the individual had previously requested this course of action (Davis, 2018). This may explain the high opposition of Quebec nurses (83%) to extend medical assistance in dying (MAID) to incompetent patients with dementia who do not show signs of distress at the end of life, regardless of an AED (Bravo et al., 2018a). As Dresser notes, it is not unreasonable to assume that some patients with advanced dementia may not experience the kind of suffering they feared when writing their AEDs (Hertogh, 2009; Hertogh et al., 2007a; Mevis et al., 2016), thus one can understand a cautious approach in promoting the use of advance directives for an unknown future condition where it is argued that a reasonable quality of life can be experienced (Cohen-Almagor, 2015; Hertogh et al., 2007a; Widdershoven & Berghmans, 2001; Wolff, 2012).

Suffering is a subjective interpretation of one's experience and not merely the result of physical distress or a symptom of a disease (CCA, 2018). It may be possible to envisage, on the basis of the individualised conception of suffering, multiple circumstances of anticipated suffering, and what would be deemed personally intolerable in an incompetent future. These circumstances, if experienced may not reflect the actual experience of the author of the AED (CCA, 2019; Mevis et al., 2016). This could create uncertainty and further burden the decision-maker deciding when, or if, the author of AED is suffering intolerably.

On the other hand, performing an assisted death in general can also have a significant emotional impact on physicians. Although helping terminally ill patients through the dying process can be one the most rewarding parts of a physicians' work, decision-making at the end of life can be particularly challenging especially in relation to euthanasia (van Marwijk, Haverkate, van Royen, & The, 2007). Among some reported positive emotions such as being in control, relief at being able to do something for patients, great satisfaction when the euthanasia process went well, and feeling touched by seeing the love and commitment of the patient's family, there have also been burdensome feelings, moral distress, general discomfort, tension before the performance, sense of loss and feeling scared during the process, feeling of being judged by society and an inability to share their emotions afterward reported among physicians (Schuurmans et al., 2019; van Marwijk et al., 2007). The challenges of end-of-life decision-making may particularly escalate with fear of prosecution for wrongdoing in cases of incompetent patients who may have forgotten their AEDs. A good example is of the Dutch physician who was acquitted of wrongdoing for euthanising a woman in 2016 with advanced dementia who had to be restrained by her family as she was euthanised, having been given a sedative in her coffee beforehand (Asscher and Van de Vathorst, 2020).

2.6.3 Role of others in obtaining assisted dying based on AEDs

Involvement of family members in the assisted dying decision and its enactment process is evident across various jurisdictions (Gamondi, Fusi-Schmidhauser, Oriani, Payne, & Preston, 2019; Roest, Trappenburg, & Leget, 2019). Families may play a critical role in enabling their loved ones to receive an assisted death, and their opposition to assisted dying can influence the patients' likelihood of obtaining such assistance (Gamondi et al., 2019; Snijdewind, van Tol, Onwuteaka-Philipsen, & Willems, 2014). Individuals with dementia, and their families/caregivers, may wish for an assisted death at the earlier stages of the disease to ensure choice and control over their death (Dening et al., 2013; Pols & Oak, 2013). Caregivers and patients have appeared reluctant to condone an assisted death when a caregiver is held responsible for making the decision to enact an AED (Tomlinson & Stott, 2015). A plausible explanation could be that advance directives become the executive agents of patients' preferences and values without necessarily providing definitive information on who should carry out the preferences (Hertogh et al., 2007a) or when and how this should be done. Individuals with reduced capacity to protect their preferences and interests are, therefore, inherently vulnerable in that they are dependent on families/caregivers and HPs to execute their interest on their behalf (MacKenzie, Rogers, & Dodds, 2014).

Families of individuals with dementia mostly decide against following an AED when they are held responsible to make a decision, even though they generally support euthanasia based on an advance directive (de Boer at al., 2011; Rurup, Onwuteaka-Philipsen, van der Heide, van der Wal, & van der Maas, 2005). Research with 2,200 patients with dementia with AEDs shows that in three-quarters of the cases, a patient's family or representative did not allow the directive to be complied (Rurup et al., 2005). A more recent study of the relatives of nursing home patients with dementia also obtained similar results: 63% of the relatives requested that physicians not comply with AEDs (de Boer et al., 2011). In addition, physicians are also inclined not to adhere to the instructions of an AED of patients with dementia particularly in cases where the content of an advance directive conflicts with their clinical judgments of patients' current condition (de Boer et al., 2010b; de Boer et al., 2011; Rietjens et al., 2007). Because of above mentioned distress and complications involved in the process, physicians and families may at times come to an agreement to forgo life-prolonging treatment instead of complying with the AED (de Boer et al., 2011; Kouwenhoven et al., 2015; Rurup et al., 2005). Research affirms that AEDs often play a supportive role in non-treatment decisions (de Boer et al., 2010b; Kouwenhoven et al., 2015; Rurup et al., 2005). In Dutch practice, non-treatment directives and AEDs are regularly formulated into one document such that non-treatment directives automatically replace AEDs should the latter not be complied with (de Boer et al., 2010a). Therefore, it appears that the patient's AED may have a marginal effect on the final decision (to enact it) compared to physicians' medical judgment, and relatives' influence (de Boer at al., 2010b).

2.6.4 Nursing home policies and assisted dying laws

The policy of nursing homes in the Netherlands also plays a role in the lower uptake of advance directives. The majority of Dutch nursing homes have some form of guidelines and policies for dealing with euthanasia requests (de Boer et al., 2010a). Nursing home policies are relevant as they are the primary place of death for the majority (92%) of patients with dementia in the Netherlands (Houttekier et al., 2010). Among nursing home physicians, one of the most frequently mentioned reasons for not complying with AEDs was that it was against their nursing home policies (de Boer et al., 2010a; Rurup et al., 2005). A study of a sample of 405 elderly care physicians (ECPs) showed that almost half (46% or 188) of them worked in a nursing home with a particular policy on euthanasia for patients with dementia (de Boer at al., 2010a). While most (63%) ECPs indicated that AEDs in cases of dementia are not complied with per se but are taken into account to support a restricted treatment policy, 16% indicated that AEDs are never complied with. The majority (88%; 165/188) of these ECPs were in agreement with this non-compliance policy in cases of dementia (de Boer et al., 2010a). A further explanation could be that this policy statement accorded with the attitudes of some physicians with a religious background who more often disregarded the presence of dementia to be a valid reason for euthanasia (de Boer et al., 2010a; Rurup et al., 2005).

2.7 Suicide and other risks

As ethical tensions and practical issues continue to remain challenging, and some physicians maintain an unwillingness to act upon a patient’s AEDs, the risk of pre-emptive suicide among individuals with dementia remains a real threat. Pre-emptive suicide has been argued for as a rational course of action for some older people with dementia (Davis, 2014). A mixture of motivations is linked with interest in rational suicide including “motivations related to autonomy (distaste for a life of dependency), non-maleficence (a wish to avoid burdening others) and beneficence (preservation of assets to hand on to others)” (Davis, 2014, p. 544). There is a considerable risk of suicidal ideation/completion for some subgroups of patients with dementia who are in the early stages, those who suffer from psychiatric comorbidities (particularly depression), or patients who are younger (Diehl-Schmid et al., 2017). Studies have shown depression in a high proportion of patients with dementia who expressed suicidal behaviour, or who committed suicide (Diehl-Schmid et al., 2017).

People with dementia have also much less control over other end-of-life decisions such as requesting the refusal of life-prolonging treatments or voluntarily stopping eating and drinking (VSED). Some patients may live for years in an advanced (dementia) state receiving life-prolonging treatments that could be refused by them if they had retained competency. As for desiring VSED, patients are required to be competent to “voluntarily” stop eating and drinking thus patients may decide to refuse food and drink while they are still capable of doing so, which may be earlier than they actually desire (Menzel & Chandler-Cramer, 2014). Furthermore, choosing this course of action and acting on it until the end requires a level of perseverance and commitment that may not be possible in the later stages of dementia. Where research from the Netherlands shows that physicians are more likely to refuse an assisted dying request when patients are at some level incompetent, patients may present a greater desire to be helped to die earlier than is needed (Jansen-van der Weide, Onwuteaka-Philipsen, & van der Wal, 2005). There may be a potential risk of pre-emptive suicide when one inference is that not being (fully) competent would result in a request being rejected. The other is that AEDs if legally available may not be adhered to without patients’ ability to give their assent.

2.8 Developments in research on assisted dying for dementia and future research

Research is focusing on a more dementia-specific domain in the context of assisted dying and AEDs. This may be a reflection of a general trend towards growing support for assisted dying, specifically in western European countries (Cohen et al., 2006; Cohen et al., 2014; Tomlinson & Stott, 2015), several US states, Canada, Australia, and New Zealand where assisted dying legislations have been recently implemented and/or been socially supported. Furthermore, inconsistencies in the existing Dutch regulation of AEDs in cases of incompetency, at both drafting and implementation phases, are being more openly discussed and investigated (de Boer et al., 2010a; de Boer et al., 2010b; Davis, 2018; Hertogh et al., 2007a; Hertogh, 2009; Mevis et al., 2016; Miller, Dresser, & Kim, 2019; van Delden, 2004). One prime feature of the due care criteria that has being particularly criticised is the emphasis on suffering as a necessary condition to grant an assisted dying wish. This argument that the presence of suffering is not an appropriate legislative requirement in cases of advanced dementia (Hertogh 2009; Menzel, 2019; van Delden, 2004) has given rise to questions of whether suffering should be included into the legal framework of jurisdictions that are looking into extending assisted dying laws to incompetent patients, and if so, how it should be defined (Bravo et al., 2019).

The perspectives and experiences of HPs' and the public in different jurisdictions are being actively sought specifically on the matter of assisted dying for individuals at different stages of dementia (Bolt et al., 2015; Bravo et al., 2018a; Brinkman-Stoppelenburg et al., 2020; Brauer, Bolliger, & Strub, 2015; Cleemput & Schoenmakers, 2019; Dehkhoda et al., 2020a; Dehkhoda, Owens, & Malpas, 2020b; Gielen, van den Branden, van Iersel, & Broeckaert, 2009; Kouwenhoven et al., 2012; Kouwenhoven et al., 2015; Loizeau et al., 2019; Schuurmans et al., 2019; Picard et al., 2019; Terkamo-Moisio et al., 2019) with an increasing focus on research exploring the perspectives of patients' and their caregivers (Bravo et al., 2019; Dening et al., 2013; Loizeau et al., 2019; Tomlinson, Spector, Nurock, & Stott, 2015), their role and involvement in the decision-making process (Roest et al., 2019), and on complexities experienced by families/caregivers with regard to assisted dying practice (Snijdewind et al., 2014). More research is emerging on dementia case reports (Dierickx et al., 2017; Mangino et al., 2020b) around issues of requesting and receiving assisted dying (Evenblij et al., 2019; Snijdewind et al., 2014).

The role and interpretation of physicians' duties at the end-of-life to alleviate unbearable suffering and preserve the patient's life has been challenged as a consequence of giving priority to the patient's autonomous preferences (Kouwenhoven et al., 2019). This implies a further change in the role of advance directives in the context of dementia (de Boer, et al., 2010a; de Boer et al., 2010b). Physicians face the challenging task of finding a balance between their professional responsibilities and respecting patient autonomy (Kouwenhoven et al., 2019). Balancing, as Gastmans and de Lepeleire (2010, p. 85) define, "is the process of finding reasons to support beliefs about which moral values should prevail". Good relationships between HPs and patients, commitments, trust, and greater communication are assumed to be prerequisites to finding the right balance (Kouwenhoven et al., 2019).

Some scholars suggest providing information about advance directives for individuals with dementia and their caregivers, as well as offering them an opportunity to draft these directives soon after their diagnosis (Dening et al., 2013; Porteri, 2018). As the specific biomarkers to aid diagnosis of each neurological disease are emerging and being more commonly used in clinical settings, the possibility of early diagnosis of dementia before the onset of cognitive impairment is becoming a reality (Frisoni et al., 2017). The primary benefit of the early diagnosis of dementia is the opportunity to plan medical and care decisions in advance, utilising the opportunity to exercise the right to self-determination (de Boer et al., 2010b). Therefore, soon after clinical diagnosis, physicians are encouraged to discuss with patients the option of executing advance directives for those with dementia who are still capable of making decisions (Dening et al., 2013; Porteri, 2018). Yet studies show that physicians are not very comfortable with either initiating advance planning conversations with nursing home residents with dementia (van der Steen, Galway, Carter, & Brazil, 2016) or discussing the questions raised by patients/families about assisted dying (Picard et al., 2019). They either primarily discuss advance planning (including end-of-life decisions such as AEDs) with patients' relatives or representatives rather than patients themselves (de Boer et al., 2010a; de Boer et al., 2011; Rurup et al., 2005) or discuss the matter with patients too late when some of them may already be too cognitively impaired (Chambaere et al., 2015; Dening et al., 2013).

More empirical, qualitative research is needed on patients' perspectives on AEDs, specifically within the context of dementia. Such research should explore the experience of dementia from patients' perspectives as well as their understanding of, and expectation from, an advance directive. While understanding of patients' experiences with advance care planning (ACP) is deemed vital to improving its implementation (Zwakman et al., 2018), exploring patients' experiences with advance directives, as a part of ACP, may also help optimise its value and achieve parallel positive outcomes. In addition to patients' perspectives, it is important to gain more insight into families/caregivers' and HPs' perspectives and experiences in this regard. There is still a need for further research into the dilemmas faced by families/caregivers in the implementation phase of AEDs and their underlying motives (de Boer et al., 2010b) particularly if they are held responsible to act in accordance with the known wishes of the patient. It appears that the high level of burden of making end-of-life decisions may interfere with families' ability to represent accurately prior competent wishes of their patients or their best interests (Emanuel, 1995). Some of the reasons identified are doubts whether the state of unbearable suffering has been reached, who should make the final decision to act upon it, difficulty picking a date to carry out euthanasia, not being ready, and conflicting feelings when their loved ones still have enjoyable moments (de Boer et al., 2011; Roest et al., 2019). This highlights the role and importance of advance directives within the context of dementia and the need for further exploration.

2.9 Conclusion

For many older individuals, the subjects of choice and control at the end of life have gained growing importance alongside respect for the autonomous choices of individuals about their medical treatment and care. As Hertogh notes, many older individuals “want to remain in control of their life and future, and specifically reject the perspective of a disease that causes their identity to unravel and brings with it a loss of competence and independence (Hertogh et al., 2007a, p. 49).

The ongoing deterioration of the brain caused by dementia causes uncertainty about the continuity of personal identity before and after the onset of cognitive loss with implications for the validity of advance directives depending on whether a person with dementia is considered to be the same person or becomes a different person to the one who originally drafted the AED (Moody, 2003). Challenges to the moral authority of an AED on this basis would argue that the psychological continuity of a person with dementia is a critical issue in determining whether such directives are seen as relevant (Buchanan, 1988). The existence of different positions to interpret the notion of personhood with regards to advance directives only emphasises the complexity of this issue. Despite these conflicting and apparently irreconcilable viewpoints, the actual drafting of AEDs (as opposed to decisions around whether to act on them) is likely to continue in the immediate future. It seems, therefore, reasonable to shift the focus to enhance the validity of contents of AEDs to reflect a well-considered and realistic awareness of their content and effects. The ethical problems are compounded by practical ones, in particular the communication difficulties which arise in advanced dementia, making the normal ‘check and balance’ discussions between physician and patient impossible. Issues such as these may have implications for the way AEDs are conceived and written. For instance, it is becoming evident that HPs’ involvement and discussion at the preparation and drafting stage suggest more likelihood of adherence to an AED in practice due to increased credibility of directives and more specific and detailed trigger criteria (Mangino et al., 2020).

From a practical point of view, as long as assisted dying laws require acting upon the AEDs of a now incompetent patient to involve similar criteria that apply to competent patients, the requirements of AEDs will remain unmet. These criteria may, therefore, need to be modified and tailored to the specific features of dementia. The degree of application consistency of such modifications is, however, under question. This directs us towards considering the development of a unified system that provides more detailed guidelines for the drafting, assessment, and implementation of AEDs and is specifically designed to safeguard the practice of assisted dying for individuals with advanced dementia. Such a system may help enhance the clarity of AEDs and reassure physicians about their validity. Similar initiatives have been taken in other areas of assisted dying. In the Netherlands in 2010, a public discussion was initiated that aimed to legalise assisted dying for elderly people without a medically classifiable condition who considered their life completed. In 2014, in response to this “Completed Life” initiative, the Dutch government established a multidisciplinary committee of acknowledged experts to explore the legal possibilities as well as related social dilemmas for those elderly people who consider their life completed to enable them to exercise autonomy for an assisted death (Kouwenhoven et al., 2019; Wijngaarden, Klink, Leget, & The, 2017). After two years of intensive research and consultation with national and international experts and stakeholders, the Advisory committee advised against changing the current law because of the risk involved (Wijngaarden et al., 2017). However, years of research leading to this decision resulted in an increased understanding of the needs, especially psychological and existential needs, concerns, motivations, and conditions of those wishing to access assisted dying in cases of a completed life. Granting an assisted death for a competent individual who is distressed by the prospect of living too long may not be analogous to granting the same request for an incompetent individual who may have forgotten their prior wish for an assisted death. Yet in both situations, societal developments are moving in the direction of more self-empowerment and respecting patient’s autonomous choice as the basis for assisted dying practice (either verbally through an ACP or request, or in an AED). One needs to consider that the alleviation of suffering may not be an ultimate desire of a patient with an assisted death wish – rather be spared a future life with dementia (Hertogh et al., 2007a). One may still choose to be assisted to die despite acknowledging that she may well become “happily demented”. Also, in both situations, people may request an assisted death because of their living conditions, either due to dementia or elderly related conditions, but are marginalised due to those conditions. Therefore, looking at options to extend AD laws to include either dementia or Completed Life (regardless of the outcome) would trigger a review of any possible things that might improve the quality of life of those targeted groups of people. It could be that, in the end, the law does not include them, or they do not receive an assisted death, but on the other hand, I think it is going to provide many more alternatives and strategies and forces us to look more closely at the quality of life these people are having. This will in turn prompt a better response to the needs of these individuals.

As we know from the literature the expectations of non-specialists regarding freedom to choose the moment of death and what HPs think they can actually do present challenges. These would continue to exist as sometimes preserving autonomy and preventing harm are in conflict. So, in this chapter, I looked closely at AEDs as a key concept in this topic and explored the reasons why they are rarely being followed. I covered the most compelling reasons such as inconsistencies within existing legislations and ethical arguments about personhood and autonomy and their influence on the attitudes of end-users and therefore on practice. I shed light on the psychological, moral, and emotional stress as a reason behind both the public and caregivers' desire for having access to AD, and HPs not wanting to provide it. I then investigated to what extent attempts have been made to overcome these challenges and how my primary research would assist in filling this gap.

Having conducted this literature review, I realised that developing potential safeguards for any practice requires a broad examination of the evidence and extensive research. However, as illustrated in the proceeding discussions, there is limited direct experience worldwide with regards to implementing and safeguarding AEDs for incompetent people. The existing published literature has been unable to provide a complete picture of assisted dying for people with dementia as experienced by the patients, families/caregivers, the public, and HPs. Therefore, I contributed to this debate by conducting the following research (Chapters 3, 4, and 5) on the views and experiences of those afflicted with dementia, the experts, and the public with an interest in this issue.

Chapter Three

Chapter 3 – Delphi study

Conceptual framework for assisted dying for individuals with dementia: Views of experts not opposed in principle

3.1 Introduction

Can assisted dying be provided for individuals who suffer from a competence-eroding disease such as dementia? If yes, how can this provision be safeguarded? In this study, I investigate the primary issues of, and concerns about, assisted dying for individuals with dementia as well as exploring a tentative conceptual framework to safeguard practice and application. The goal of this chapter is not to argue for or against the assisted dying legalisation, but rather to seek to establish consensus views of experts on the challenges and possible ways forward.

Assisted dying brings forward the death of individuals, on their explicit request, who are already well advanced on their illness trajectory towards death. Subjects as controversial and contentious as assisted dying engage with our fundamental personal morals and thus provoke rather strong points of views. Whether or not a person fully agrees with assisted dying in principle, the necessity of a robust safeguard cannot be denied particularly where end-of-life preferences can be difficult to articulate. With regard to assisted dying for individuals with dementia, while acknowledging the very few literature-based attempts to suggest some conceptual recommendations that can be built into current laws (Auckland, 2017; Downie & Lloyd-Smith, 2015), specific safeguards or best practices have not yet been rigorously developed. Nonetheless, the development and use of procedural guidelines may be beneficial in relation to assisted dying for individuals with dementia as suggested in other disciplines such as palliative care: “procedural guidelines can be formulated to provide a framework for decision making and implementation to best promote and protect the interests of patients, their families and the healthcare providers administering care” (Cherny, Radbruch, & Board of the European Association for Palliative Care, 2009, p. 583).

The necessity of developing guidelines for dementia is crucial because dementia has become a public health priority worldwide. As more people live longer, a dramatic increase in the number of individuals with dementia is predicted (Frankish & Horton, 2017; Winblad et al., 2016), which may translate into more people seeking assisted dying when they determine their life has reached a point where their suffering is unbearable. The Dutch Regional Euthanasia Review Committees (RTE) have reported an increased number of assisted dying requests for individuals with dementia from one reported case in 2004 to 169 cases in 2017 in the Netherlands (RTE, 2019), with a reported rise in the percentage of physician-assisted deaths related to dementia to 3% in 2015 (van der Heide, van Delden, Onwuteaka-Philipsen, 2017). Reports also show a gradual increase in the prevalence of assisted dying for individuals with dementia in Belgium from 2008 onwards (from five reported cases in 2008 to 14 cases in 2013) (Dierickx et al., 2017). This trend may be due to several factors: an increase in the number of individuals diagnosed with dementia; greater awareness of assisted dying practices through various media (including social media); health professional's discussions with patients about the options available to them at the end of life; and advocacy by organizations that support assisted dying.

Faced with progressive debilitation in bodily and intellectual functions (Cunningham, McGuinness, Herron, & Passmore, 2015; Mitchell, 2015), people with dementia may experience feelings of fear, confusion, and loneliness (Beattie, Daker-White, Gilliard, & Means, 2004; Clare, 2003); uncertainty about future decline (Harman & Clare, 2006); fear of losing dignity, independence, and competency (Gastmans & De Lepeleire, 2010); and feelings of losing their sense of self (Gillies, 2000). Alongside the loss of bodily functions, there is also a loss of control, and for some, feeling useless, which exacerbates a sense of dependency and becoming a burden (Clare, 2003; Gastmans & De Lepeleire, 2010; Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, Mahtani-Chugani, & Balaguer 2012). Among these multidimensional manifestations of suffering caused by life-threatening diseases, loss of self, dignity, autonomy, and lack of control over one's bodily functions and manner of death, and fear of future decline are linked with the wish to hasten one's death (Monforte-Royo et al., 2012; Schroepfer, 2006; van Tol, Rietjens, & van der Heide, 2010). Despite studies confirming the negative aspects associated with dementia, there has been a growing body of literature exploring the promotion of quality of life and wellbeing for individuals diagnosed with dementia, and their families and caregivers (Banerjee, 2010; Martyr et al., 2018; Tonga et al., 2020). Wishing to retain control of their life and unknown future beyond their loss of decision-making capacity and to gain psychological comfort or relief, some people with dementia wish to be medically assisted to die (Gastmans & Denier, 2010; Hertogh, de Boer, Dröes, & Eefsting, 2007a; Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016).

In the Netherlands, despite the legality of patients' written declarations of interest for assisted dying, known as an advance euthanasia directives (AEDs), that can be used beyond their loss of ability to make informed decisions (de Boer et al., 2011; Dyer, White, & Garcia Rada, 2015; Legemaate & Bolt, 2013; Lewis & Black, 2013), an assisted death resulting from patients' AEDs has mostly been performed on patients with early-stage dementia when their mental faculties are still intact (Bolt et al., 2015; Legemaate & Bolt, 2013). This low uptake of AEDs in the advanced stage of dementia (one reported case in 2011 and three cases in 2017 (RTE, 2019)) is an indication of ethical, legal, and practical complexities of the act in medical settings. In theory, although the majority of the Dutch general public agree with assisted dying for patients with advanced dementia who have AEDs, only a minority of physicians seem to be inclined to provide assistance in dying for individuals with dementia (Bolt et al., 2015; Kouwenhoven et al., 2013; Legemaate & Bolt, 2013; Tomlinson & Stott, 2015) as they regard such assistance personally, morally and legally problematic (Kouwenhoven et al., 2015). Without a competent communication at the advanced stage, the difficulties assessing the voluntariness of such directives, the validity of decision-making process that led to directives being drafted, the unbearableness of suffering, and determining the exact moment of enacting directives have been repeatedly realised in the literature (de Boer Dröes, Jonker, Eefsting, & Hertogh, 2010a, 2011; Hertogh, 2009; Kouwenhoven et al., 2015; Rurup, Onwuteaka-Philipsen, van der Heide, van der Wal, & van der Maas, 2005; van Delden, 2004).

While it seems that compliance with AEDs continues to depend upon communication, mutual understanding, and joint decision-making, the impact of patients' families and health professionals' (HPs) judgment on upholding these directives (Hertogh et al., 2007a; Widdershoven & Berghmans, 2001) who may or may not hold a different view with regard to termination of their lives (Rurup et al., 2005; Williams, Dunford, Knowles, & Warner, 2007) becomes vital. These personal and interpersonal conflicts may particularly escalate in events where patients' precedent and current wishes are different. For example, it is reasonable to assume that a patient with advanced dementia does not experience the suffering s/he once presumed unbearable while drafting AEDs (Hertogh, 2009; Hertogh et al., 2007a). Nonetheless, some physicians make an executive decision not to let presumed suffering of such individuals continue and support an assisted death. This highlights the need to develop guidelines that are safe and practical for patients and their families, and for the HPs involved with them. In this study, I aim to establish consensus views of experts on the primary issues of, and concerns about, assisted dying for individuals with dementia as well as exploring a tentative conceptual framework to safeguard its practice and application.

3.2 Method

3.2.1 Study design

A three-round Conventional Delphi study was conducted to seek the consensus of opinions of a selected group of geographically dispersed experts, through structured group communication (the reporting checklist for Conducting and REporting of DElphi Studies (CREDES) was followed (Juenger, Payne, Brine, Radbruch, & Brearley, 2017)). Sackman (1975, p. xi, quoted in Wainwright, Gallagher, Tompsett, & Atkins, 2010, p. 656) defines Delphi as follows:

> Delphi is an attempt to elicit expert opinion in a systematic manner for useful results. It usually involves iterative questioning administered to individual experts in a manner protecting the anonymity of their responses. Feedback of results accompanies each iteration of the questionnaire, which continues until convergence of opinion, or a point of diminishing returns, is reached. The end product is the consensus of experts, on each of the questionnaire items, usually organised as a report by the Delphi investigator.

The hallmark of the Delphi study is the application of multiple iterations with controlled feedback allowing the reassessment of initial opinions and stimulating additional clarity and insight. Furthermore, the Delphi method's structure provides anonymity, which reduces the effects of group pressure for conformity and opinion polarization. In order to fully investigate the research questions, this method was selected as it is a validated qualitative technique designed to collate systematically experts' knowledge on topics with contradictory or insufficient information (Dalkey & Helmer, 1963; Hasson, Keeney, & McKenna, 2000; Hsu & Sandford, 2007; Powell, 2003). It is argued that the insight into the knowledge, opinions, experience, preferences, and practice of interested parties in moral questions can contribute to the development of healthcare ethics (Wainwright et al., 2010). The use of Delphi methods, although rare, have been reported in the healthcare ethics literature such as developing a protocol for use in assisted dying (Onwuteaka-Philipsen & van der Wal, 2001), providing recommendations for ACP application (Rietjens et al. 2017), exploring ethical aspects of research into Alzheimer's disease (van der Vorm et al., 2009), spiritual care in palliative home care (Vermandere et al., 2013), and investigating healthcare ethics problem faced by the public (Breslin, MacRae, Bell, & Singer, 2005).

Ethics approval was obtained from the University of Auckland Human Participants Ethics Committee (UAHPE Reference Number 016552).

3.2.2 Panel of experts

An imperative requirement of a successful Delphi study is the selection of qualified experts with a deep understanding of the issues; a Delphi study is a group decision mechanism among a group of experts (Okoli & Pawlowski, 2004). Hence, the areas of relevant expertise and experts with the desired level of knowledge need to be carefully identified. It is suggested in the literature that a heterogeneous panel of experts are found to create more creative and comprehensive responses (Okoli & Pawlowski, 2004). Therefore, in this study, I identified a variety of appropriate disciplines relevant to dementia and assisted dying.

In order to populate the disciplines with names, a combination of purposeful and snowballing sampling techniques was used as previously suggested in the literature (Okoli & Pawlowski, 2004). More specifically, I used purposeful sampling based on actor types, which is best described as a method that “seeks representativeness in terms of perspectives by sampling actors from diverse affiliations” (Hirschhorn, 2019, p. 313). In terms of actor types, this study aimed to include different types of stakeholders including academics, practitioners, and activists with dispersed geographical locations with and without assisted dying laws in place.

To initially identify potential English-speaking experts in each discipline, my supervisors’ personal list of contacts was used to contact individuals. A further assessment was also conducted to validate the relevance and quality of potential experts’ work for the topic as well as the variety of their roles in different settings/locations. Another primary selection criterion was to identify experts who were not opposed in principle to assisted dying, which was made clear in the invitation emails as well as the participant information sheet. This was done to avoid the discussion being drawn away from “how” this might be done (the study purpose) into “whether” it should be done. The inclusion of experts with opposing views to the principle of assisted dying practice would best suit the purpose of Policy Delphi design that is to generate the strongest possible opposing viewpoints on issues and clarify arguments among a group of experts (de Loe, Melnychuk, Murray, & Plummer, 2016). Not being opposed in principle did not necessarily mean that the selected group of experts were supportive of assisted dying.

Taking all inclusion criteria into account, nine experts were nominated and approached via email some of whom suggested three more potential experts for inclusion in the list. These twelve experts were approached, and all agreed to participate in the study. No separate consent was sought as it was made clear to participants that by completing the questionnaire they consented to being involved. Following the literature (Keeney, Hasson, & McKenna, 2011), a range of 10 to 15 experts had been considered a sufficient number for this study. Therefore, the recruitment process was concluded by a total number of 12 experts from five different countries including The Netherlands, UK, USA, Canada, and New Zealand. My panel of experts covered knowledge from domains including dementia care, palliative care/medicine, gerontology and geriatric medicine, psychology, psychiatry, ethics in palliative care, neuropsychology, epidemiology, ageing and mortality, healthcare and end-of-life ethics, healthcare and end-of-life law, and advance care planning and end-of-life decision-making. Due to the small numbers of participants, I have included a demographic table (Table 3.1) with minimum information to ensure their anonymity.

Table 3.1 | Demographic characteristics of the participants

Characteristics	**Numbers**
Gender	
Female	8
Male	4
Age	
35-44	2
45-54	1
55-64	7
65-74	2
Countries	
The Netherlands	3
United Kingdom	1
United States of America	1
Canada	1
New Zealand	6

3.2.3 Data collection and analysis

All three-round questionnaires were designed and distributed online via Qualtrics Survey Software. Each round was distributed in order: first round February and April, second in June and August, and third in August and October 2017 with three email reminders for each round.

3.2.3.1 Round one

The first-round questionnaire consisted of short introductory statements addressing the focus of the study, definitions of essential terms in the survey, and five broad open-ended questions designed to generate a wide range of responses to the topic. The construction of an initial set of open-ended questions was guided by a literature review on the research questions and objectives. The questions were designed in a way that did not set any limit to the ideas that could be expressed by the experts. To identify any ambiguities in the questions, questionnaire was pre-piloted by a few suitable subjects. The questions are presented in table 3.2.

Table 3.2 | Demographic characteristics if the participants

Question 1	Is it possible to devise safeguards that would permit physician-assistance in dying and euthanasia for people with dementia?
Question 2	If so, what form would you expect these safeguards to take?
Question 3	Why do you think this would work well in practice?
Question 4	Briefly summarise what you think would be the main concerns and issues regarding the possibility of physician-assisted dying and euthanasia for people with dementia.
Question 5	Please feel welcome to express any further comments on this topic.

The open-ended questions generated nearly 460 lines of content fitting the research aim. Thematic analysis was performed on responses to all open-ended questions. Following Braun and Clarke (2006) guidelines, from all first-round comments I extracted some general generic statements retaining participants' verbatim wording as far as possible – only minor changes were applied for semantic clarity. The next step began with manually generating initial codes across the entire data set (generated statements) in a systematic manner, collating data relevant to each code. At the next step, identified codes were sorted into potential themes and all relevant coded data extracts were collated within the identified themes. A theme, in this sense, contains an important information in relation to the research question (Braun & Clarke, 2006). All identified main themes and sub-themes were then refined and rechecked by the authors in terms of their meaning and coherency in relation to entire data set. Once a satisfactory thematic map of the data was achieved, themes were further defined and named for the purpose of data analysis within them. All analyzed statements containing similar themes were collated together. Through further screening, all almost identical statements were synthesized into one statement and those that were judged to have subtle differences were kept separate. Thematic analysis at this stage served the purpose of synthesizing statements into round two, which was then used as the basis for reporting the results.

An initial coding of the entire data set was done independently by the main author. Given that internal reliability issues in Delphi studies tends commonly to be a function of lack of clarity, the category descriptions were independently checked by a second observer in order to eliminate any potential ambiguities, overlaps or other threats to reliability. It is of course the case that since the same participants are engaged in every round of the study, they always have the opportunity to specify if their views from a previous round are not accurately represented.

3.2.3.2 Round two

The second-round questionnaire comprised 119 statements. Participants were asked to review and rate each statement to establish preliminary areas of dis/agreement among those statements. All statements were presented with a space underneath for any further comments. I used a six-point Likert scale ranging from "strongly/moderately/slightly" agree to "slightly/moderately/strongly" disagree. The "neither agree nor disagree" option was not employed. Using this modified scale, statements were left unranked only if participants judged that they were outside their areas of expertise.

Work commitments resulted in the temporary withdrawal of one expert at this point. On return of 11 questionnaires, all the Likert evaluations were entered into the SPSS data analysis software and the frequency of agreement level for each statement and the concordance degree between participants' rating were calculated. Consensus was considered to have been achieved if $\geq$70% of participants were either agreeing or disagreeing; this reflects the dis/agreement of eight participants out of 11. To determine the strength of the consensus, the percentage of participants choosing "strongly dis/agree" and "moderately dis/agree" was considered as "high dis/agreement" and the percentage of participants choosing "slightly dis/agree" was allocated a value of "low dis/agreement".

The definition of consensus in Delphi studies is subject to interpretation, as there is no set rule for the level of agreement to attain consensus as noted by Keeney et al. (2011). In this study, 70% was ruled to reflect a sufficient level that accords with the number of participants. Evaluation of the 119 statements in round two resulted in consensus on 86 (72%) items. Of those 86 statements, seven items, which might have been re-evaluated in the light of comments generated in the second round, were re-sent to the third round along with the other 33 statements[11]. Therefore, 40 statements were circulated in the third round.

3.2.3.3 Round three

In round three, 40 statements were re-presented to all 12 participants. Each participant received an individualized questionnaire informing them of the number of participants who attributed to each score; any comments raised by others in the previous round; any clarification needed; and each participant's previous responses, which were highlighted (Appendix A: #5, p 156). They were asked to consider their answers in the light of the group's distribution of scores and qualitative comments raised in the second round and reconsider their answers should they wish. Additional comments raised in rounds two and three were primarily concerned with clarifying a comment previously expressed in the round one and/or two. Therefore, they were circulated into the subsequent rounds serving the same purpose of providing additional information with regard to a specific response. These comments were, hence, not thematically analyzed and incorporated into the results.

One participant who dropped out for workload commitments in round two returned in round three. On return of the 12 questionnaires, participants' ratings were analyzed and calculated in the same manner as round two to identify any statements that had now fallen within the prescribed range of consensus. Due to the one participant returning to the study in round three, the criterion for consensus increased to 75% to reflect the compatible agreement rate of 9/12 participants with 8/11 participants in the second round (this was determined by consensus of the authors).

As estimated, in round three the overall rating for those seven items changed, which resulted in five being rejected. A further three items out of 33 remaining statements reached consensus at this point, to give the overall consensus of 84 of the 119 (70%). As participants' ratings for the last two successive rounds showed no significant differences, I stopped iteration and concluded my Delphi study with three rounds with the response rate of 100%, 92%, and 100% respectively.

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[11] Analysis of participants' comments on these seven statements suggested that some experts might have slightly misunderstood the statements. Therefore, to increase the value of response, these seven statements were re-represented to the experts along with a statement of clarification.

3.3 Results

Thematic analysis on round one of the data set resulted in the identification of seven core domains: “applicability of assisted dying” for people with dementia; “ethical”, “practical”, and “pathological” issues regarding the application of assisted dying; and “ethical”, “legal”, and “professional” recommendations to overcome those identified issues/concerns.

3.3.1 Applicability of assisted dying

Experts acknowledged the importance of public discussion about assisted dying and individuals’ views on the value and quality of end-of-life. They unanimously believed that the issue of individuals with dementia and end-of-life decisions would become more relevant to public discussion as the population in most countries grows older and rates of dementia increase. Despite concerns unanimously raised by all experts about the complexity of dementia, experts did not reach consensus that adequate safeguards for assisted dying for people with dementia cannot be devised, commenting that developing safeguards that protect people in their most vulnerable state could be achieved, as too the safeguards that encompass guidelines for protecting people with other critical medical conditions. Table 3.3 shows a selection of experts’ reasoning regarding the necessity and applicability of assisted dying for dementia that reached consensus.

Table 3.3 | A selection of experts’ comments and their overall concordance (Statements are reported verbatim in this table)

Summary of experts’ comments that reached consensus	**%Consensus (R2: >70% - R3: >75%)**	**%High Agreement [a]**	**%Low Agreement [b]**	**Frequency [c]**
Applicability of Assisted Dying (AD)				
We need a system that lets people know if they are sure that AD is the right option for them, then their request will be taken seriously	90.9	**63.6**	27.3	1
It is important for the HPs [d] embed discussion about AD within an overall understanding of what death means for society	81.8	**63.6**	18.2	1
The issue of patients with dementia and end-of-life options will become more and more relevant to the public discussion as the population in most countries is growing older	100	**100**	0	1
It is not about living a year less or a year more per se, it is about how we value human life	81.8	**72.7**	9.1	1

[a] High Agreement = Strong Agreement + Moderate Agreement

[b] Low Agreement = Slight Agreement

[c] The total number of experts who made the statement

[d] Health professionals

3.3.2 Issues and concerns

3.3.2.1 Ethical issues

According to all experts (100%), one primary ethical concern on ensuring access to assisted dying for people with dementia is that patients' caregivers may project their own fears of developing dementia into the situation, or they may pressure or encourage the patient to request assisted dying, especially when the patient may be susceptible to that pressure. It was also recognised that the pressure to request assisted dying may also come from society. Some common perceptions about dementia may unintentionally trigger the request of assisted dying among people diagnosed with this disease. For example, 90.9% of experts believed that "Older people are prone to feel they are burden to others when they need help and are worried that they may cause trouble in terms of care needs and care costs, thus, they may feel pressure to relieve the burden they put on others."

There was also a concern that the provision of assisted dying would ultimately downplay the "urgency and creativity to look for other solutions to meet patients' suffering", which did not receive consensus. In their support, one expert commented that "legalizing assisted dying is precisely part of our creativity to assist people at their most vulnerable", emphasizing the need to develop new measures to mitigate patient suffering. Experts also did not reach consensus on the risk of state abuse to relieve caring cost and burden: "There might be a risk of state abuse in which the state would end the lives of patients who cost society huge sums of money and resources." A further concern expressed the risk of harm to HPs' psychological wellbeing in the absence of sufficient training and appropriate support from their professional community (81.8% of experts agreed).

3.3.2.2 Practical issues

Experts agreed that it might be difficult to assess patients' suffering and preferences at the advanced stage of dementia (72.7%) and to determine when conditions set by individuals to activate their assisted dying request have been met (100%). However, the majority of experts (72.7%) did not agree with the statement that "Deciding whether a patient's motivation to request an assisted death is objective, rather than coerced by internal fears or external worries, is not possible." Some commented that an objective motivation to request an assisted death would not necessarily be more legitimate than a person's subjective motivation grounded in their fears/worries. Also, on a more philosophical level, one expert commented that there are no rational or objective motivations as humans are corporeal beings with a very powerful sub consciousness that affects their decisions at different levels. On the other hand, experts had a polarized view on whether it is possible to determine the validity of an assisted dying request: “It is hard to determine whether the statement regarding assisted dying decision is one that truly represents an informed statement, in the sense of truly understanding what dementia and its stages are.”

3.3.2.3 Pathological issues

Unanimous consensus of 100% was achieved on dementia-related issues such as loss of communication to express needs, preferences, level of suffering, and current quality of life and care. Another issue, according to the majority of experts (81.8%), concerned patients’ incapacity to articulate a stable long-lasting request: “As people with dementia may lose their sense of self or memory of their former preferences, they may change their view on the assisted dying request as their condition worsens.” Having agreed on this, 81.8% of experts also believed that respecting patients’ assisted dying wish would potentially decrease their level of psychological distress: “[…] Even if we are concerned that persons may no longer feel this way [wanting to be helped to die] having lost their faculties, it is expected that until that happens they will be less distressed as they will feel more in control and not have to stress about all the things that lead them to prefer death over living with dementia.” To 90.9% of experts, the challenge is then to determine whether any apparent changes are due to patients’ cognitive decline or to a conscious change of mind. Some experts felt such an assessment would be impossible to make.

The further finding was recognition (by 81.8% experts) that every person with dementia has a different pathology that requires special needs at different stages of the disease. As such, individuals’ trajectory of the condition may require different strategies in managing the needs that arise. Table 3.4 shows the summary of issues/concerns that reached consensus.

Table 3.4 | Summary of issues and concerns and their overall concordance (Statements are NOT reported verbatim in this table)

Summary of experts’ concerns that reached consensus	%Consensus (R2: ≥70% - R3: ≥75%)	%High Agreement [a]	%Low Agreement [b]	Frequency [c]
Ethical Issues				
Risk of coercion and projection of caregivers’ wishes/fears into the patients	100	**81.8**	18.2	2
Risk of increasing pressure on patients to request AD [d] on a societal level	90.9	**72.7**	18.2	1
Risk of harm to psychological wellbeing of HPs [e]	81.8	**72.7**	9.1	3

Societal perception that life with dementia is not worth living	81.8	**72.7**	9.1	3
Risk of failure to provide support for HPs	72.7	**63.6**	9.1	2
Societal conception that devalues people without intact cognition	72.7	**63.6**	9.1	2
Practical Issues				
Determining the proper time to enact the AD request	100	**81.8**	18.2	1
Assessing patients' suffering and preferences in advance dementia	72.7	**72.7**	0	1
Assessing patients' true motivations to request AD	72.7 [f]	**54.5**	18.2	1
Pathological Issues				
Loss of communication to express needs, current quality of life, etc.	100	**81.8**	18.2	1
Differences in disease trajectories and required need	90.9	**72.7**	18.2	1
Changing mind due to cognitive decline or loss of the sense of self	90.9	**63.6**	27.3	2
Inability to articulate a long-lasting request	81.8	**81.8**	0	2

[a] High Agreement = Strong Agreement + Moderate Agreement

[b] Low Agreement = Slight Agreement

[c] The total number of experts who made the statement

[d] Assisted Dying

[e] Health Professionals

[f] The only item that reached consensus on disagreement

3.3.3 Recommendations for developing a framework

3.3.3.1 Ethical recommendations

Experts stated that ethical guidelines can prevent illegal and harmful assisted dying practices and can ensure delegation of the responsibilities of the principal stakeholders involved: patients, families/caregivers, and HPs. To fulfil this, experts recommended ethical safeguards that are in accordance with the particular cultural context and include the views of principal stakeholders along with careful procedures to protect them. For example, to preserve patients' autonomy and respect their personal choice, experts agreed (81.8%) that safeguards must prevent others making an assisted dying request for people with dementia: "[…] it (AD) can never be the decision of another person"; or prevent others coercing patients into requesting assisted dying (100% agreement). To preserve the psychological well-being of HPs, experts fully agreed on ensuring safeguards that prevent them being forced to perform assisted dying. With regards to preserving families'/caregivers' wellbeing, all experts (100%) suggest informing patients' families/caregivers about the assisted dying request of their patients while providing them support (see Table 3.5 for detailed recommendations). Experts also reached agreement on including a safeguard to ensure that assisted dying "was not carried out if the person was to indicate that they felt life was still worth living", which seems to be at odds with preserving a patients’ former request for assisted dying. Some experts, however, agreed upon this view if patients were competently capable of articulating this new wish.

3.3.3.2 Professional recommendations

According to all experts, HPs need training in the necessary skills in providing assisted dying, including providing support for patients and their families, as well as professional organizational support, and accountability within reporting processes. Along with this, they need to educate patients on how dementia may progress in their particular context and what issues may arise prior to them making any assisted dying decisions.

As part of safeguarding patients and HPs, it was unanimously agreed that HPs must periodically assess: “[…] patients’ medical condition, cognitive ability and capacity, rationality, pain and suffering, care environment and the quality of care, symptoms of any psychiatric disease, and patients’ understanding of the typical courses of their dementia and consequences of their end-of-life decisions.” During these ongoing patient-centered assessment sessions, HPs are also required to explore the reasons triggering an assisted dying request (90.9% agreement), signs of coercion/projection (100%), uncover fundamental conditions that patients would wish to trigger assisted dying (90.9% agreement), and ensure consistency of the assisted death wish (100%).

While acknowledging the necessity of a psychiatric assessment and the absence of depression as part of the assisted dying request process (81.8% agreement), three experts made comments challenging the view that having depression and making an informed decision are mutually exclusive. Experts also agreed that while seeking the views of experts from different backgrounds – ethical, psychosocial, etc. – might be helpful, it could constitute a serious barrier to access.

3.3.3.3 Legal recommendations

A legal framework would guide stakeholders, mainly HPs, to assist patients to formulate a feasible assisted dying request. Instructional directives such as advance directives that provide clarity about patients’ medical preferences appear to be a key element in safeguarding principal stakeholders. In this regard, patients would need to make a clear written request detailing their medical preferences and specific wishes for assisted dying (100% agreement). The decision to enact the advance directives would then be made on patients’ previous and clearly stated wishes (90.9% agreement). To validate the authenticity and continuity of such directives, they need to be regularly updated and assessed by

HPs (100% agreement). One suggestion included patients: “Taking part in recorded semi-structured interviews with a different doctor and psychologist without the presence of their family.” These interview sessions are also required to be video recorded (75% agreement).

All experts agreed on patients being demonstrably competent to ***request*** assisted dying, however, not all of them agreed that assisted dying needed to be performed in the earliest stage of the disease while patients’ mental faculties are still intact. However, when the competency is lost, experts had a polarized view on whether a physician should make decision based on their interpretation of the situation. The ones who did not agree with this statement, believed that the current views of now incompetent patients cannot override their prior competent wishes. Having said that, experts did not reach consensus that HPs should be responsible for making decisions based on their interpretation of the former and current wishes of their patients when capacity is lost. Table 3.5 shows the summary of recommendations that reached consensus.

Table 3.5 | Summary of recommendations and their overall concordance (Statements are NOT reported verbatim in this table)

Summary of experts’ recommendations that reached consensus	**%Consensus (R2: ≥70% - R3: ≥75%)**	**%High Agreement** [a]	**%Low Agreement** [b]	**Frequency** [c]
Ethical Recommendations				
Prevent others coercing patients into requesting AD [d]	100	**91.9**	9.1	2
Protect all stakeholders from any harm or abuse	100	**90.9**	9.1	2
Preserve psychological wellbeing of HPs by not forcing them to perform AD	100	**81.8**	18.2	2
Inform caregivers about the AD requests of their patient	100	**81.8**	18.2	1
Preserve HPs’ [e] integrity & reputation after their involvement in AD	90.9	**90.9**	0	1
Protect HPs from prosecution	81.8	**81.8**	0	1
Preserve patients’ autonomy by leaving the decision to their discretion	81.8	**72.7**	9.1	2
Respect patients’ stable and authentic wishes	81.8	**72.7**	9.1	2
Prevent others making decisions for patients	81.8	**72.7**	9.1	1
Consider the view of all stakeholders involved (patients, caregivers, & HPs)	81.8	**63.6**	18.2	1
Consider the cultural context	81.8	**63.6**	18.2	1
Professional Recommendations				
Assess patients’ cognitive abilities, mental capacity, medical condition, suffering, psychiatric state, AD request, and their understanding of their typical disease course	100	**100**	0	5
Train HPs in the necessary skills required to action AD	100	**100**	0	2

Study evidence emerging from jurisdictions with AD legalization	100	**100**	0	1
Provide ongoing review appointments and assessment	100	**90.9**	9.1	2
Educate patients prior to making an AD decision	100	**90.9**	9.1	1
Provide support for team members	100	**90.9**	9.1	1
Explore the reasons triggering AD request through communication	90.9	**63.6**	27.3	1
Assess care environment and quality of care as one of the underlying reasons to request AD	90.9	**54.5**	36.4	2
Assess that there is no diagnosis for depression	81.8	**63.6**	18.2	1
Legal Recommendations				
Require patients to be demonstrably competent only to draft AD request	100	**100**	0	1
Establish strict accountability system for independent monitoring	100	**100**	0	1
Consider legal consequences of those acting outside the law	100	**100**	0	1
Require patients to sign an advance directive prior to their loss of capacity	100	**100**	0	1
Provide robust reporting system for HPs	100	**90.9**	9.1	3
Require patients to include detailed medical and personal preferences into advance directives	100	**90.9**	9.1	2
Require HPs to set eligibility criteria for AD request	100	**90.9**	9.1	1
Require patients make clear written advance directives	100	**90.9**	9.1	1
Update and assess advance directives regularly to the reduce the risk of coercion/projection	100	**72.7**	27.3	1
Require a nominated other to store lethal medication to prevent patients taking them in error	100	**54.5**	45.5	1
Require patients to include AD enactment requirements into their advance directive	90.9	**72.7**	18.2	2
Provide video documentation of patients' request for AD and consent interview	75	**66.7**	8.3	1
Require HPs to set up recorded semi-structured interviews with a different doctor and psychologist	72.7	**63.6**	9.1	1

[a] High Agreement = Strong Agreement + Moderate Agreement
[b] Low Agreement = Slight Agreement
[c] The total number of experts who made the statement
[d] Assisted Dying
[e] Health Professionals

3.4 Discussion

A Conventional Delphi study was employed to explore consensus on devising an optimal conceptual framework that would realise the provision of assisted dying for people with dementia. This multidisciplinary focused discussion among an international group of experts has identified preliminary recommendations that may benefit future research and practice. Similar to the delivery of optimal end-of-life care for people with dementia, having a professional consensus framework on factors contributing to the delivery of optimal assisted dying practices for people with dementia would be key to inform policy and practice (Poole et al., 2018). To my knowledge, this study is the first to explore professional views to address the barriers for individuals with dementia accessing assisted dying.

Adherence to legal assisted dying requests of people with dementia is challenging. One of the dominant issues is that of suffering. Assessing the level of unbearableness of suffering in people with advanced dementia is found to be difficult in practice (de Boer et al., 2007). In accordance with my findings, this difficulty is reported to be associated with the subjectivity of suffering, and the inability of some individuals with dementia to communicate meaningfully their level of suffering (Hertogh et al., 2007a; van Tol et al., 2010). These difficulties are two of the main barriers to implementing assisted dying in cases of dementia (Diehl-Schmid et al., 2017; Hertogh, 2009). There is evidence that some physicians are mostly inclined to filter patients assisted dying request through their own perspective of suffering and are less willing to grant the request (van Tol et al., 2010). My findings, nevertheless, may imply that “unbearable suffering” is subjective to the patient. However, as with the Dutch act, the scope of this provision remains unclear as it is the physician’s assessment that is determinative and it is not clear what will be considered to constitute sufficient suffering in the context of dementia (Downie & Lloyd-Smith, 2015). As well as obscurity in determining to what extent the suffering is unbearable, the assessment may also be confounded by behavioral symptoms or cognitive deficit of dementia that overlap with behavioral indicators of pain and suffering, particularly when the roots of suffering are mental/psychological (Lichtner et al., 2014).

Physicians at the heart of granting the assisted dying request are also faced with the challenging task of interpreting the specifications of the circumstances and timing of assisted dying expressed by formerly competent patients in their advance directives (de Boer, Hertogh, Dröes, Jonker, & Eefsting, 2010b; Gastmans & De Lepeleire, 2010). Acknowledging the difficulty in determining whether the conditions previously set by patients have been met to enact the request, my experts suggested that preferences should be written in detail, for example, including types of function that need to be evidenced prior to enactment of any assisted dying request, and must be very clear to follow so that the decision cannot be doubted. A clear written advance directive encompassing detailed and structured end-of-life preferences and assisted death enactment requirements may safeguard its application by providing clear guidance for HPs and families/caregivers about what should be done in the light of the patient’s condition at the time an assisted death is considered. Communication is central to determine the right moment to carry out the assisted death directive, the pre-stated circumstances, as well as their validity (de Boer et al., 2010a; Hertogh, 2009; Kouwenhoven et al., 2015). When communication is no longer possible, reassurance about the timing and validity of the assisted dying wish may be achievable through some other means such as audio and/or video recordings of the decision-making process prior to loss of competency/communication. These research findings indicate that having both written and video recorded documents would allow everyone involved to witness how an individual's decision-making manifested and would put the person centrally into the decision-making process. Such a process of having video-recorded interview sessions to validate the decision-making process is itself creative, which would also increase the chances of detecting any coercion from relevant others such as families/caregivers, proxies, and/or HPs. Video-recorded consultation is an established method for primary care research and has been recommended as the best method for researching "doctor-patient" communications because it obtains all modalities of the interaction between doctor and patient (and other people present in the session such as a family member) in a consultation (Coleman, 2000). Coleman notes that having a complete record of both HPs' and patients' interaction inform the researcher of what actually happened in the consultation sessions (Coleman, 2000).

Finding alternative ways of communicating in advanced stages of dementia is essential if the needs and wishes of people with dementia are to be recognized and respected (Gove et al., 2010). While the prevalence of discussion between patients and proxies/caregivers/HPs about end-of-life care and completion of advance directives continue to be low (Dixon et al., 2018; Emanuel, 1995; Robinson et al., 2013), it is advisable that advance directives are encouraged, and when drafted, that they are regularly updated and assessed. Requiring ongoing review appointments and assessments may enhance communication between HPs and patients, whilst building trusting relationships. It has been proposed that these essential elements would help HPs to find the balance between their professional responsibilities and respecting patients' autonomy (Kouwenhoven et al., 2019). Coupled with the use of video-recording means, findings concluded that regular updating of AEDs would be helpful in protecting the person with dementia against the decision of proxies who may hold a different view or may be considering a view expressed long time ago by the patient with regard to their end-of-life preferences. The differences between proxies/caregivers' and patients' decision-making regarding end-of-life preferences have been acknowledged by others (de Boer et al., 2010b; Emanuel & Emanuel, 1992; Hertogh et al., 2007a).

Decision-making then, is not "a process of individually combining preferences and options, but a shared process of interpretation and understanding" (Widdershoven & Berghmans, 2001, p. 182). Through this process, HPs help patients to clearly articulate their deeply held preferences. A key finding was the importance and significance of ongoing conversations between HPs and patients about dementia and its challenges and progression and the end-of-life options available to them (not just an assisted death), prior to any decision-making process. Educating HPs about how to convey this information and initiate conversations about advance directives with patients and their families/caregivers was suggested to be beneficial in this regard. The necessity of better education and training of families/caregivers of patients with dementia and the HPs involved in their care have been highlighted in studies (Gove et al., 2010; Poole et al., 2018; Sachs, Shega, & Cox-Hayley, 2004; Volicer & Simard, 2015). Educating HPs in the required skills may help their conservative approach in approaching patients and their families/caregivers/proxies (Dickinson et al., 2013; Poole et al., 2018).

The study experts unanimously emphasize competency only at the time of drafting AEDs than at the time of assisted dying provision, as insistence on the latter may result in patients dying earlier than necessary because they worry their window of opportunity may close, thus, they take advantage of the law sooner rather than later. This view is also supported by others (Bolt et al., 2015; Cohen-Almagor, 2015).

While AEDs are deemed to form the nucleus of assisted dying provision to protect the will of individuals with dementia, how do we balance the precedent wishes of a competent patient against their current wishes when they may conflict? To the majority of the experts, assisted dying should not be carried out if patients appear to be happy and content despite the presence of written assisted death directive. According to this finding, it may seem justified to override an advance directive that instructs for an assisted death. Contrary, as previously noted, a majority of the experts agree that the decision to enact an assisted dying request should be made on the ground of patients' previous and clearly stated wish in advance directives. This may suggest that it is in patients' best interests that their advance directives are followed. Such interests are a legacy of a person's entire life and thus should not be left to a physician's interpretation of the current situation. These discordant findings illustrate the dilemma in the practice of assisted dying practice in the context of dementia: where in theory it is presumed important to maintain individuals' integrity and authority by respecting their autonomous choices (documented in the advance directive), in reality, HPs may find their patients' precedent assisted death request in conflict with their contemporary best interests who are no longer competent to make decisions, who may be outwardly content and happy. Evidence shows that physicians are inclined to base their decision-making about patients assisted dying requests on their understanding of patients' best interest at the present time rather than looking to their former expressed wishes (Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2006).

Despite the issues surrounding the provision of assisted dying for individuals with dementia, my findings lead me to cautiously suggest that 'adequate' safeguards may be devisable. This provision may be realised through designing a unified and accountable regulatory system for independent monitoring that acknowledges the important role of education aimed at increasing the awareness of dementia, assisted dying, and end-of-life decision-making in the context of advance directives on the personal, professional as well as societal level. Taking into account the particular cultural context, such a regulatory system may include instructions for procedural guidelines for HPs to help inform the patient to draft efficacious directives, perform assisted dying, and to robustly report the practice, for standard eligibility criteria, regular assessment of advance directives, and lastly, for post hoc monitoring. It may also set out legal consequences for those acting outside the law while protecting those acting within the law from prosecution.

3.4.1 Future research and limitations

This Delphi study adds to the very limited data available on assisted dying in the context of dementia, suggesting a preliminary conceptual framework to be used in practice regardless of a particular cultural context. In order for the conceptual framework to provide benefits in different societies, it needs to incorporate relevant and specific socio-cultural characteristics, which suggest opportunities and directions for future research. One primary example of these cultural differences relates to cultural traditions and values of minority ethnic groups concerning death and end-of-life care. For instance, the quality of life at the terminal phase of illness is highly important for most people from western countries and therefore hastening the death can sometimes be accepted results at the end-of-life care, whereas for those from non-western countries sanctity of life is often highly valued and assisted dying is considered unaccepted (Buiting et al., 2008).

Although participants' expertise in the area of end-of-life care and including dementia is a strong contributor to the quality of the generated findings, this study did not include the views of people with dementia and their families/caregivers who constitute experts by virtue of living with dementia. The success of the Delphi method partly depends on the accuracy and coverage of an initial questionnaire to start the process. It is crucial that those generated statements truly reflect all the key elements of the research topic. Given that the views of individuals with dementia and their caregivers are missing, there is a chance that the developed questionnaire might have failed to include some issues and concerns with regard to assisted dying in the context of dementia. The consensus therefore lacks input from the very group most directly afflicted. In addition, the consideration of the views of more experts may have brought more insights into the challenges/issues or led to different outcomes.

Chapter Four

Chapter 4 – Netnography study

Views on assisted dying for individuals with dementia: A Netnographic approach

4.1 Introduction

While assisted dying and its moral and ethical underpinnings are debated worldwide, much more attention is directed towards extending its provision to individuals with dementia (Bravo et al., 2019; Evenblij, Pasman, van der Heide, Hoekstra, & Onwuteaka-Philipsen, 2019; Picard et al., 2019). Alongside the growth in public discussion in the past decade, some societies have witnessed an exponential increase in a) acceptability among health professionals (HPs) of providing such assistance (Bolt et al., 2015; Bravo et al., 2018a; Bravo et al., 2019; Cleemput & Schoenmakers, 2019; Rietjens, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2005; Rurup et al., 2006) b) the number of requests from persons with dementia (Schuurmans et al., 2019), and c) the desire for access to an assisted death from individuals with dementia and their families (Bravo et al., 2018b; Cleemput & Schoenmakers, 2019; Kouwenhoven et al., 2013; Tomlinson & Stott, 2015). The presence of an advance euthanasia directive (AED) that is written prior to the loss of decisional competency significantly contributes to increased acceptance to extend assisted dying to those who are at an advanced stage of dementia.

In the Netherlands, a written AED constitutes a legitimate request for a person with advanced dementia who has lost mental capacity. In the Netherlands, the occurrence of assisted death for those with dementia has more than tripled since 2011 (RTE, 2020), although the rate is low (Evenblij et al., 2019; Schuurmans et al., 2019). Among the Dutch granted assisted dying requests, the majority were reported as concurrent requests that involved patients deemed competent in the early stages of dementia (RTE, 2020). This may be an indication of the unfeasibility of an AED for individuals in the advanced stages of dementia (de Boer Hertogh, Dröes, Jonker, & Eefsting, 2010; van Delden, 2004). From the beginning of assisted dying legislation, the validity of AEDs for this group of individuals has been central to debate (Dierickx, Deliens, Cohen, & Chambaere, 2017) because such directives are subjected to rigorous moral and ethical evaluation. It is encapsulated in the question, ‘should the earlier wish (to have an assisted death) of an individual, made when clearly competent, be seen as applicable at a later stage when competence is not apparent?’

The influence of social media on such topical debates cannot be ignored as they reflect and exemplify public opinions on such issues in a complex and nuanced way (Jaye, Lomax-Sawyers, Young, & Egan, 2019). With social media, issues that were previously confined to the margins of private discussion are now able to attract global support and attention (Snowden, 2016). In the literature, the use of the online medium has been highly valued as a research tool as it can lead to trustworthy interpersonal communication, spontaneous self-expression, and increased access to more geographically dispersed groups (Branthwaite & Patterson, 2011; de la Peña & Quintanilla, 2015; Langer & Beckman, 2005; Närvänen, Saarijärvi, & Simanainen, 2013; Sade-Beck, 2004). In particular, research in the online expression of illness experiences provides a rich source of data to understand the views, preferences, and needs of people, patients, and professionals relevant to healthcare (Eysenbach & Till, 2001). These online expressions are a unique source of data that are different from narratives obtained through other research means such as interviews (Anderson, Hundt, Dean, & Rose, 2019).

Previous research has explored the attitudes of particular groups of people including physicians, nurses, informal caregivers, and the general public on the matter of assisted dying in the context of dementia (Braverman, Marcus, Wakim, Mercurio, & Kopf, 2017; Bravo et al., 2018a, 2018b; Dehkhoda, Owens, & Malpas, 2020; Kouwenhoven et al., 2015; Terkamo-Moisio, Pietilä, Lehto, & Ryynänen, 2019; Tomlinson & Stott, 2015). However, most of the research conducted in specific geographical settings such as the Netherlands and Canada have primarily utilised surveys or interviews with a limited number of participants. The data provided by these instruments may be potentially biased as these tools rely on self-reports and are drawn from a confined pool of subjects (Muller, Junglas, vom Brocke, & Debortoli, 2016). Although social media has already offered insightful information on a range of health-related issues, including the caregivers of individuals with dementia (Anderson, Eppes, & O’Dwyer, 2019; Anderson, Hundt, et al., 2019), to our knowledge, limited research (if any) has used the online medium to qualitatively explore how the publics’ experience with dementia contributes to their views on assisted dying. In this study, we explored naturally evolving and occurring online comments pertaining to assisted dying for people with dementia. The purpose was to explore how the practice of assisted dying for people with dementia is conceptualized and understood in the context of online communication using shared experiences, challenges, and the preferences of online contributors to Facebook communities.

4.2 Review of the literature

Dementia is a major global challenge facing health and social care, requiring concerted international action and a commitment to prevention, treatment, and social interventions. Such action is essential if we are to improve the living and dying experiences for individuals with dementia, their families/caregivers, and society as a whole (Livingston et al., 2017). Dementia shortens life expectancy to varying degrees, with studies reporting a median survival time of 3.3 to 11.7 years from the onset of diagnosis until death (Cunningham, McGuinness, Herron, & Passmore, 2015; Todd, Barr, Roberts, & Passmore, 2013). Despite this, it is often not recognized as a terminal condition, which can result in failure to adopt a timely palliative care approach (Livingston et al., 2017; Sampson, Gould, Lee, & Blanchard, 2006) and involve patients in advance care planning (Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012). Along with a number of associated challenges with the low uptake of palliative care for patients with dementia (McInerney, Doherty, Bindoff, Robinson, & Vickers, 2018), there may also be limited access to hospice care because of poor prognostic indicators of 6-month mortality (Lewis, 2014). Optimal care at the end of life for those with dementia may be variable, taking away the chance of improved quality of dying, and quality of support and care-management for caregivers (Lewis, 2014).

The implications of dementia for individuals, families, and caregivers have been increasingly investigated (Anderson, Eppes, et al., 2019; Oh, Yu, Ryu, Kim, & Lee, 2019; Prorok Horgan, & Seitz, 2013). Studies show that dementia affects not only a person’s abilities and quality of life, it also disrupts the wellbeing of caregivers, family, relatives, and friends who witness the gradual decline of their loved one (Frankish & Horton, 2017; George et al., 2008; Livingston et al., 2017; Oh et al., 2019). With the continuous progression of dementia, the need for family and professional support will grow exponentially, which may lead to greater physical, psychological, psychosocial, and existential suffering (Tomlinson, Spector, Nurock, & Stott, 2015). Whether or not dementia is necessarily a state of dreadful suffering is contested (de Boer et al., 2007); some evidence, however, suggests that suffering and the fear of future suffering can result in the desire to request an assisted death (Evenblij et al., 2019; Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, Mahtani-Chugani, & Balaguer, 2012). Others who fear developing dementia may contemplate writing an AED in anticipation of the suffering that may follow (de Boer et al., 2007) and becoming a burden on others (Tomlinson et al., 2015). Others have interpreted such requests in terms of exercising autonomy and control over one’s life and a right to die (Kouwenhoven et al., 2019).

A division of attitudes on assisted dying for individuals with dementia has been demonstrated across different populations alongside the severity of dementia. Despite some inconsistencies in results, research shows that HPs generally hold more restrictive views than those of the public (Terkamo-Moisio et al., 2019; Tomlinson & Stott, 2015). Although a myriad of factors is responsible for this dichotomy (Bolt et al., 2015; Schuurmans et al., 2019; Terkamo-Moisio et al., 2019), it appears that depth of involvement in the act of assisted dying itself is negatively associated with the level of support. Support from the public (including informal caregivers) and nurses who are more involved in the care of patients and less in the practice of assisted dying requests are respectively greater than from physicians who are most likely responsible for performing an assisted death (Bravo et al., 2019; Kouwenhoven et al., 2013; Rietjens et al., 2005). This restrictive view of HPs can be seen in the Dutch mortality follow-back study in 2015 which shows that more than half of assisted dying requests were rejected (1.2/2.1) by Dutch physicians (Evenblij et al., 2019), while all granted cases in the same year were related to patients in earlier stages of dementia when competency was less of an issue (RTE, 2020). The desire to extend assisted dying laws to include individuals with dementia who are now incompetent is also greater among older adults and informal caregivers than for HPs (Bravo et al., 2019).

The sensitivity of this research focus only adds to the already existing difficulty of gathering dementia research data (Carmody, Traynor, & Marchetti, 2015). Existing sources of data on social media, however, may provide powerful insights and will inform future research in identifying and overcoming challenges to optimal end-of-life care, particularly by drawing attention to the struggles of individuals with a desire to access assisted dying. This may provide helpful information to develop political and social infrastructures.

4.3 Method

Technology and the Internet have laid the groundwork for new forms of social organization in online communication with communities growing alongside real-world communities. This has resulted in new research methodologies to gain insights into these emerging online interactions. Netnography, or online ethnography, is one prime example. Netnography is a qualitative research methodology based on observations of technologically mediated communication (Kozinets, 2002, 2010; Langer & Beckman, 2005) “to arrive at the ethnographic understanding and representation of a cultural or communal phenomenon” (Kozinets, 2010, p. 60).

Netnography is particularly useful to study personally or politically sensitive topics and stigmatic phenomenon, as well as communities where access based on conventional methods is difficult (Costello, McDermott, & Wallace, 2017; Langer & Beckman, 2005). Netnographic approaches commonly involve three clear stages: (i) entrée: research design, specification of research questions and identification of suitable online sites; (ii) data collection: direct copying of the texts from communication sites and observations of the community and its members, interactions, and meanings; and (iii) analysis and interpretation: classification, coding analysis, and contextualization of communications (Kozinets, 2002; Langer & Beckman, 2005).

4.3.1 A Netnographic study plan

Social online communities may be studied through utilizing either a participative (active) approach (closer to traditional face-to-face methods) or a purely observational (passive) approach, in which the netnographer merely observes the community they are interested in. The presence of the researcher is often found to be counterproductive (Eysenbach & Till, 2001; Garland, 2009; Kozinets, 2002). We employed an observational approach to reduce the impact of the researcher’s presence (Garland, 2009; Kozinets, 2002). In such an environment, the interpretation of data is grounded in the content of naturally occurring communications.

4.3.2 Entrée and Sampling strategy

A type of purposeful sampling – critical case sampling – was used that involved choosing a number of the most illustrative cases (e. g., online sites) to explore the study objectives in-depth and facilitate logical generalizations (Patton, 2014; Schuman, Lawrence, & Pope, 2018). A thorough screening of a wide range of online sites was carried out in order to find the most relevant communities that address assisted dying and dementia. The definition of community in netnography has been adapted over the years (Kozinets, 2015). We considered any dispersed groups or communities that shared an exchange pattern of “relevant narrative themes” as our target community (Kozinets 2015, p. 119). No communities were identified that solely focused on assisted dying for people with dementia, therefore, we targeted communities that discussed assisted dying in general to extract any naturally occurring communication with regards to dementia. Having considered this, the compilation of a list of online sites’ characteristics indicated Facebook as the most relevant study field in the research scope: having higher traffic of postings, between-member interactions, active communication, and written comments (Kozinets, 2002; Kozinets, 2010). Facebook allows its followers to preserve their anonymity and privacy should they wish, which is considered as an advantage to inspire open communication among followers, particularly when discussing sensitive topics (Langer & Beckman, 2005).

Consideration of the variety and quality of content and professionalism identified five Facebook communities from the United Kingdom, Australia, Canada, the United States of America, and New Zealand. All of these were ‘open communities’ that did not require an invitation, registration, or approval to join: these were essentially public spheres. All communities were virtual representations of non-profit organizations in each country that either advocated for or promoted assisted dying laws for mentally competent adults who experience unbearable suffering as a result of a terminal illness aiming to educate and raise awareness among the public. Followers of these communities could be generally considered public as these communities are open to anyone to comment and do not require contributors to hold a particular stance on the issue of assisted dying. In support of the theory of “echo chamber” (Sunstein, 2001), one could argue that these advocacy communities would create an environment in which their followers encountered only opinions that coincided with their own so that their existing views are reinforced and alternative ideas are not considered. Although it is argued that online public Facebook communities are fragmented and clustered into homogenous groups, it is also believed that this fragmentation decreases with the involvement of significantly higher numbers of users (Batorski & Grzywińska, 2018). The engagement of our communities’ contributors was relatively high and consistent with the number of followers in each community. By the time that the data gathering concluded, the number of people who followed or liked these Facebook communities varied from 3,247 for the smallest community to 322,961 for the most active community. Furthermore, contributing to these ‘open’ advocacy communities may not necessarily suggest that contributors are unanimously in favor of assisted dying in principle as none of the communities required contributors to hold a particular stance on the issue of assisted dying. Nor does it suggest that the ones in favor would also hold the same permissive opinion with regards to its extension to cases such as dementia.

The coverage of these communities’ postings was primarily country-specific influenced by current local events/discussions potentially prompting a variety of shared experiences among the contributors given the differences between these countries, especially since they included countries with and without assisted dying laws in place. Communications could also, of course, go beyond individuals’ societal, cultural, ethnic and national boundaries (Jaye et al., 2019) and potentially contribute to the global nature of the issues under discussion.

4.3.3 Data collection and analysis

I observed the five Facebook communities on a daily basis over 20 months from August 2016 to March 2018, screening a total number of 110,450 online textual comments. Fieldnotes were also taken that mainly consisted of the netnographer's reflection on the ongoing communications and their relevance and meaning. For two reasons an extended period of observation was required to reach data saturation and offer a more meaningful account: i) the selected communities were not solely focused on dementia within the context of assisted dying, and ii) the broad nature of the research objectives, which most likely bring a delayed stage of data saturation (Suri, 2011).

The qualitative analysis software program NVivo Pro 11 was used to filter the large amount of data collected. Data screening and indexing strategy was then applied using the keywords "dementia", "demented", and "Alzheimer" to ensure that only relevant data were selected for coding. This purposive search identified around 1,000 comments, in reply to 316 posts, that were specifically related to dementia. These comments were supplemented by others identified through fieldnotes but not necessarily using the chosen search terms.

We conceptualized our qualitative data using an inductive approach. The process of coding was employed using thematic analysis (Braun & Clarke 2006), systematically generating initial codes then analysing these to identify themes. Initially, thirteen themes, five of which had two subthemes, were identified which were then reduced to four central themes and five sub-themes. To establish dependability (Schuman et al., 2018) and reliability, themes were constantly refined and rechecked by research associates – PhD level experts in psychology and medical ethics – in terms of their meaning and coherency in relation to entire data set. This was done to eliminate any potential ambiguities, overlaps or other threats to reliability. Fieldnotes were maintained at this stage to contextualize the data/themes and thereupon to check and refine our understanding of them to ensure the confirmability of the study (Wester, 2011). For refinement, the primary researcher was regularly checking the generated themes with new emerging contextual comments during the data analysis process.

4.3.4 Ethical consideration and informed consent

As noted by Langer and Beckman (2005), "netnography is a suitable methodology for the study of sensitive research topics, enabling the researcher in an unobtrusive and covert way to gain deeper insights into consumers' opinions, motives, and concerns" (p. 189). Even though the use of the covert study of public online communities about sensitive topics is arguably both ethical and legitimate (Langer & Beckman, 2005), its covert nature of the way data is explored and collected has raised particular ethical concerns. Issues of privacy, autonomy, informed consent, and confidentiality are at issue (Eysenbach & Till, 2001; Zimmer, 2010).

Individuals may contribute to social media platforms expecting privacy, and not becoming research subjects (von Benzon, 2019). Unauthorized secondary documentation of online users' contributions by the researcher could be considered a violation of privacy (von Benzon, 2019; Zimmer, 2010) interfering with their ability to control information about themselves (Zimmer, 2010). This emphasis on the inherent vulnerability of online contributors highlights the need to protect authors with an ethical approach to research. Online contributors have, on the other hand, control over the flow of their shared communications across different spheres through privacy settings of most social networking sites including Facebook (Moreno, Goniu., Moreno, & Diekema, 2013). von Benzon argues that "a framing of these writers that foregrounds their potential vulnerability, naivety and even ignorance is in fact highly paternalistic", which deny their agency and diminish the act of online publication (von Benzon, 2019, p. 182). In her argument, von Benzon provides examples of public opinions and the law (e.g., in England, the Defamation Act 2013; the Racial and Religious Hatred Act 2006; etc.) that recognize online contributors as informed and competent agents who are responsible for appropriate use of the internet for self-expression. Similarly, some argue that the online contributors deserve credit for their creative and intellectual work; the works that should be treated as 'published' (Bruckman, 2002).

Our data consisted of naturally occurring communications that were freely available to the open public online communities. The University of Auckland Human Participants Ethics Committee – who approve research projects through a peer-review process – exempts researchers using published or publicly available data from requiring ethics approval[12] (University of Auckland Human Participants Ethics Committee [UAHPEC], 2019). It has been argued that when data are collected anonymously in the public domain/online communities (certainly the case for our communities), informed consent is not required (Eysenbach & Till, 2001; Kozinets, 2002; Kozinets, 2010). Taking this into account, we assumed that our communities' contributors were aware of the fact that their posts were publicly

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[12] According to the Guiding Principles for Conducting Research with Human Participants – approved by University Council on 11 March 2019, no ethics approval is needed from UAHPEC for the following proposals: a) observational studies in public where participants are not identifiable, and b) research using only published or publicly available data.

available and open to anyone to read, thus consent was not required. Furthermore, online users' anonymity has been eliminated by the new Facebook policy (2018) under which the identity of Facebook contributors is not identifiable using their direct quotes in the Facebook search engine. This presumably protects the identity of contributors whose direct quotes are used in this study. Regardless, additional care was exercised through seeking consent from those whose direct excerpts were chosen to be published (Kozinets, 2002). The information such as the date and time of the chosen quotes recorded in the Nvivo database was used to identify the authors[13] and approach them to seek consent via their Facebook account. All approached contributors were supportive of the study being undertaken to acknowledge the importance of such research, with some offering further help should it be needed. Quotes were used directly retaining online contributors' verbatim wording with the person's emphasis – only minor changes were applied for semantic clarity.

Within the context of this particular study, I believe the methodology chosen can be ethically defended because the research was conducted in a public sphere (and not a private or closed sphere) where individuals had control over the information they disclosed. I view these shared comments as social commentary and a legitimate piece of secondary data (von Benzon, 2019). The same approach has been used in a variety of research on sensitive topics such as sex-related subjects (Berdychevsky & Nimrod, 2017), attitudes of heterosexual men about prostitutes (Blevins & Holt, 2009), death and expression of grief (Radford & Bloch, 2012), loneliness and isolation (Janta, Lugosi, & Brown, 2014), depression (Nimrod, Kleiber, & Berdychevsky, 2012), the "deep web" for drug addiction (Orsolini, Papanti, Corkery, & Schifano, 2017), public attitudes on assisted dying (Jaye et al., 2019), and many others.

4.4 Results

Observation and analysis of the online comments demonstrated that our five online communities serve two main functions. First, they provide a medium for followers to express their views. Second, they provide a safe forum for followers to share their personal stories, show their support, provide empathy, and to engage in outreach. The majority of shared comments referred to the contributor's feelings and

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[13] The identity of the quote's author may be identifiable by others using the same method – exporting the communities' comments into NVivo or other similar tools and using keywords search to trace the quote and its related information.

views around one's situation with dementia. Based on partial self-reported demographic data that were made available in the text of comments (e.g., a nurse describing their relationship to the patient), shared narratives/comments mainly reflected formal and informal caregivers' views on their own and patients' experiences in those situations. Occasionally, there were some comments from patients in the earlier stages expressing their journey with dementia. Regardless of the content of a post being specifically about dementia or not, contributors frequently started their online conversations with a discussion of dementia – usually with a short introduction of how they relate to dementia and a description of the difficulties and challenges they are facing. The positive aspects of their journey with dementia were rarely addressed by the contributors. Our longitudinal approach (August 2016 to March 2018) showed an increase in the frequency of dementia-related comments towards the end of the data collection period. These comments contained discourses about feelings and emotions, concerns and dilemmas, critiques of current assisted dying laws and the healthcare system, and the need for changes primarily in legislation, end-of-life care for dementia, and support for patients and their families/caregivers. From the data as a whole, the following themes and sub-themes were extracted.

4.4.1 Theme 1: Understanding dementia

Our online contributors had a lived conception of dementia disease trajectories, signs and symptoms, and types by virtue of living with, or caring for, individuals with dementia. Whether this understanding was clinically realistic was unclear. They often portrayed dementia as a debilitating disease that significantly affects all aspects of a person's life, as well as those around them. To them, the gradual deterioration of the mind and body causes mental and emotional suffering not only for those with the disease but also for their families and caregivers. In that sense, dementia was conceptualized as a cruel disease because of the way it erodes the essence of those afflicted by it.

> Please, I have had to watch too many beloved people starve to death, their last week, before they died. My mother with Alzheimer's dementia had to live like a vegetable for 5 years and at 50 lbs had to starve till her organs all shut down.

> Having worked in nursing homes with dementia residents and in a palliative ward of a hospital and having had a family member passed from dementia and terminal illness myself, you see the suffering first hand, not just of the patient but of the family as well. The angst of the family when their loved one continues to linger but are past the stage of complete consciousness, when in the

> ending stages. It’s heart breaking. This law needs to be changed so the option [assisted dying] is available.

4.4.1.1 Sub-theme: Quality of life

Dementia can leave patients not knowing who they are, who their loved ones are, and what is happening to them. It can also take away a person’s ability to feed, bathe, and toilet themselves. Communities’ contributors stated that quality of life is often diminished for individuals who have no cognition, mobility, speech, or control over their bodily functions, but most importantly, who are unable to recognize their family, friends or self. This was intimately tied to aspects of dignity, especially with respect to the inability of an individual to carry out self-care.

> My dad can’t care for himself anymore, he can’t control his bowels, and he chokes on everything he eats or drinks. No one should have to live this way, this isn’t living!

> I have watched my mum, dad and step-mum die of vascular dementia and there is no quality of life when a person has the inability to feed, bathe, clothe themselves and lose their memory and speech. It’s a disgrace.

A reflection on what constitutes a dignified death often arose with comments linking this to the right to die, not having someone else make that choice for you, and a good death that is free of suffering and complete dependence on others for daily care.

> My nan was terrified of getting Alzheimer, but she did and “lived” with it for ten years in nursing homes, mistaking my dad, her son for her husband, using bedroom drawers as a toilet and many more degrading things that she would have been horrified about pre dementia before deteriorating to a skeletal figure in a chair, […].

4.4.2 Theme 2: Understanding assisted dying laws

Watching loved ones suffer from the consequences of dementia resulted in some family members/caregivers reflecting on their own end-of-life options including assisted dying. The majority appeared to have a clear idea of what, if anything, their jurisdiction laws allowed regarding assisted dying.

To protect patients with dementia, and their caregivers from unnecessary suffering, the majority of the communities’ contributors believe that the legal provision of assisted dying is essential. This may relate to the view that such patients would find comfort in knowing they could control their end of life prior to losing capacity and insight.

> […] I am still traumatized by my parents dying procedures. AND despair that this could be my barbaric ending. IF ‘end of life choices’ were legalized, I could live out the remaining of my life knowing ‘ahead’ I would be spared such disgrace.

In addition to this, the majority of contributors held the view that assisted dying laws that excluded competence-eroding conditions failed to address the psychological and existential suffering of patients who perceive they may have years of uncertainty, distress, and pain ahead, and of those caregivers who watch this suffering.

4.4.2.1 Sub-theme: Rights

Unsurprisingly, contributors of the online communities generally supported the right to choose to die on one’s own terms arguing that no one but patients themselves, who know their own interests better than anyone else should have the right to choose in advance to request an assisted death.

> We choose the way we live our life and I believe strongly that we should be able to choose what should happen if we find ourselves with a terminal illness, or a debilitating one, or one that takes our minds and memories away.

> It is a fundamental human right to choose how we LIVE our lives and that should be followed through to the end when we should have the right to end our lives. I saw my Mum slowly disappear over 5 years to dementia and a once proud woman be reduced to a non-speaking shell of the wonderful person she was. I don’t want to follow the same path and want the right to say “enough is enough” when I’m ready.

It was argued that a consequence of most jurisdictions assisted dying laws excludes i) patients lacking decision-making capacity from requesting an assisted death, ii) patients having a right to choose, forcing them to endure a long and drawn-out dying – which was often perceived as meaningless, iii) an ability to be involved in their end-of-life decisions, and iv) patients ending their life prematurely while they still had the ability to do so. Contributors consistently referred to laws recognizing obligations to ensure animals do not suffer, yet the laws often do not permit a human who is suffering to be helped to die when that is their preference.

> […] No one should have to suffer such excruciating indignity. We don’t let animals suffer towards the end of their lives – why, oh why do we make human suffer so?!!
>
> When she [my mum] had moments of awareness she would beg us to end her life and we had to tell her we couldn’t, it was so painful to watch and go through. We don’t let our pets go through this pain, but other people tell us we have to let our loved ones live in so much pain. I think it should be up to the individual when they want to die, not to other people.

The legal requirement of having to have decision-making capacity at the time a request for an assisted death is performed was considered to be discriminatory. The majority of communities’ contributors supported assisted dying laws to include non-compos mentis patients who have previously signed advance directives that explicitly request an assisted death in their current situation. They believe that while patients are of sound mind, they should be able to make a plan in advance to determine when they would wish to die if they become incompetent.

> I know that my desire is a little different. I watched my mom die very slowly from dementia in 2011 and now I am my dad’s caregiver, he suffers from Lewy body dementia. I know you must be of sound mind when you make this decision. Right now, I am of sound mind and I know I don’t want to suffer or cause my family this pain. I hope that when my time comes my wish will be able to be carried out […].

In the online communities of countries that permitted legal assisted dying (such as Canada), many of their communities’ contributors wanted the legal requirements specifying terminal illness removed from legislation, or to change the classification of “terminal” to cover all other debilitating and irreversible illnesses such as dementia. They also wanted the requirement for a six-month life expectancy removed.

4.4.2.2 Sub-theme: Advance directives

Although almost all contributors supported the provision of assisted death for people with dementia, they recognized the need for adequate safeguards. They strongly believed that the provision of clear AED, written by competent patients, would safeguard individuals with dementia. Not every situation is straightforward, however, particularly in the absence of written advance directives. In response to these concerns, other contributors preferred to leave the discretion to patients’ trusted family members or individuals with Power of Attorney to decide about a patient’s end of life based on their understanding of the patient’s expressed wishes and lived life.

Some objections to the provision of assisted dying for patients with dementia were also made, and although limited, they led to the following concerns being raised by some communities' contributors: family members or HPs might pressure their patient or family member to request an assisted death against their will; patients may change their mind as their disease progresses; and laws and regulation, however stringent, might be broadened or abused at some future point in time. Despite this, some contributors commented that the provision of assisted dying for competence-eroding conditions needs to be a legal option at the end of life. The sense of disappointment in assisted dying laws that ban AEDs was pervasive among communities' contributors.

> This choice and decision can be made beforehand, in case this [dementia] happens. It is not playing god. This door needs to be opened as it is cruelty keeping someone alive after they have left and a shell remains.

4.4.3 Theme 3: Caregivers' feelings

Responses to contributors' online comments were supportive and empathic often expressing sympathy by sharing similar experiences and telling contributors that they are not alone.

4.4.3.1 Sub-theme: Psychological/Existential distress

In the absence of assisted dying laws in many countries, one common option perceived by communities' contributors at the very end of life for people with dementia was to stop all treatment (other than medicine to manage pain and other symptoms), and hydration and nutrition. Many caregivers had experienced the decision to withhold hydration and nutrition, which resulted in their loved ones "starving to death", which was described as "torture" or "torment".

> […] I lost both my parents to dementia and watching them suffering was unbearable.

The difficulty of witnessing "pointless suffering" was repeatedly expressed by many caregivers, some claiming that their experiences would follow them for the rest of their lives. Some caregivers and family members expressed a sense of prolonged grief. They wrote of losing a loved one twice – social death and then physical death.

> […] I watched my Dad, who was Superman, slowly succumb to frontotemporal dementia. I know if he had that option, that's what he would have wanted. In pain, confused, unable to talk, etc. Watching his suffering is a kind of pain I never experienced. Now I am watching my Mom go

> through the same. If I am ever diagnosed with dementia, I want the option to map out my own death plan and spare my children the pain of the looonnnngggggg [long] goodbye.

Caregivers and family members also shared feelings of guilt and uselessness; guilt because they couldn’t assist their loved ones to die as they wished; useless because they were unable to ease the pain and suffering – sometimes over many years.

> To my shame I let my darling husband struggle on for years with dementia. If I had to do it again, I would have HELPED him out, because he would have done the same for me. Politicians need to get a reality check along with a large dose of humanity.

The feeling of burden was also significant. The majority of caregivers did not want their families and friends to have to suffer the distress of watching them slowly deteriorate and die as they had witnessed their loved ones.

> […] what I watched him go through was inhuman. The nightmares and guilt it has left me with is unbearable. While I do not regret anything, I did for dad I cannot put my own children through the same things. If I am approaching the same end, I will take my own life […].

All caregivers who had gone through the process of nursing someone with dementia feared following the same path to death. Without an AED in place, they commented on their fear of an unknown fate as they are aware of the suffering one may have in years of dementia with no hope of a peaceful ending.

> […] it has taken me a long time to get over their deaths (dad, mum, and brother-in-law). Now I can say that I am not frightened by death, but I am frightened by the possibility of dying slowly in prolonged agony, unable to communicate, feed myself, etc. I want to have the option of assisted dying available to me so should I need it.

4.4.4 Theme 4: Moral/personal dilemmas

Online communities also provided a space that allowed their followers to express openly their emotions and personal dilemmas.

4.4.4.1 Sub-theme: Suicide

Some explicitly discussed narratives of suicide attempts/plans from people with dementia, which did not go as intended either because they had lost their ability to carry it out or forgot their plan.

> You can only suicide yourself if you have the strength and method. My darling mother had dementia, when she knew what was happening to her, she stored tablets under the sink in plastic bags. These tablets she thought were sedatives, but [it] transpired they were vitamin pills. Tragically she forgot anyway that she even had them and died of end term dementia and pneumonia ten years later after suffering the knowledge, the undignified end.

Having watched this, some caregivers stated they were fully aware that they may consider suicide well before it becomes necessary, some contemplating if ever diagnosed with dementia, ending their own lives while they still have the physical ability to do so.

> […], my mum died with Dementia and I will not die starved and choking to death not knowing my family, if I can choose how I die I will, suicide or Dignitas.

> […] my mother has dementia and if I ever diagnosed with it then I will take my own life immediately even if I could still have a few decent years left rather that end up like she has and unable to get out of it.

Some reports of implicit and explicit requests from patients to help them die also arose, with contributors sharing experiences of being begged by patients and their loved ones to help them "end it".

> My mother-in-law has dementia...she is constantly asking us to end her life…the law needs to change asap [as soon as possible].

> […] I think denial [of an assisted death] will encourage more early suicides while people still have enough physical control to do it themselves […].

Without an AED, many caregivers found themselves in a dilemma over whether to help their loved ones to die as they had wished, or to watch them endure the dying process.

> […] People are often far more damaged by having to watch their relative suffer for every last breath while they beg for release […].

The majority of caregivers also expressed the will of their loved ones who wished to die in their lucid moments.

> My mum was 95 when she passed and had vascular dementia. For over 6 months every day she just wanted to die. Every day she cried. Absolutely heart-breaking.

Although family members would dearly miss their loved ones, on some occasions, they also prayed for them to die sooner.

> […] she [mom] would hide her tablets etc., imagine people were in her bedroom, cooking, doing auctions, etc., & deteriorated, into a bedridden skeleton which we had to watch get worse & worse! In the care home!! Refusing to eat/drink for that last 9 months!! (I know this sounds awful, but I used to pray for her to "go to Dad!" [pass away] but she dragged on & on!! & me knowing there was no cure or relief from the disease kept willing her to "go to Dad"!! (You couldn't keep a dog in that condition!! Where was mum's dignity!!?)

4.5 Discussion

The public nature of our online communities allowed anyone from geographically dispersed locations to engage and contribute together. Among these diverse populations, there is a profound fear of developing dementia and its ensuing physical and cognitive decline, which has made them consider alternative end-of-life options such as expressing their preferences in an advance directive and considering an assisted death (Hertogh, de Boer, Dröes, & Eefsting, 2007). The fact that the communities' contributors have been actively starting conversations about dementia, may underlie an increase in public awareness and concerns/fears in relation to a dementia diagnosis (Hertogh et al., 2007; Poole et al., 2018). As the population in most countries grows older and rates of dementia increase, dementia and end-of-life decisions (including the matter of assisted dying) are likely to become more relevant to public discussion. Dementia, in this regard, may provoke feelings of loneliness, uncertainty about future decline, fear of losing meaning, control, and freedom of choice, and lastly, the fear of a prolonged death. This may cause existential distress to patients and families/ caregivers (Albinsson & Strang, 2003; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Schulz et al., 2008).

The present findings suggest that high levels of existential distress experienced by individuals with dementia and families/caregivers is one of the main reasons for caregivers considering assisted dying for themselves (Tomlinson et al., 2015). Existential and psychosocial dimensions of suffering are reported to be as important as physical suffering (Albinsson & Strang, 2003; Tomlinson et al., 2015). There is evidence that Dutch physicians are mostly inclined to grant an assisted dying request when the suffering is directly related to pain or physical symptoms, rather than psychological/existential kinds of suffering (van Tol, Rietjens, & van der Heide, 2010), but in cases of competent individuals with dementia, majority of Dutch physicians would be willing to accept an assisted dying request on the basis of present or future “unbearable refractory existential suffering” (Schuurmans et al., 2019). The fact that the gradual progression of dementia may allow the person to adapt and adjust to their changing situation (de Boer et al., 2007) does not counterbalance the impact of anticipated suffering in the future. People with dementia may experience several years of confusion, fear, and uncertainty regarding their future life (de Boer et al., 2007). Although there may well be positive experiences associated with living with and caring for individuals with dementia (Lloyd, Patterson, & Muers, 2016), our communities’ contributors’ experiences and perspectives were largely negative. The importance of meaning and purpose in psychological well-being has of course been recognised for many years, in particular since the publication of Frankl’s (1946) seminal text “Man’s Search for Meaning”, and later emphasised by Neimeyer (2001) as central to dealing with grief, arguing that the more a death could be placed into a coherent narrative, the easier it would be do deal with. The apparent meaningless of a drawn-out process of dying (e.g., “…why, oh why do we make human suffer so?!!” quote above) may have the potential to impact on the grieving process and could form the basis for further studies.

Caregivers and some early-stage patients commonly expressed difficulty assigning meaning to the suffering in the absence of capacity. Individuals find meaning by making choices and decisions and assigning values to them; these transitory experiences provide the basis to give meaning to life (Farran et al., 1991). Losing the ability to reflect on one’s past experiences may threaten the meaning of life. To find meaning in suffering, patients need to be able to communicate their suffering and to reflect on it in order to accept and overcome their existing situation (Farran et al., 1991). Therefore, when past experiences are no longer accessible to people with advanced dementia, and when communication and thinking processes are lost, families and caregivers may find their loved ones’ suffering meaningless. This may confirm caregivers’ belief in the rights of patients to end their suffering by requesting an assisted death (should they wish) when all hope for recovery and capacity is lost. This aspect has previously been linked to the public argument in favor of assisted dying for advanced dementia (Kouwenhoven et al., 2015).

The right to die is one of the central arguments in the assisted dying debate and issues primarily from the principle of autonomy: that individual’s choices should be respected about how they live their lives. Therefore, it is not surprising that the majority of our communities’ contributors supported an individual’s right to die in their chosen manner when expressed previously in advance directives. These findings are in line with other studies showing that caregivers supporting incompetent patients' right to die (Braverman et al., 2017; Tomlinson et al., 2015). The majority of caregivers also supported the provision of an assisted death for themselves should they too develop dementia. A significant proportion of the UK and Dutch general public (Williams et al., 2007), as well as Quebecois older adults, caregivers, and nurses are supportive of the provision of assisted dying for themselves (Bravo et al., 2019) if they were to become demented. One relevant factor in their desire for an assisted death may relate to their wish of not becoming a burden to their families should they develop dementia. The fear of putting families under the mental and emotional stress of caring has been raised by the general public as an acceptable reason to provide assisted death (McPherson, Wilson, & Murray, 2007).

A different approach reflects the desire for the right to die as construed as an attempt to retain their sense of control. Hertogh et al. (2007) link interest in an assisted death for people with dementia to fear of a future with dementia, as well as a desire to preserve choice and control: "They want to remain in control of their life and future, and specifically reject the perspective of a disease that causes their identity to unravel and brings with it a loss of competence and independence" (p. 49). Being in control of one's death is a way of exercising autonomy at the end of life, which can be retained through an advance directive. Contributors' expression of support of assisted dying through AEDs was a declaration of an attempt to put an end to suffering while maintaining some control (Monforte-Royo et al., 2012). Consistent with the literature, our data highlight the (fear of) loss of control, autonomy, and independence associated with dementia (de Boer et al., 2007).

Over half of Quebec nurses caring for elderly people with Alzheimer's disease, or a related disorder, reported having been exposed to a wish for a hastened death by their care recipients (Bravo et al., 2018a). Our findings mirror similar wishes, suggesting that assisted dying requests may be an inevitable challenge of end-of-life care. Advance directives for an assisted death, in such circumstances, may protect the will of patients beyond their loss of capacity without pressuring caregivers to decide on their behalf. Without such directives, the risk of a burden on proxies to make decisions on behalf of their loved ones with dementia is increased (Tjia, Dharmawardene, & Givens, 2018).

The results also support the need for professional support to improve the quality of care for patients with dementia and their families/caregivers; such support could include end-of-life related education, bereavement support, and more effective communication regarding treatments and end-of-life care.

Resources such as palliative care may often be lacking in hospital beds, with hospices unable to meet the demand. Although hospice or palliative care potentially has a positive contribution to make, their availability may be limited or “too little, too late” (Lewis 2014; p. 1224).

4.6 Conclusion

This study provided a grassroots view of assisted dying in the context of dementia. The experience of living with dementia and/or caring for dementia sufferers first-hand has influenced the views of many of those concerned with regards to the right to an assisted death. The feeling that their loved ones were increasingly experiencing more pain and suffering coupled with the loss of joy and dignity with no hope of recovery appears to be a turning point for the majority of contributors to see assisted death as a desirable end-of-life option. Dementia, particularly in more advanced stages, was often perceived as a disease with little quality of life, with assisted dying often being considered as a more dignified alternative. Similar feelings in caregivers of loved ones with dementia have also been reported to play a part in preferring a comfortable death over continued living at the cost of intensive or uncomfortable interventions (Lewis, 2014).

Studies also show a trend towards holding more permissive attitudes on assisted dying over time (Tomlinson & Stott, 2015). Laws in most jurisdictions, on the other hand, neither allow an assisted death for incompetent patients nor recognise an advance directive request for an assisted death. This situation has left people frustrated with some of the options they have at the most vulnerable stage of their life – one of which is to withhold life-prolonging treatments and/or nutrition/hydration (The, Pasman, Onwuteaka-Philipsen, Ribbe, & van der Wal, 2002), to access assisted dying prematurely while they are still competent and living a quality life (de Beaufort & van de Vathorst, 2016; Legemaate & Bolt, 2013), or, for some, to commit suicide to avoid dying with dementia (Anderson, Eppes, et al., 2019; O’Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016).

A meta-synthesis study on changes in family dynamics in caregiving for a person with dementia shows that caregivers lacking support from their family are likely to seek help from new social groups of people who are experiencing the same challenges (Oh et al., 2019). Our online communities appear to serve such a function, providing support, empathy, and sympathy for contributors. Communities also provide a medium for followers to narrate their stories and to freely engage in outreach to advocate for their right to die. Our study data occurred naturally where authors constructed their own meanings from these phenomena and prioritized and categorized their own narratives in their own way (von Benzon, 2018). Our data were, therefore, less contrived (Muller et al., 2016) adding perspectives of how dementia can influence public perceptions of assisted dying. The continuous efforts made by communities' contributors to raise awareness of their dementia-related challenges and end-of-life preferences are a testimony to the need for further research and exploration in this area.

4.6.1 Limitations

The present research has a number of limitations. The first is the issue of selectivity and bias – that is, the followers who contributed to these online communities all voluntarily chose to do so and may not be representative of the general public. They are potentially more inclined to express and defend their views than those who may have a positive view or experience with dementia. The overwhelming sense that one gets from reading comments is how negative the experience of living with dementia was for the communities' contributors. A second limitation is the use of a single platform – Facebook – to gather data. We did not include data from other online social networking sites that could have complemented or contrasted the views on assisted dying for people with dementia. Given the dominant position that Facebook holds in the social media world, however, we are hopeful that this did not produce excessive bias. Third, it is predominantly an "outsider" view of dementia and assisted dying. It includes limited data on the perspectives and insights from those living with dementia, who are facing their own decline. These limitations represent opportunities and directions for future research.

Chapter Five

Chapter 5 – Feasibility study

Exploring safeguards for assisted dying for individuals with dementia: Views of an informed group

5.1 Introduction

Access to assisted dying for individuals with dementia is challenging because of some of the particular characteristics of dementia that conflict with specific legislative provisions and ethical norms in the practice of assisted dying (de Boer, Hertogh, Dröes, Jonker, & Eefsting, 2010b; Downie & Lloyd-Smith, 2015; van Delden, 2004).

> The interplay of common ethical rationales for permitting assisted dying (e.g., autonomy and alleviation of suffering) with common features of dementia (e.g., loss of competence before the terminal phase of the illness, loss of the capacity to communicate before the loss of the capacity to suffer) raises challenges for translating one's ethical position on assisted dying for individuals with dementia into law. (Downie & Lloyd-Smith, 2015, p. 98)

In order to realise the intended or expected legislative provisions in cases of assisted dying for individuals with dementia, very careful consideration needs to be made. A shift is required to transform the role of advance directives as mere executive agents of patients' preferences and wishes (Hertogh, de Boer, Dröes, Jonker, & Eefsting, 2007a) towards a practical framework that guides and informs others as to how and when these preferences (for an assisted death request), should be addressed. One initiative could be to carefully consider and integrate the typical characteristics and challenges for individuals with dementia into AED in order to assist the patient in determining their own preferences. Legally, an initiative may focus on a careful modification of existing assisted dying regulations tailored to the particular needs of these particular patients (Downie & Lloyd-Smith, 2015).

To ensure the advanced care wishes of people with dementia are respected, their views on assisted dying should be ascertained early in the disease trajectory well before their ability to consider their future is compromised (Dening, Jones, & Sampson, 2013). However, it may be easier for people to establish an advance care plan based on some clearly defined choices rather than a "multitude of unknown potential eventualities" (Poole et al., 2018, p. 7). For example, a study on the views of patients with dementia and their family caregivers about end-of-life care shows that family caregivers are often positively responsive to an aspect of healthcare planning such as “do not resuscitate order” while they struggle to understand the value of establishing such an order in the abstract (Poole et al., 2018). Although it is impossible to account for every possible contingency that may arise, a framework that takes into account the most likely challenges (for instance, consequences and possible outcomes) that individuals with dementia may face in their (perceived) incompetent future may help them and their families/caregivers establish the best possible advance directive – that is, what is right for them. It may help individuals to write their AEDs with a greater degree of clarity and precision regarding what is important to them as they look towards their future. This would entail much greater involvement of HPs in the early stages of discussing an advance care plan, or in drafting an advance directive (Auckland, 2017; Widdershoven & Berghmans, 2001), especially in providing guidance to those who are looking to make their medical preferences clear.

In all permissive jurisdictions, a request for an assisted death has to be a personally driven choice that a patient explicitly expresses for themselves. No individual can legally make an assisted dying request for another, no matter the level of that person’s competency, distress, or suffering. Challenges can occur at the implementation phase of such requests where the decision to uphold AEDs depends on the clinical judgement of the HPs to assess the compatibility of the directive’s content with the current situation of the patient, and/or on the moral judgement of family/caregivers to decide (upon the HPs’ request) whether to comply with these directives (de Boer et al., 2010b; Hertogh, 2009; Rurup et al., 2005). Several studies have revealed differences between the wishes and preferences of people with dementia and their family/caregivers (Dening et al., 2013; Rurup et al., 2005) and the reluctance of HPs to uphold patients’ AEDs (de Boer et al., 2010b; de Boer et al., 2011; Rietjens et al., 2007). Therefore, when it is the responsibility of the HP to make the final decision on whether a patient with dementia is eligible for an assisted death, it may be beneficial to involve the use of structured guidelines to assist in the decision-making process.

In order to explore tentative safeguards for the practice and application of assisted dying for individuals with dementia, this study aimed to explore what we can learn from an analysis of the combined central views of experts (Chapter 3) and the public (Chapter 4) on what implications these results may have on safeguarding the practice. The inductive reasoning approach of collecting empirical data in two previous studies (Delphi and Netnography) resulted in the emergence of some patterns with regards to the views of experts and the public on the primary challenges and concerns about assisted dying for individuals with dementia and ways forward. This led to some tentative hypotheses (statements in this study – see table 5.3) that could be further examined. These synthesised statements suggest some general guidelines for practice both at the individual and organisational level and raise some concerns that need to be considered to mitigate possible harm. The logical next step was to assess whether these identified issues could be summarised enough to be comprehensible in survey form, and to get an idea of how many people would see these as worth pursuing. Therefore, in this study, I aimed to assess the feasibility of such a study and to gather some preliminary data by collecting empirical data from an *informed* group of individuals. For these purposes, it was important to obtain the views of people who have the knowledge and perhaps experience or expertise in relation to my topic and therefore have thought about the implications of assisted dying for people with dementia, their families, and care team. While providing a more nuanced view on the area, the results of this research may further assist in determining areas of uncertainties and challenges that require further exploration, therefore building a foundation for future research.

5.2 Method

5.2.1 Design and population

This study using a deductive reasoning approach (Myers, 2013) to obtain the preliminary data needed to assess the feasibility and acceptability of the recommendations, to rule out those that might sound appealing on the paper but cannot be implemented effectively in practice. As it is suggested, "the conceptualization of pilot studies as planning tools focused on feasibility and debugging, rather than on the estimation of effect sizes, provides opportunities for innovative approaches to designing pilot studies that provide useful information for the subsequent confirmatory studies (Duan, 2013; p.328). Ethics approval was obtained by the University of Auckland Human Participants Ethics Committee, to conduct a cross-sectional questionnaire survey (Reference Number 022679). Qualtrics Survey Software (Qualtrics XM) was used to design an anonymous questionnaire. The questionnaire consisted of two parts (Appendix C: #4, p. 206). The first substantive part contained 28 statements that captured the central findings of the Delphi and Netnography studies. The second part involved three questions on the demographic characteristics of the chosen population, including gender, age, and education.

Accompanied by the Participant Information Sheet (PIS), which contained relevant information on the study's aims and objectives, participation procedure, data use, and storage, and anonymity and confidentiality aspects (Appendix C: #1, p. 202), the questionnaire was sent by email from the End-of-Life Choice (EOLC) Society of New Zealand Incorporated[14] to all members of the organisation (Appendix C: #3, p. 205). EOLC is an advocacy organisation in New Zealand and a member of the "World Federation of Right to Die Societies". At the time of participant's recruitment, their aim was to change the law in New Zealand that entitles competent adults who are experiencing irremediable suffering from a terminal or incurable illness to receive medical assistance to end their life at a time of their choosing and to provide information about the opportunities for an open and frank discussion on assistance in ending their lives. As some level of knowledge on the topic was necessary to assess the survey's statements, the EOLC Society was chosen as it is a mutually homogeneous (in terms of their knowledge) yet internally heterogeneous (in terms of their personal views on AD in cases of dementia) group. Members of the EOLC Society have a considered and particular view on AD and may have experience or expertise in caring for someone living with a terminal and/or competence-eroding illness such as dementia. Members were considered heterogeneous in the sense that their support of assisted dying for individuals with dementia was neither clear nor could be implied by their support of assisted dying in principle. All that could be drawn from the EOLC members was that they are supportive of assisted dying in principle and, thus, more willing to engage in the study.

5.2.2 Data collection and analysis

The questionnaire was piloted with the EOLC committee board members to ensure the coherence of the statements. This resulted in the minor editing of two statements for clarity. Data were collected from March to May 2019, with one reminder email sent out during this time. The EOLC members were asked to evaluate 28 statements (two of the statements contained seven sub-statements) according to their level of agreement or disagreement on a 7-point Likert scale: strongly disagree (1), disagree (2), slightly disagree (3), do not have the knowledge (4), slightly agree (5), agree (6), and strongly agree (7) (the numbers were not presented to the participants). It was estimated that the online questionnaire should take approximately 10-20 minutes to complete. No separate consent was sought as it was made clear to participants that by submitting their questionnaire they consented to be involved – this was consistent with the ethics approval given.

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[14] The EOLC Society has given their written permission for the name of the organisation to be identified in the research/publications.

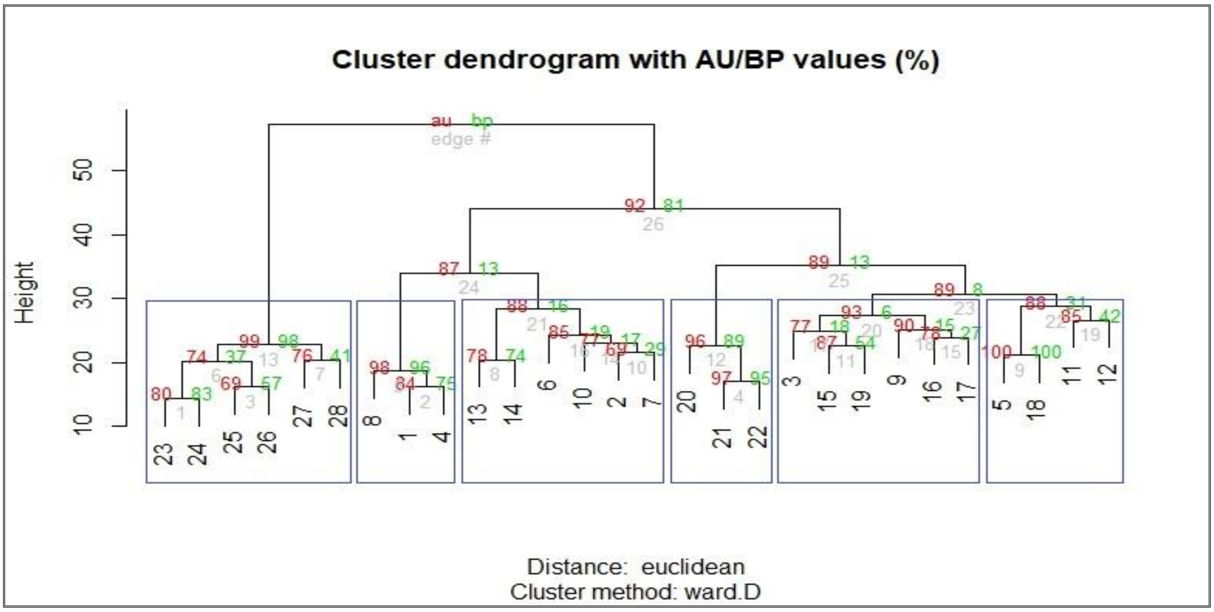
5.2.2.1 Descriptive statistical analysis

After completion of the data gathering phase, data analysis was conducted using IBM SPSS Statistic software, version 25.0. No responses were excluded from the data analysis as the missing values were 0.25%; the Series Mean (SMEAN) technique was applied to correct all the missing values. Previous studies use either descriptive statistics analysis or a combination of descriptive analysis with t-tests, regression, Chi-square test, etc. to understand the relationships between the dependent variables (e.g. attitudes of respondents) and the independent variables (e. g. different demographical characteristics) (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2010a; de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2011; Kouwenhoven et al., 2013; Terkamo-Moisio, Pietilä, Lehto, & Ryynänen, 2019). As the focus of this study was to run a confirmatory test on previously identified statements, a descriptive statistical analysis was applied accepting those statements that were highly or very highly agreed based on measures of central tendencies and dispersion such as mean and standard deviation (SD) (Appendix C: #5, p. 210). Having considered the median and SD of the responses, levels of agreements were defined as a mean of 6-7 for very high agreement (Likert points of 6-7), a mean of 5-6 for high agreement (Likert points of 5-6), and a mean of 4-5 for low agreement (Likert points of 4-5).

5.2.2.2 Hierarchical clustering analysis

Having considered the findings of the two previous studies (discussed above) and the literature on assisted dying laws and practices in a number of jurisdictions, we categorised the current research statements into six categories that would serve the aim of developing a conceptual framework. The same purpose-driven categorising approach is followed by other studies in this field (de Boer et al., 2010a, 2011; Schmidhuber, Haeupler, Marinova-Schmidt, Frewer, & Kolominsky-Rabas, 2017; Tomlinson et al., 2015). We also checked the accuracy of the categories that were manually generated to ensure that the statements were appropriately grouped together. In this regard, the statistical clustering method was used to compute the similarity or dissimilarity between research statements according to responses collected from the EOLC participants. In this method, similar statements appear in the same cluster whereas dissimilar statements were classified in different clusters. In a typical clustering method, it is required to perform four fundamental tasks including cluster feature selection, similarity measure identification, cluster computation, and cluster presentation. In this study, for the "cluster feature selection", participants' responses are selected in order to calculate the similarity between statements (Jain, Murty, & Flynn, 1999). Jain et al. (1999) suggest there is no universally accepted approach to calculate the similarity between selected measures. Therefore, a variety of distance measures have been applied in previous studies, including the Euclidean Distance, Pearson Correlation Coefficient, K-means, Cosine Similarity (Jain, Murty, & Flynn, 1999; Kolini & Janczewski, 2017). I applied Pearson's Correlation Coefficient Distance, which is recommended for producing more accurate results (Leydesdorff & Zaal, 1998) for the purpose of "similarity measures" to calculate the similarity/dissimilarity between our research statements. Moreover, for "cluster computing", we selected a hierarchical cluster (based on Pearson's Correlation) that can classify all research statements and draw a link between these identified clusters. A dendrogram, which is based on the ward linkage (Ward, 1963), is often used to present the hierarchical clusters as shown in Figure 5.1. Hierarchical clustering analysis was applied using the R programming language for statistical computing.

Figure 5.1 | Hierarchical Cluster Dendrogram



From the comparison between the manual classification of research statements performed by the primary researcher and automated clustering analysis, I have noted a similarity of 82.8% (25 out of 28 statements) between the six categories that were indicated using the manual classification approach (Table 5.1). This finding shows that the manual approach is not biased and is accurate enough for the representation of the findings. These clusters/categories are discussed in the next section.

Table 5.1 | Hierarchical and manual clustering of research statements

Categories/Clusters	Statements' numbers – Manual clustering	Statements' numbers – Hierarchical clustering	Differences
1. Inclusion criteria	1, 4, 8, 12[a]	1, 4, 8	No (one item)
2. Drafting criteria	3, 15, 17, 19	3, 9[a], 15, 16[a], 17, 19	Yes (two items)
3. Implementation criteria	5, 11, 18	5, 11, 12, 18	Yes
4. Harm/abuse mitigation criteria	2, 6, 7, 10, 13, 14	2, 6, 7, 10, 13, 14	No
5. Prerequisite for optimum practice	9[a], 16[a], 20, 21, 22 (20a, 20b, 20c)	20, 21, 22 (20a, 20b, 20c)	Yes (two items)
6. Contributing factors to desire access to an assisted death	23, 24, 25, 26, 27, 28 (21a, 21b, 21c, 21d, 21e, 21f)	23, 24, 25, 26, 27, 28 (21a, 21b, 21c, 21d, 21e, 21f)	No

[a] Statements' numbers of 9, 12, and 16 are the only statements that were clustered under different categories.

5.3 Results

The questionnaire was completed by 382 EOLC members (response rate 27.43%): 72.4% were female, 27.3% were male, and 0.3% identified as gender diverse. More than two-thirds of participants (82%) were aged over 65 years and almost two-thirds (68.7%) had tertiary education. The demographic characteristics of participants are shown in Table 5.2.

Table 5.2 | Demographic characteristics of the participants

Characteristics	N	%
Gender		
Female	257	72.4
Male	97	27.3
Gender diverse	1	0.3
Age		
18-44	10	2.8
45-54	19	5.4
55-64	33	9.3
65-74	151	42.5
75-84	104	29.3
≥85	38	10.7
Highest educational qualification		
Primary school	3	0.8
Secondary school/college or equivalent	68	19.2
Bachelor's or Graduate	113	31.8
Postgraduate or Bachelor's Honours	53	14.9
Master's degree	54	15.2
Doctorate (PhD)	16	4.5
Medical Doctorate (MD)	8	2.3
Other	40	11.3

In an attempt to synthesise the target outcomes of the two qualitative studies to form a set of recommendations for safeguards, six primary domains emerged that helped to categorise the results more systematically, with each domain targeting different aspects of the practice. These domains are followed.

5.3.1 Inclusion criteria

95.6% (Mean 6.47) of participants very highly agreed that assisted dying laws should include provisions for patients with dementia. Likewise, 95.3% (Mean 6.58) very highly agreed that the classification of “terminal illnesses” in assisted dying laws should include dementia. Overall, participants highly agreed (92.6%, Mean 6.28) that the provision of assisted dying for people with dementia would protect them and their caregivers/families from unnecessary suffering at the end of life.

In the event of patients suffering from depression, 73% (Mean 5.50) reached a high agreement that having depression and requesting assisted dying are not mutually exclusive. Caution, however, must be applied in interpreting this result as 19.6% of participants did not have the knowledge to judge whether depression may or may not interfere with having documented a well-considered request for an assisted death.

5.3.2 Drafting criteria

Overall, there were very high agreements of 97.1% (Mean 6.52) and 88.5% (Mean 6.23), respectively, among participants on the need for more information and education about the role of dementia and assisted dying at a societal level, as well as a need to improve the quality of end-of-life care, and to tailor such care to the unique needs of individuals with dementia. In this regard, a very high agreement of 92.4% (Mean 6.42) was made regarding the drafting of AEDs to be a personal choice, so only individuals could choose an assisted death in advance, and no one else could make that choice for them. With a very high agreement of 96.4% (Mean 6.49) and high agreement of 88.7% (Mean 5.95), respectively, participants agreed that *patients* should decide what unbearable suffering means for them, including it is clearly stated in their AEDs. To safeguard these directives, 92.1% (Mean 6.8) of participants highly agreed that the provision of a video recording of patients’ interviews would increase the validity of these AEDs for HPs.

5.3.3 Implementation criteria

In the event that the previously expressed preferences regarding the assisted dying request of a competent individual (AEDs) conflicted with their now current (incompetent) desires, participants failed to show substantial agreement that assisted dying must NOT be carried out (low agreement of 50.8% with a Mean of 4.29). The percentage of agreement, however, implies that although participants slightly gave value to patients' precedent autonomy, they appeared divided over which wishes should take precedence in these conflicting situations. When competency is lost, participants had a low agreement that "*health professionals* and *families/caregivers* should NOT have authority to make assisted dying decisions based on their interpretation of the former and current written wishes of the patients" by 51.1% (Mean 4.35) and 63.3% (Mean 4.94), respectively. Low agreement on these statements may imply that members left some degree of freedom for HPs and families/caregivers to interpret the AEDs.

5.3.4 Harm/abuse mitigation criteria

Participants attached significant importance to AEDs in the drafting phase by agreeing that the provision of clear directives, written by competent persons, would safeguard their instructions in the future. This statement was very highly agreed with by 96.3% (Mean 6.55) of participants. Regarding determining the level of competency of patients with dementia who request an assisted death, 97.9% (Mean 6.62) of participants very highly agreed that competency should be confirmed at the time of drafting the AEDs, rather than at the time of assisted dying implementation. They also agreed very highly (96.8%, Mean 6.54) on the role of such directives in mitigating the psychological and existential suffering/distress of the patient by providing reassurance and control – at the time of writing – that their wishes would be implemented at the end of life.

To protect patients' AD preferences, 71% (Mean 5.18) of participants highly agreed that the current wishes of now incompetent patients (with dementia) must NOT override their prior competent wishes. This highlights the importance of respecting patients' precedent autonomy. Accordingly, a high agreement of 89.2% (Mean 6.9) was reached to allow a HP to act upon the AEDs even when the patient could now no longer confirm those previous wishes, which is consistent with the finding that gives weight to the validity of patients' sound mind at drafting phase rather than at implementation. It was also agreed that a regulatory system that monitored assisted dying practices for individuals with dementia would mitigate abuse (high agreement of 88%, Mean 6.13).

5.3.5 Prerequisite for optimum practice

Participants very highly agreed that HPs need support and need to provide support to other professionals involved in the assisted dying process, as well as support for patients and their families/caregivers (98.7%, Mean 6.55). That includes initiating conversations about assisted dying and conveying relevant information (96.1%, Mean 6.42); and providing an assisted death service (95.1%, Mean 6.34).

5.3.6 Contributing factors to desire access to an assisted death

Participants were asked to rate the results that were found to be positively associated with the desire of families/caregivers to access assisted dying for themselves. Six different scenarios were presented to participants under which the families/caregivers of people with dementia were more likely to desire access to assisted dying for themselves. As presented, all participants highly agreed with scenarios in which families/caregivers have: a fear of following the same path as their loved one (90.6%, Mean 6.15); suffered the distress of watching their loved ones die and do not want to burden their family if they developed dementia (90.4%, Mean 6.08); feelings of guilt and/or uselessness when they can't assist their loved ones to die as they wished (88.2%, Mean 5.54); difficulty witnessing their loved ones' "pointless suffering" (88%, Mean 6.3); thought they might end their life while they were still able to do so (83.8%, Mean 5.89); and if they have experienced a tension between helping a loved one to die (illegally) as they had wished, or watch them suffer at the end of life (80.2%, Mean 5.94).

Overall, out of 28 statements, a total of 25 were accepted with 13 achieving very high agreement, 12 with high agreement, and 3 rejected by reaching low agreement (Table 5.3 – the statements' numbers are presented based on their original sequence in the questionnaire as also shown in the Dendrogram).

Table 5.3 | Descriptive statistics of the responses

Categories – Statements	**Means**	**Medians**	**SDs** [a]	**Minimums**	**Maximums**
Inclusion criteria					
1. Assisted dying laws should include dementia.	6.47	7.00	0.990	1	7
8. The classification of "terminal illnesses" in assisted dying laws should be changed to cover all debilitating and irreversible illnesses, including dementia.	6.58	7.00	1.029	1	7
4. The provision of assisted dying for people with dementia is essential as it would protect them and their caregivers/families from unnecessary suffering.	6.28	7.00	1.240	1	7
12. Having depression and making an assisted dying request are NOT mutually exclusive.	5.50	6.00	1.443	1	7

Drafting criteria					
5. Only individuals should choose an assisted death in advance; no one else should make the choice for them.	6.42	7.00	1.191	1	7
6. Patients should decide what unbearable suffering means for them.	6.49	7.00	0.895	2	7
7. Patients must clearly state in their AEDs[b] what they mean by “unbearable suffering”.	5.95	6.00	1.329	1	7
8. Having video-recorded interviews with patients would increase the validity of their AEDs.	6.08	6.00	1.122	1	7
Implementation criteria					
9. If the previously expressed assisted dying request of a competent individual conflicted with their current (incompetent) desire, assisted dying must NOT be carried out.	4.29	5.00	2.015	1	7
10. When competency is lost, health professionals should NOT have authority to make assisted dying decisions based on their interpretation of the former and current written wishes of the patients.	4.35	5.00	2.276	1	7
11. When competency is lost, family/caregivers should NOT have authority to make assisted dying decisions based on their interpretation of the former and current written wishes of the patient.	4.94	6.00	2.095	1	7
Harm/abuse mitigation criteria					
12. The provision of clear AEDs, written by competent persons, would safeguard their instructions in the future.	6.55	7.00	0.909	2	7
13. Competency should be confirmed at the time of drafting AEDs, rather than at the time of assisted dying administration.	6.62	7.00	0.702	2	7
14. Controlling their end of life through AEDs may decrease the psychological and existential suffering/distress of the patient.	6.54	7.00	0.886	1	7
15. The current wishes of now incompetent patients with dementia must not override their prior competent wishes.	5.18	6.00	1.781	1	7
16. A health professional should act upon the competent AEDs even when the patient can no longer confirm those previous wishes.	6.09	6.00	1.344	1	7
17. A regulatory system that monitored assisted dying practices for individuals with dementia would mitigate abuse.	6.13	6.00	1.194	1	7
Prerequisites for optimum practice					
18. There is a need for more information and education about the role of dementia and assisted dying on a societal level.	6.52	7.00	0.748	3	7
19. There is a need to improve the quality of end-of-life care tailored to the unique needs of each individual with dementia.	6.23	7.00	1.076	1	7
20. Health professionals need to be trained in:					
20a. Initiating conversations about assisted dying and conveying relevant information	5.54	6.00	1.430	1	7
20b. Providing an assisted death service	6.34	7.00	0.950	2	7
20c. Providing support to other professionals involved in the process and to the patients as well as their families/caregivers.	6.55	7.00	0.657	2	7

Contributor factors to desire for an assisted death					
21. Families/caregivers of people with dementia are more likely to desire access to assisted dying for themselves if they have:					
21a. Feelings of guilt and/or uselessness when they can't assist their loved ones to die as they wished.	5.54	6.00	1.430	1	7
21b. Difficulty witnessing their loved ones' "pointless suffering".	6.03	6.00	1.201	1	7
21c. Suffered the distress of watching their loved ones die and do not want to burden their family if they developed dementia.	6.08	6.00	1.093	1	7
21d. A fear of following the same path as their loved one.	6.15	6.00	1.083	1	7
21e. Thought they might end their life while they were still able to do so.	5.89	6.00	1.277	1	7
21f. Experienced a tension between helping a loved one to die illegally as they had wished or watch them suffer at the end of life.	5.94	6.00	1.188	1	7

[a] Standard deviation

[b] Advance euthanasia directives

5.4 Discussion

The findings of this research build on the very limited data available on AD for individuals with dementia with regards to its application as well as providing information on the essential prerequisites towards an optimum and safe AD practice.

This research shows strong support for the necessity of AD laws to include individuals with dementia. The laws in most permissive jurisdictions are drafted in a way that provides little (if any) access for individuals with dementia (Davis, 2018; de Boer et al., 2010a; de Boer et al., 2010b; Hertogh et al., 2007a; Hertogh, 2009; Miller et al., 2019; van Delden, 2004). That is, the primary requirements of "terminal illness" and "competency" embedded in most AD laws are mutually conflicting. The trajectory of dementia may adversely impact the competency of a patient before their disease becomes terminal. And a patient with dementia at the terminal stage may no longer be competent to make decisions about their medical treatment and care. Findings suggest including dementia within the classification of terminal illness may entail its provision at the earlier stage when the disease is not yet terminal. This result is consistent with a review of AD for individuals with dementia at the nexus of ethics and law by Downie and Lloyd-Smith (2015) that proposes early access to assisted dying while not yet terminally ill, or late access at the advanced stage of dementia through an advance directive.

To further clarify the use of AEDs in the advanced stage of dementia, my findings give weight to the requirement of competency at the point of drafting such directives rather than at the time of implementation. Considering the inevitable competency loss in the dementia trajectory, this result implies that competency at the drafting phase should suffice. The inability of patients to reconfirm their previously stated AD request due to loss of competency and communication has been repeatedly reported as one of the access barriers of AD for people with dementia (Evenblij et al., 2019; Kouwenhoven et al., 2015; Mangino, Nicolini, De Vries, & Kim, 2020b).

In my studies, the required level of competency to form a well-considered AD request is also judged to be less influenced by patients' depression. Several studies have confirmed a positive link between depression and a desire to request an assisted death in terminally ill patients (Breitbart et al., 2000; van der Lee et al., 2005; Wilson et al., 2007), whereas others have found no significant link leaving it unclear whether depression increases the likelihood of making an assisted death request (Levene & Parker, 2011). Thus, the extent to which depression may influence assisted dying requests is questionable. Grisso and Appelbaum (1995) believe that cognitive difficulties and weighing for positive and negative information associated with depression may affect patients' competence, but the medical decision-making competency of most patients remains intact (cited in Levene & Parker, 2011). Acknowledging that competency can be retained in depression, it is recommended to determine whether depression is a contributing factor in the desire for an assisted death rather than assess whether it is present (Levene & Parker, 2011).

The principle of patient autonomy plays an important role in the growing interest in advance directives preserving patients' precedent autonomy in the context of dementia (Widdershoven & Berghmans, 2001). Respect for one's precedent autonomy enables a competent person to extend their autonomous decision-making capacity into their future when the capacity for decision-making no longer exists (Ikonomidis & Singer, 1999). Aligned with my findings, the principle of autonomy recognises the right of individuals to make decisions about their future care. On one hand, according to Widdershoven and Berghmans (2001), the principle of respect for autonomy is, problematic in the case of incompetent patients as any decision for treatment and care has to be made based on relevant information and an understanding of the situation (which requires competency and communication) unless there is an advance directive that guides the future treatment and care. On the other hand, they and other scholars, argue that advance directives cannot replace decision-making as they are not executed in isolation raising the concept of relational autonomy. There is also evidence that Dutch HPs often discuss with patients' families or representatives whether to comply with AEDs (Rurup et al., 2005). In this context, my findings are consistent with the involvement of HPs and families/caregivers in interpreting a patients' current situation in light of their advance directive – however, only to the point that other's involvement does not override the previously expressed assisted dying wish of the patient. In practice, patients' confirmation of previously stated assisted dying wishes continues to be an essential factor for compliance with AEDs (de Boer et al., 2011; Hertogh, 2009; Kouwenhoven et al., 2015). These findings, nonetheless, show that the absence of confirmation due to loss of communication should not result in ignoring a patients' assisted death wish. Along with some scholars (Davis, 2014; Dworkin, 1993; Porteri, 2018; Tjia, Dharmawardene, & Givens, 2018), these findings give priority to respecting patients' precedent autonomy by executing their formerly competent AD wish.

Lack of communication becomes more central to the assisted dying debate when a currently incompetent patient's condition seems to contradict their advance directive instructions. Participants failed to show substantial agreement on whether to act upon AEDs when there is a clear conflict between formerly (competent) and contemporary (incompetent) states of the patient, although results were slightly skewed toward respecting precedent autonomy. This conflict usually entails trying to understand the level of suffering that was anticipated by the patient and the level of suffering that is perceived by physicians when the patient is unable to communicate. AD legislation requires physicians to determine whether the incompetent patient's suffering is to the level required by law. Some patients with advanced dementia may manifest their suffering through "non-verbal means" or "involuntary physical manifestations of pain" while some may not (Downie & Lloyd-Smith, 2015). Some physicians may thus deem the patient's suffering absent or bearable when there is no explicit or obvious manifestation of suffering. They, may, or may not assume that patients' precedent and contemporary conditions are in conflict. As Downie and Lloyd-Smith note, "absence of evidence of suffering is not evidence of absence of suffering" (2015, p.115). This said, my findings confirm that the level of unbearable suffering is to be determined in advance and by patients, rather than physicians or families/caregivers, which gives authenticity to the subjectivity of suffering from the patient's point of view. This result is also consistent with other research within which the authors recommend that permissive legislation not requiring evidence of contemporary suffering where patients are incompetent, in situations where that patient had an AED (Downie and Lloyd-Smith. 2015).

AEDs seem to facilitate the safeguarding of patient’s autonomous choices regarding assisted dying. Clear and well-written AEDs would safeguard an individual’s instructions and hence support the implementation of AD practices in situations where AEDs were available. To fulfil this goal, AEDs should encompass clear and detailed preferences that make it possible for HPs and/or families/caregivers (primary stakeholders) to understand what should be done. Ensuring the importance and significance of the drafting process is therefore an important part of honouring the patient’s wishes when envisaging the end of their life. Video-recordings of patients outlining their AED may clarify and enhance the validity of such directives, by providing clear and compelling evidence of the person’s intentions, motivations, and reasoning. In healthcare settings, the use of video-recordings has been recommended as the best method for researching doctor-patient communication as it captures all modalities of the interaction between participants in a consultation (Coleman, 2000). In other areas of medicine, this modality has been used to improve the validity of diagnosis and treatment of mental illnesses (Coleman, 2000; Howe, 1996; van der Pasch & Verhaak, 1998). While video-recording methods are being used, for example, to determine how GPs detect depression or psychological distress, they can also be used to understand how an individual’s end-of-life decisions have been made as well as ascertaining patients’ internal motivations, and any external pressures underlying such requests.

An AED that carefully and explicitly sets out what the person wants in the future (were they to lose competency) may thwart the views of the family who may want the directive overridden. If thoroughly and sufficiently well-drafted, these directives may replace the primacy of other stakeholders in any decision-making process, which would provide individuals with a sense of control over their future. Retaining control about how decisions may be made beyond the loss of competency is positively associated with psychological comfort (Gastmans & Denier, 2010; Rodríguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016). My findings support the role of AEDs in mitigating the psychological and existential distress of patients by equipping them with the means to exercise control over their end of life.

Fear of losing control was among other existential dimensions of suffering that patients’ families/caregivers experienced in my research in the Netnography study (see Chapter 4, pp.). Fearing that they may also develop dementia (Tomlinson & Stott, 2015), some families/caregivers experienced almost all the central elements of existential distress including loss of freedom that involves responsibility and choice, and hence anxiety and guilt, loss of meaning, the unpredictability of the future, and a prolonged dying at the end of their life (Albinsson & Strang, 2003; Yalom, 1980). The presence of existential distress significantly contributed to families'/caregivers' desire to access assisted dying for themselves. Consistent with these findings, the desire for an assisted death has been raised by patients and family caregivers hoping to retain control and choice at the end of life, and not to become a burden to their families (Dening et al., 2013; Hertogh et al., 2007a; McPherson, Wilson, & Murray 2007). Suicide among family caregivers of individuals with dementia is an overly neglected concern (Diehl-Schmid et al., 2017). There is evidence of some cognitively healthy adults seriously considering suicide if they were diagnosed with Alzheimer's disease (Diehl-Schmid et al., 2017), and depression due to the burdensome care of a patient with dementia is a contributing factor for high rates of suicide ideation in this specific group of family caregivers (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016).

Families/caregivers experience feelings of guilt, of not having done enough and not being able to offer enough help and support to make their loved one's remaining time as pleasant as possible (Andershed & Harstäde, 2007). Their sense of having fulfilled their care duties and responsibilities is also negatively associated with feelings of guilt (Andershed & Harstäde, 2007). In my findings, feelings of guilt and/or uselessness were agreed to be affected by caregivers' inability to grant patients' final wish of an assisted death. Not having the option of a legal assisted death, my findings acknowledge the psychological burden on families/caregivers who may contemplate illegally hastening the death of their loved ones with dementia (based on the patients' explicit wish) or continue to watch them suffer. Although there is little evidence to support this as a mediating factor for the desire to access assisted dying, an effort of some older people to make an advance care plan may be seen as a way to reduce the burden that families/caregivers may face in having to make end-of-life decisions for their loved ones (Dening, Jones, & Sampson, 2011).

The findings of this study indicate the need for the delivery of better-quality end-of-life care tailored to the unique needs of individuals with dementia, including better education and training of families and the caregivers of such patients, and the HPs involved in their care in the context of AEDs. Studies have also highlighted this need (Gove et al., 2010; Poole et al., 2018; Sachs, Shega, & Cox-Hayley, 2004; Schmidhuber, et al., 2017; Volicer & Simard, 2015). In the context of AD and dementia, well-trained health professionals are the key to the optimal delivery of this practice, including training HPs on providing services for assisted dying, support for other HPs involved in assisted dying practices, and in the provision and access of information to patients and their families/caregivers. The latter is especially important considering a lack of initiatives around starting conversations about advance care planning (Dickinson et al., 2013; Poole et al., 2018). Evidence from the Netherlands shows that greater involvement of HPs in decision-making may result in them addressing the Dutch due care criteria more exhaustively or more comprehensively (Buiting et al., 2008).

I conclude that important strides can be made in addressing the challenges of providing AD practice for individuals with dementia through educational initiatives aimed at increasing awareness of advance directives (including their implementation), in changes to clinical practice that focus on end-of-life decision-making in the context of advance directives, and through accountability and a regulatory system that robustly monitors practice to mitigate possible abuse. Ensuring the accountability of individuals and/or agencies results in improved health system performance and serves the purposes of reducing abuse, assuring compliance with procedures and standards, and improving performance/learning (Brinkerhoff, 2004). “All health systems contain accountability relationships of different types. Health ministries, insurance agencies, public and private providers, legislatures, finance ministries, regulatory agencies and service facility boards are all connected to each other in networks of control, oversight, cooperation, and reporting” (Brinkerhoff, 2004, p. 371). Among these actors, regulatory systems/agencies reassure procedural and quality standards and in turn increase accountability (Brinkerhoff, 2004). Accountability and a regulatory system within the context of AD for patients with dementia have yet to be clearly outlined and framed.

5.4.1. Limitations

A limitation of this study is related to the selectively and bias of the population studied. The study participants were generally older New Zealanders who may have been influenced by societal discussions about assisted dying as a consequence of the End-of-Life Bill being discussed in parliament at the time the study was undertaken. During the study period, the Justice Select Committee had recently released their report concerning David Seymour’s End of Life Choice Bill, which is now passed and comes into force on November 7th, 2021 (New Zealand Legislation, 2020). Moreover, participants were representative members of an organisation actively seeking a change to the law, who have personal and/or professional experience caring for others at the end-of-life. These experiences provide an important perspective for thinking about the implications of AD for individuals who have dementia, for their families, for health professionals, and for society more broadly. Regardless, the findings need to be interpreted by having participants’ certain propositions to AD laws considered. This calls for further exploration of whether publicly supporting AD in principle would mean supporting AD for everyone, particularly for individuals with competence-eroding diseases. Additionally, as the general demographic information of the EOLC Society members was not provided (except the total number of the members), it was not possible to determine the representativeness of our participants. However, it became apparent that the majority of members participating in the study were situated in the age group 65 years and above, which may suggest a potential response bias. To give the results further generalisability, the study could be further extended to wider ethnic and age variation.

Chapter Six

Chapter 6 – Concluding discussion

Assembling potential safeguards

In this final chapter, I first want to draw together the findings and arguments developed in the three preceding chapters by engaging in the literature and theoretical arguments presented in Chapter Two. Following the discussion around the implications of my explorations on AD for individuals with dementia, I present some preliminary safeguards. I then conclude this chapter by delineating the contributions that my research makes to the body of knowledge in this area, the limitations of my studies and directions for future research. It is, however, important to note that in this concluding chapter I draw together some starting points for further investigation as well as mapping the issues rather than reaching substantive conclusions.

As a result of my exploration, I have come to understand that within the context of AD for individuals with dementia, a number of complex challenges exist. Even within jurisdictions that permit assisted dying, these challenges remain and extend beyond the individuals to family members/caregivers and health professionals. At the heart of this issue, is whether it is ever ethically permissible to grant an individual with dementia an assisted death based on an advance directive and whether any such a directive has legal standing. When people create advance directives, they are concerned about their future medical treatment and care. At some point, dementia's progression will ensure that patients are no longer able to communicate their preferences, but that need not imply that their prior preferences no longer matter, neither need it imply that their current situation should take precedence over earlier preferences. Regardless, the desire for AEDs is increasing and the predicted increase in the prevalence of dementia (WHO, 2020a) will likely raise demand in the future.

To some people, the risk of harm in permitting AEDs for incompetent individuals is too great to justify including them into existing AD laws in any form. To some others, it might appear reasonable to consider allowing them under certain circumstances believing that safeguards could be implemented to mitigate risks. The limited breadth of knowledge and experience on safeguards due to them being practiced in very few jurisdictions may also add to the uncertainly about this practice. The diversity in these opinions presented an opportunity for me to further reflect on the risks and challenges involved in the specific situations in which AEDs might be allowed for individuals with dementia and to explore safeguards to see where and which some of these challenges might be met. Clearly, professionally agreed safeguards are of central importance. Such guidelines, however, need to incorporate the perspective of other people involved, particularly individuals with dementia and their families/caregivers, to ensure that such practice is person-centred and of optimal quality. The importance of the incorporation of a variety of views has been the highlight of my studies. As it is also endorsed by other studies (Nakanishi, Cuthbertson, & Chase, 2021; CCA, 2018), understating the concerns and challenges of health professionals and substitute decision-makers helps define the inherent limitations of AD for incompetent patients and may guide towards potential safeguards.

In phase one of my research, the first question I set out to answer in the Delphi study was whether experts think it is possible to devise safeguards that would provide access for AD for individuals with dementia. If so, I wanted to see what form would they expect these safeguards to take? And based on their professional, clinical, and scholarly points of view, what challenges and issues need to be considered along the way? In my analysis I presented their consensus views concerning the necessity and applicability of AD for dementia. While acknowledging the need for a system to support individuals' choices and to embed discussion about AD in the context of dementia experts unanimously raised some issues regarding the application of AD that needs to be considered. These included ethical issues (such as the risk of coercion, harm, and societal stigma), practical issues (such as difficulty assessing and determining suffering, and the right time to enact AEDs), and pathological issues (such as loss of communications, differences in patient's dementia trajectories, and changing one's mind, etc.). Further concerns include abuse, pressure from families and society, and stigma. Others are, however, particularly problematic when the capacity to communicate is lost. For example, as we know from the literature some practitioners may struggle with conversations about advance care planning especially when it involves an assisted death wish. In addition, it's been repeatedly expressed that patients with dementia and their families often lack information about the practice of AD, written or verbal directives, and the specific challenges that may arise in their dementia trajectory that would make decision-making difficult. "Clinical experience also shows that if the guidelines remain vague and open, they can easily be misinterpreted by healthcare staff, but if the directives are too concrete and contextual, they are difficult to apply in changing circumstances" (Gómez-Vírseda a & Gastman, 2021, p. 6). Therefore, such wishes may not be documented, or written using generic and vague terms with not enough information for health professionals to understand or proceed with the wish. In the absence of HPs' timely involvement and discussion about AEDs and measurable and adequate triggers that instruct to initiate

AD, it is hard to assess the validity of the directives, to know whether they are voluntary and well-considered, and when to enact them. One very important finding that raised conflict among the experts was whether it is ethically justified to perform AD when the patient’s current condition and the preferences expressed in their directive seem to be contradictory. The role of health professionals is challenged because in these conflicting situations it becomes unclear how to balance the precedent and current autonomy of the patient without violating their professional responsibility. The identification of these issues contributed to some recommendations to safeguard AD application, which will be discussed in section 6.2. Although preliminary, these recommendations led me cautiously to conclude that some actions could be undertaken to mitigate the impact of identified issues and therefore safeguard the practice.

The second question in the first phase I set out to answer in my Netnography study was: what is the ‘grassroots’ view of the challenges and experiences regarding AD in the context of dementia? Therefore, I included the views of the public whose personal, professional, and/or social lives were intertwined with dementia using the public online medium as my platform. Choosing online social media as my source of data offered an insightful understanding of their members’ experiences, challenges, and preferences regarding AD. In my analysis, I reflected on how online members fear developing dementia and its ensuing physical and cognitive decline and how this fear along with other factors contributed to their desire for access to AD. I drew attention to how members’ understanding of dementia, the quality of life for an individual diagnosed with it, the psychological/existential distress and moral dilemmas experienced by individuals with dementia and those in close contact with them influenced online members belief that provision of AEDs – written in sound mind – is not only essential but also would prevent unnecessary suffering and protect individuals’ wishes and their freedom of choice when decision-making competency is lost. My findings suggested that ethical dilemmas had different manifestations for these interested public members compared to the experts, especially for caregivers and loved ones of patients with dementia. The types of ethical dilemmas that they were usually dealing with were not *whether* or *when* to follow an assisted death request, but whether to help their loved ones die as they wish and therefore face the legal consequences or to watch them suffer. This, in turn, had led to prevailing feelings of guilt and uselessness. Along with these contributory factors to a desire for AD, there were indications of what changes members think need to be applied to the existing AD laws and end-of-life care system to optimise care delivery for patients and their families/caregivers.

Synthesised together (in Chapter 5), Chapters 3 and 4 mapped out some preliminary guidelines for drafting and implementing AEDs and mitigating harm as well as outlining some prerequisites to consider (such as education and training) for the successful delivery of AD practice. Exploring the combination of these opposing data in a form of a survey helped me to understand and categorise the content more systematically, with each category targeting different aspects of the practice such as inclusion, drafting, implementation, and harm mitigation criteria. This feasibility study provided a better understanding of the practice AD for people with dementia by for example, pulling together why people want to have access, or what needs to be considered in the drafting and implementing phases, or how to prevent harm at the system and societal level by for example training and education. It, however, revealed that further studies need to be conducted to determine how these will be achieved in practice and to address the conflicting areas within my findings. This opens opportunities for further research. In comparing my studies' findings on the grassroots views with expert professional consensus views, some areas of agreement and discordance emerged which have considerable implications for practice and policy. These implications will be further discussed in the next section followed by a discussion on how these integrated findings further contributed to identifying potential safeguards.

6.1 AEDs in practice: what are the potential impacts?

The impact associated with extending AD laws to include AEDs in jurisdictions both nationally and internationally will require long-term assessment and analysis. Some evidence, however, has been drawn from my findings on the potential impacts of permitting or prohibiting AEDs for individuals with dementia and their families/caregivers and healthcare provider team.

6.1.1 Rights for autonomy

With an AD law that permits AEDs, individuals with dementia who still retain their competency to make decisions, would be able to exercise their autonomy. As discussed in the literature review (Chapter 2), denying such individuals the opportunity to create an AED, would deny their right for precedent autonomy and, conversely, allowing it could strip incompetent individuals of their current autonomy. Throughout my analysis of the three studies, conflicting results emerged with regard to respect for individuals' autonomy. These results suggest that other autonomy-related conceptions, including individual and relational, need to be considered besides the above-mentioned concepts of autonomy to explain the discordance between the findings.

Analysis of personal narratives shared by participants in online medium (Chapter 4) illustrated that many individuals and their caregivers consider autonomy from an individualistic approach, in which individuals have the right to self-govern their decision without the interference of others (Varelius, 2006). They were of the impression that they should have the right to die on their own terms as long as they have expressed them in their AEDs when they were competent to do so. Some, however, while acknowledging individual autonomy may question why should a person be bound by a document written many years ago in ignorance of what the future held? And by extension, why should this personally autonomous wish of a person create an obligation for responsible third parties to respect or assist them in attaining it? The latter points to the relational concept of autonomy in which the attention, without undermining an individual autonomous decision, is drawn to the importance of social relationships when an individual makes a decision (Sherwin, 1998). This concept of autonomy is highly relevant to AD, particularly in cases of incompetent individuals, as AD is an inherently relational act that involves HPs, patients, and often their families/caregivers. With some degree of variation between the participants' views, findings all together argue for a middle ground that does not blindly follow the directives, nor simply discards them when the patient becomes incompetent. A middle path considers a patient's repeated and stable desire for an assisted death expressed in the directives and the motivation behind them. It also takes into account the current preferences of the now incompetent self-communicated non-verbally. At the same time, it acknowledges the impact that advocating and granting an assisted death may have on the responsible others. Having this considered, the act of AD seems to be more aligned with the relational, which promotes the relationship between patients, caregivers, and HPs rather than the individualistic concept of autonomy. This view is also acknowledged by other scholars (CCA, 2018; Gastmans & De Lepeleire, 2010; Sherwin, 1998). In the context of dementia and AEDs, this approach may imply that an AED, although autonomous, has a marginal force when its enactment is dependent on the decision of others such as HPs and/or families/caregivers.

Further investigation into the concept of autonomy in the feasibility study (Chapter 5) suggests that precedent autonomy is of higher importance. In this study, most participants highly agreed that the current wishes of now incompetent patients (with dementia) must not override their prior competent wishes. However, when the possibility of conflict between the precedent and current wishes of the patient with dementia was raised with the informed group, they appeared divided over which wishes should take precedence. Contrary to the views of this group, experts in my Delphi study (Chapter 3) showed a greater consensus, generally holding the view that AD should not be carried out in times of such conflict. From these findings, it can be inferred that individuals' precedent autonomy is more valued in the views of a grassroots group (my informed group in this case) compared to the experts, which is consistent with the literature (Bravo et al., 2019; Diehl-Schmid et al., 2017; Kouwenhoven et al., 2013; Rietjens, van der Heide, Onwuteaka-Philipsen, van der Maas, & van der Wal, 2005; Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal, 2006; Tomlinson & Stott, 2015). Regardless of differing perspectives on precedent/current autonomy, participants in both studies (experts and informed group) acknowledged the involvement of responsible third parties in interpreting and assessing individuals expressed wishes in AEDs in relation to their current situations.

These differences in views may relate to the conceptions of individual/relational autonomy that I raised earlier. The individualistic approach aligns closely with respecting precedent autonomy. My findings highlight this point: according to all participants across three studies, the decision to enact an AED should be made on the ground of patients' previous and clearly stated wishes in the directives. This illuminates respect for autonomy, in highlighting the patient's self-determination and non-interference. However, once a conflict has occurred, the personal and/or professional judgment of HPs and families/caregivers of patients' conditions gain greater importance underpinning the relational aspect of AD for an individual with dementia. Compared to patients and families, HPs are more aware of the possibility of complexities that may arise due to their experience and knowledge (Bolt et al., 2015; Rietjens et al., 2005; Terkamo-Moisio et al., 2019). A recent study by Mangino et al., (2020a) has similarly shown that when ethical and practical complexities in following an AED are presented to the public, they become less supportive of the AD act based on AEDs for individuals with dementia. This shows how these concepts of autonomy are intertwined, with each having a different influence on how AEDs are perceived and used. HPs and families/caregivers may judge that it is in the patient's best interest to follow their AEDs having considered these directives from an individualistic point of view; conversely, they may also come to an opposite conclusion when taking a relational point of view and considering their own responsibilities in complying with directives. Although these contradictory results open opportunities for further discussion and research, findings altogether suggest that any decision-making with regards to AD should acknowledge and take into account the various, possibly conflicting, meanings of the term ‘autonomy’.

6.1.2 Relief of suffering

The provision of AEDs would permit individuals with dementia (who remain competent to make an AED) to request an AD which may provide relief of future anticipated suffering. Some studies may assist in understanding the potential impact of suffering to request and/or receive an assisted death. For example, analysis of characteristics of Dutch individuals with dementia who received AD based on a concurrent request (in the early stage of dementia) or an AED shows that past personal experience with dementia and a fear of future suffering and deterioration contributed to the patient’s current unbearable suffering and by extension to their assisted death (Mangino, Nicolini, De Varies, & Kim, 2020b). Many of the online respondents (Chapter 4) who had experience of caring for an individual with dementia and witnessing suffering at first hand described their desire to avoid the same fate if they were to develop dementia. The existential, physical, physiological aspects of suffering, witnessing family members’ suffering, past experiences with the care of individuals with dementia, and loss of decision-making competency, control, and autonomy have been repeatedly mentioned in the literature, as well as in my Netnography study, as factors associated with a desire to AD (Gamondi, Fusi-Schmidhauser, Oriani, Payne, & Preston, 2019; Li et al., 2017; Monforte-Royo et al., 2012; Tomlinson, Spector, Nurock, & Stott, 2015; Roest et al., 2019).

An assisted death in this sense is considered an option to relieve anticipated suffering and retain a sense of control over an unknown future. There is evidence that without a legal possibility for AEDs some patients with dementia and their families/caregivers may attempt to ensure choice and control over their death in two ways: some may request to die earlier than they would have preferred (de Beaufort & van de Vathorst, 2016; Dening et al., 2013; Legemaate & Bolt, 2013; Li et al., 2017; Pols & Oak, 2013; RTE, 2020) or to consider suicide well before it becomes necessary while they still have the ability to do so (Anderson, Eppes, & O’Dwyer, 2019; O’Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016). These types of attempts and desires were repeatedly mentioned in the shared personal stories of my online communities’ members (Chapter 4) and later acknowledged by the members of EOLC society (Chapter 5).

While it is argued that individuals who face a longer period of suffering, including those with dementia, are most likely to feel the need for AD (Sleeman & Chalmers, 2019), many online contributors (in Chapter 4) held the view that AD laws that excluded competence-eroding conditions fail to address the psychological and existential suffering of patients who perceive they may have years of uncertainty, distress, and pain ahead, and of those caregivers who watch this suffering. Similarly, in their report on advance requests for medical assistance in dying (MAID), the Council of Canadian Academics (CCA, 2018) report the frustration felt by many patients and caregivers at not being able to draft an advance request for AD. They also noted a great deal of relief reported by some patients after knowing that an AD could be a possibility for them (CCA, 2018). These findings suggest that the provision of AEDs may have a positive impact on the psychological wellbeing of individuals by giving them a sense of control to choose a death free of suffering. While some studies highlight the emotional burden that some families and caregivers face during the decision-making process and AD performance, including its aftermath (Gamondi, Pott, Forbes, & Payne, 2015; Roest et al., 2019), allowing AEDs may provide psychological comfort or relief for the ones who value retaining control of their life and unknown future and fear their loss of decision-making capacity.

6.1.3 Psychological burden of end-of-life decision-making on third parties

Families and caregivers, and HPs who are at the heart of respecting an AED are faced with the challenging task of finding the right balance between their professional and personal responsibilities to the individual in front of them and respecting their autonomy. The role and authority of these third parties in following AEDs require careful consideration and may be balanced by directives that reflect a well-considered and realistic awareness of their content and effects. However, when it comes to dementia, it is indeed difficult to foresee future decline and suffering as every dementia trajectory is different and people are found to be capable of adapting to situations that they previously envisaged impossible to bear (Hertogh, 2009; Hertogh et al., 2007a; Kouwenhoven et al., 2015). From the findings of my studies, it could be inferred that the decision-making process to follow an AED can be complicated by a myriad of moral and practical reasons including a) ambiguity in the directives, b) uncertainties expressed by individuals with dementia to their families/caregivers or healthcare team prior to the loss of capacity (signs of changing mind); c) conflict among families/caregiver and HPs on their patients’ best interest, d) conflict between the anticipated condition of the patient (previously expressed in directives) and their current one, and e) difficulty assessing the unbearableness of suffering and the exact time of performing

AD. Were AED’s to be permitted, these complexities, also raised by other studies, may cause additional distress and burden on those responsible for following AEDs (Davis, 2018; de Boer et al., 2011; CCA, 2018; Gastmans & de Lepeleire, 2010; Hertogh, 2009).

These psychological and moral burdens could be substantially reduced if AEDs are clearly drafted so that the need for third party interpretation is reduced. When following an AED may indicate harm to the current wellbeing of an individual with dementia, knowing to what extent the AED’s author anticipated and acknowledged the now occurring events would help these third parties to decide whether or not to respect the directive. As AEDs cannot encompass unforeseen possibilities and conditions, it is critical that patients think carefully about the any risks associated with committing themselves in advance, for example the risk of changing their mind. It is also imperative for individuals with dementia to acknowledge potential changes and positions in the drafting phase of an AED and consider that they may adapt to their living situation and maintain a good quality of life. This means that they may need to instruct for an assisted death having considered the possibility that they may not suffer as they had presumed or they may, contrary to their expectations, even enjoy life with dementia. While the responsible third parties are still required to interpret the enactment criteria in light of their patient’s current situation and while it may seem very difficult for the patients to indicate instances of what suffering they may expect and whether that would be bearable for them, less interpretation would be required if their request is clear and well-considered.

6.1.4 Pressure to draft or enact an AED

In line with the literature, my exploration of how AD and dementia are understood within the familial and societal context shows that families/caregivers and the public have both influence on and involvement in decision-making on AD (Gamondi et al., 2019; Roest et al., 2019). The role of families is, however, not officially recognised within the existing AD laws (ten Cate, van Tol, & van Vathorst, 2017). Their influence on an AD request, either for their loved ones or for themselves if they were to develop dementia, appear due to several related factors found in my studies, in particular, a) feelings of guilt and/or uselessness when they can’t assist their loved ones to die as they wished, b) difficulty witnessing their loved ones’ “pointless suffering” or undignified life, c) having suffered the distress of watching their loved ones die and do not want to burden their family if they developed dementia, d) experiencing fear of following the same path as their loved one, e) having experienced a tension between helping a loved one to die illegally as they had wished or watch them suffer at the end of life, and f) lacking of access to quality palliative or hospice care. Intentionally or not, they may, therefore, put pressure on HPs for an assisted death or on their loved ones to ask for it. Some of these findings have been raised by other scholars (Andershed & Harstäde, 2007; Lewis, 2014; Schuurmans et al., 2019).

At a societal level, my findings suggest that allowing AEDs to be a legal extension to AD laws may contribute to the stigmas and misconceptions associated with dementia. It is noted that society perceives dementia as a disease that reduces an individual's quality of life, with AD often being considered as a dignified alternative (Schuurmans et al., 2019). Stigmas negatively influence individuals with cognitive impairment resulting in barriers to diagnosis, treatment, care, and support (Herrmann et al., 2018; WHO, 2020b). Dementia-related stigmas also have consequences for families and caregivers, some of whom fear being negatively judged by others (Herrmann et al., 2018; Lewis, 2014). Although stigmas are reduced among people who have personal and family experience with an individual with dementia, and those with more knowledge about dementia (Herrmann et al., 2018), as shown in my Netnography study, stigmatising views that an individual with dementia may become a burden on family and society may influence individuals with dementia to write an AED.

"The public health impact of reducing dementia stigma could potentially lead to better care access, greater support engagement, and ultimately a higher quality of life for people with dementia and their families." (Herrmann et al., 2018; p. 317). As a result of increased dementia awareness, AD requests may be less triggered by stigmatising reasons.

6.1.5 Changes to eligibility and assessment criteria

AD laws in most permissive jurisdictions attach great importance to the issue of competency, and the ability to communicate, as well as the presence of unbearable suffering at the terminal phase of the illness. The presence of these legal requirements in cases of dementia is challenging in the context of AD due to the particular ways in which some characteristics of dementia interact with particular legislative provisions: individuals with dementia would typically lose competency and capacity to communicate and express their level of suffering before the terminal stage of the disease. Consequently, individuals with dementia who may wish for an assisted death may have less access (if any) to one. As the Council of Canadian Academics has suggested for Canada, it may appear less harmful to allow AEDs under a specific set of circumstances, for example only for individuals with dementia in an unconscious state as is the case in Belgium and Luxembourg (CCA, 2018). Incorporating specific circumstances such as unconsciousness would extensively limit access, as can be seen from the available case reports on these countries (CCA, 2018; Dierickx et al., 2017; Picard et al., 2019). My findings emphasise that current AD laws consider ways of being more inclusive of AED's, which may only be realised through some changes or modifications to the existing AD eligibility criteria.

Evidence from countries that allow AEDs, particularly case reports from the Netherlands and Belgium, show that the provision of AEDs has made little impact on AD rates in the advanced stages of dementia. In these countries, the majority of individuals who have legally accessed an assisted death are people in the early stages of dementia (Dierickx et al., 2017; RTE, 2020). Some of these individuals may have died sooner than they would have preferred because they were fearful that the progression of their dementia would result in the loss of competency to make one's preferences known (Bolt et al., 2015; Cohen-Almagor, 2015). Others may argue that the law is failing those who do not trust that if they lost competency, they would be assisted to die through their AEDs. If AEDs were to be followed in advanced stages of dementia, the requirement of patient competency may need to be confirmed only at the point of drafting an AED. A similar conclusion was made in Canada with regards to the requirement of final consent immediately before MAID is delivered. Recent changes to this requirement allow individuals to waive final consent just prior to MAID administration, if natural death is reasonably foreseeable and while the person had decision-making capacity: a) they were assessed and approved to receive MAID, b) their practitioner advised that they are at risk of losing capacity to provide final consent, and C) they made a written arrangement with their practitioner in which they gave consent in advance to receive MAID on the chosen date if they no longer have capacity to consent on that date (Government of Canada, 2021).

A person may write an AED not only to avoid anticipated suffering at the end of life, but also to spare them and their loved ones from a lingering decline or because they don't want their family to witness them disintegrating (they don't want them to have that memory of them). Determining unbearable suffering is a subjective measure thus individuals with dementia (prior to the loss of competency) need to include in AEDs how the assessment and eligibly criteria are determined. This may imply that AD laws do not require evidence of current unbearable suffering where patients are now incompetent in situations where that patient had an AED (Downie & Lloyd-Smith, 2015). While excluding the presence of suffering from the legislative provisions may solve HPs' problems in assessing the unbearableness of suffering in the absence of capacity and communication, it may result in a failure to consider the impact of patients’ suffering on an HP’s decision to grant an assisted death. However, one look at removing the requirement to include suffering in an assessment for AD, a HP may determine the moral acceptability of assisting in different ways.

6.2 Potential safeguards

If AEDs were to be included in AD laws and if they were to be adhered to in more advanced stages of dementia, a number of potential safeguards could be implemented to address the challenges inherent in respecting individuals’ end-of-life wishes. Safeguards may work at different levels, from ensuring that an AED is clearly documented and that its content represents an authentic, informed, and voluntary decision of individuals with dementia, to ensuring that HPs and families are supported in the responsibilities they have in relation to the decision-making process. While some of these safeguards may be able to mitigate the challenges raised in the proceeding section and address some of the concerns associated with allowing AEDs, their feasibility, and effectiveness are yet to be assessed. In the following section, I will present some preliminary safeguards that were drawn from the findings of my studies (a summary of safeguards is presented at the end of this section in Table 6.1). These conceptual safeguards could provide some foundations for future research and are consistent with some of the proposed safeguards presented in the Council of Canadian Academics report (CCA, 2018), in which evidence is gathered to inform understanding advance requests for MAID within the clinical, legal, cultural, ethical, and historical context in Canada.

6.2.1 Safeguards to improve AEDs

An AD law that requires clearly written AEDs encompassing detailed and structured end-of-life preferences and assisted death preferences may safeguard its application in providing clear guidance. Efficacious directives would guide HPs and families/caregivers about what should be done in the light of the patient’s condition at the time an assisted death is considered. One might argue whether it is possible to know what is going to happen to individuals with dementia in their particular context with such certainty and clarity about their future condition. This will no doubt require significant support and education so that they can articulate preferences that are informed and detailed.

6.2.1.1 Increased professional assistance in drafting an AED

AEDs inform third parties involved, particularly HPs, to ascertain what the person's preference is at a particular point in time and, more importantly, determine when that particular point in time has come. A Dutch study shows that patients often draft AEDs alone contributing to the reason why HPs find these directives to be of little practical help in assisting them to make a decision about the appropriateness of an AD for the patient (Vezzoni, 2005). While the Dutch code of practice indicates that directives drafted in the patient's own words are considered more significant than a pre-printed standard form (RTE, 2015), it also noted that patients frequently use generic terms to express their preferences in their directives (Vezzoni, 2005). It can be inferred from my findings that early involvement and assistance of HPs at the point of drafting AEDs seem valuable to increase the effectiveness of AEDs and ensure that criteria are explicit and realistic. In their evaluation of AD of individuals with dementia, Mangino et al., (2020b) note that Dutch HPs are more likely to adhere to an AED if a physician had been involved at the preparation stage. Underlying this research is the essential role of HPs in assisting their patients with questions about the AD process, providing any information required, and understanding what is important to their patients about their future lives. If individuals with dementia were encouraged to write an AED "in consultation with their care team, it would allow them to receive medical advice to ensure their document was clinically relevant, to initiate a discussion about their beliefs and expectations" around an assisted death (CCA, 2018; p. 151). My findings revealed that shared written documentation of AEDs and ongoing dialogue to make caregivers and HPs as familiar as possible with patients' views to make decisions consistent with those core values is an essential step to better instruct when to initiate AD. They, however, provide limited information about triggers or measures that could be put into AEDs to facilitate this process. As this is a critical issue for AEDS, further research is encouraged.

An updated and regularly discussed AED written with the assistance of HPs may also help determine that an assisted death request is a voluntary and personal choice (Mevis et al., 2016). However, at what points AEDs are to be updated is also an important point to consider, as it is vital to carefully modify relevant regulations to ensure that AEDs don't become legally ineffective due to time delays. For instance, AEDs, in Belgium and Luxembourg are valid for five years after they are either signed or updated (CCA, 2018; Downie & Lloyd-Smith, 2016), meaning that if a patient has been incompetent for more than five years, their AED is no longer valid for an assisted death.

6.2.1.2 Provision of ongoing assessment

My findings suggest an ongoing assessment of patients' conditions at different points of the disease trajectory including cognitive abilities, understanding of the disease progression, medical condition, psychiatric state, quality of care, and suffering, as well as the specific conditions in which patients wish their directive to be acted upon. Ongoing assessment of the content of each directive in light of the patient's condition may overcome the difficulty of determining the circumstance as well as the right time to implement the assisted death request. In addition, the Council of Canadian Academics report (CCA, 2018) note that having communication around the possibility of AD during the initial stages of the disease would allow individuals to start communicating with an alternate HP early in the process if their current HP were unable or unwilling to assist them. The necessity of much greater involvement of HPs in decision-making and ongoing assessment reveals the need for long-term patient-HPs relationships and a patient-centred communication approach from diagnosis until the loss of a patients' ability to make decisions and communicate their preferences. Careful consideration is nonetheless required on how these assessments and communication approaches could/should be implemented in practice. For instance, who would be responsible for undertaking these assessments and how would they be funded, and at what level?

A further safeguard would be documentation of the assessment and discussion session(s) process. One proposed initiative is to require the drafting process of AED's, and the assessment discussion session(s) to be video recorded. Video recording of patients outlining their assisted dying directive may enhance the strength and validity of such directives, by providing clear and compelling evidence of the person's intentions, motivations, and reasoning in their own words. Such communication would be of use in situations where a designated HP does not know the patient now under their care. Given their patient's current inability to communicate and express their preferences, these documented discussions could demonstrate how an individual's decision-making progressed to an AED, and whether their wish for an assisted death has been authentic and consistent over time. Furthermore, my findings suggest the involvement of a psychologist in the early stages of this process which might further assist HPs to detect any external pressures or coercion from others and any signs that a patient has changed their mind regarding the drafting of their AEDs. The inclusion of mental health providers as well as a social worker, who may be better equipped to evaluate the impact of personal and contextual factors on motivations for an assisted death, has been highlighted by other studies (CCA, 2018; Fujioka, 2018).

6.2.2 Safeguard to improve support for HPs and families

As discussed earlier in this chapter, the provision of AD for an individual with dementia has the potential to both alleviate, and contribute to, the psychological and ethical burden experienced by families, caregivers, and HPs. To care for a patient with dementia and to be involved in their desire and subsequent planning for an assisted death is a significant responsibility. As Holm states “no amount of rules will ever be able to relieve the caregiver of his or her obligation to personally assess the desires and decisions of demented and possibly incompetent patients and ethically choose which to respect and which to counteract” (Holm, 2001; p. 158), It is perhaps stating the obvious to note that, everyone involved in the process of enacting an AED to the assisted death, needs professional, educational, spiritual, and emotional support (Cleemput & Mangino et al., 2020a; Picard et al., 2019; Schuurmans et al., 2019).

6.2.2.1 Provision of support, training, and education

Health professionals – In the context of AD, well-trained HPs are key to the optimal delivery of the practice. A cross-sectional study on nurses’ view on legalising AD in New Zealand shows that “a lack of either accredited training or education for assisted dying provider tasks and roles” is a contributing factor to barriers to engagement in AD (Wilson, Oliver, & Malpas, 2019; p. 122). The provision of clear policy, guidelines, education, and training to assist HPs in the assessment and delivery of AD should be a priority for safe AD practice. The Support and Consultation on Euthanasia in the Netherlands (SCEN) provides training and information for physicians to help them during the decision-making and AD performing processes (RTE, 2015). This training is not standard procedure in the Netherlands and although consultation with a trained SCEN physician has helped safeguard the practice for HP’s and patients, the majority of Dutch health practitioners want more clarification of their professional guidelines especially when dealing with a case of dementia (Schuurmans et al., 2019). Apart from practical and clinical support, professionals involved in AD also benefit from the support of their family, and peer support from their colleagues (Schuurmans et al., 2019), a point that also emerged in my findings. Ultimately, training would provide HPs with the necessary skills to participate in the decision-making process, assess patient’s condition and intentions, and most importantly to offer adequate support to other people involved including their colleagues.

Patients, families/caregivers, and the public – Improvements are still required for the better delivery of quality care towards the end of life for individuals with dementia and their families, especially in terms of practical and emotional support in making difficult decisions (Brazil, Galway, Carter, & van der Steen, 2017; Pool et al., 2017). It is also shown that patients and families often have high expectations of the feasibility of AEDs (Brinkman-Stoppelenburg et al., 2020; Mevis et al., 2016) while they are, at points, poorly informed about what current assisted dying laws entail with regards to patients who are no longer competent (Picard et al., 2019). Contrary, my observation of online community members showed that members had a good understanding of what AD laws entailed in their place of residence, the need to improve quality of end-of-life care tailored to the unique needs of each individual with dementia, support for family caregivers and their loved ones, and educating them prior to making an AD request was an important finding. This somewhat greater knowledge of this interested public compared to the general public may relate to their involvement in Facebook communities. The primary goal of these online communities is to increase public awareness, which is found to be effective on the views of online members that I investigated.

On a societal level, a lack of adequate information about dementia and its progression may negatively impact individuals' attitudes towards dementia and perpetuate fears about developing dementia and what that may entail in the future. People may not realise that some individuals with dementia are still capable of a very wide range of feelings, including experiencing joy, peacefulness, comfort, and acceptance. Addressing the kinds of stereotypes, stigma and fear that can exist when people think about a future with dementia, may provide a counterbalance to the negativity that surrounds the disease. As Gómez-Vírseda and Gastman state, with open and engaging dialog about end-of-life care, society will be encouraged to nuance its views on aging and dependency, reducing stigma against and fear of dementia (Gómez-Vírseda a & Gastman, 2021). This may mean that well-trained HPs have an important role in educating patients on how dementia may progress in their context and address what issues may arise for them, which in turn may help patients make more informed decisions regarding their future care.

6.2.2.2 Establishment of an independent monitoring system

Without statutory and monitoring safeguards of AD practice, the safety of patients, HPs and their professional careers may be compromised. Although not fully developed in my thesis, my findings draw attention to the establishment of an accountable regulatory system for independent monitoring of AD for people with dementia. This system may include procedural guidelines, eligibility criteria, processes for the assessment of AEDs, a robust reporting system for HPs, and retrospective monitoring of AD. It ought to set out legal consequences for those acting outside the law, while protecting those acting within the law, from prosecution. However, regulation is not just about the law. To make regulatory provisions alive and accountable, a wide variety of factors must be taken into account. For example, such an agency needs to prescribe scopes of practice for its profession; prescribe necessary qualifications; educate and inform parties involved; monitor AD performance to make sure the law is adhered to; and support resolution of a dispute.

Table 6.1 | Potential safeguards associated with AD for people with dementia

	Safeguards
Systems-Level Safeguards	▪ Increased discussion about ACP [a] & AEDs [b] ▪ Improved quality of care for PWD [c] ▪ Improved individualised care approach ▪ Establishment of reporting system for HPs [d]
Legal Safeguards	▪ Mandatory AEDs ▪ Time limit on the validity of AEDs (mandatory update) ▪ Modification of existing safeguards (e.g., informed consent, unbearable suffering, life expectancy, & terminal illness) to make them relevant to dementia ▪ Establishment of an independent monitoring system ▪ Additional review requirements (e.g., consultation with a psychologist)
Clinical Safeguards	▪ Increased involvement with drafting AEDs ▪ Repeated, documented discussions among patients and their care team ▪ Ongoing assessment of PWDs' conditions and care
Support for HPs	▪ Training for HPs on legal and clinical aspects of AD [e], ACP, AEDs ▪ Emotional support for HPs
Support for Patients & Families	▪ Emotional and practical (e.g., legal advice) support for improved decision-making ▪ Providing information on prognosis and end-of-life care ▪ Facilitation of conversation among PWD and families about AED

Note: The format and content of this table is inspired by a similar table presented by the Council of Canadian Academies [CCA], 2018

[a] Advance Care Planning

[b] Advance Euthanasia Directives

[c] People with dementia

[d] Health Professionals

[e] Assisted Dying

6.3 Summary of the research and its contributions

In this chapter, I drew together the findings and arguments developed in my empirical studies in light of the existing literature. The studies' findings drew attention to a myriad of issues including ethical and practical that may arise during an end-of-life decision-making process that includes AD. The ethical and practical difficulties inherent in interpreting and following the AD wish of a person who may not recall them being documented likely explains the status quo of low AED compliance. The low rate of adherence to AEDs in the jurisdictions that allow such access and the lack of legal provision for such directives in other jurisdictions have implications for individuals with dementia, families, formal and informal caregivers, health professionals, and ultimately society as a whole. I illustrated that although it is extremely difficult to guarantee a straightforward case in which HPs and family caregivers are sure if or when they should enact an AED, steps could be taken to reduce this level of uncertainty. All the above-mentioned aspects and implications were considered in this chapter along with suggested safeguards required to ensure the safe application of AEDs in the context of AD for dementia.

Taking these into consideration, this thesis contributes to the very limited research available for AD for individuals with dementia as it incorporates the divergent views of experts, and the interested and informed public. It illuminates the experiences of people whom personal and/or professional lives are affected by dementia, as well as their attitudes regarding legislative provision of AD for individuals with dementia. In this sense, this research extends the scope of care framework beyond the patient with dementia by re-orienting the normative standard of good EOL care for patients with advanced dementia. The interest of these patients is protected if the interests of all other stakeholders responsible for their care are also considered. This approach prompts us to put at the centre of the discussion not only the person with dementia but also their family members, and healthcare professionals responsible for their care. In addition, it advances our knowledge of some of the primary issues and challenges in considering AED for patients with dementia; moral and legal challenges; and inconsistencies within current legislative provisions concerning dementia and AD. It ultimately provides some preliminary safeguards in an attempt to contribute to dementia and AD debates. The value of this research is in its ability to strengthen clinical practice by providing guidance for understanding the practice of AD in the context of dementia. Researchers can build on this research (more particularly on the preliminary framework presented in the table 3.4 of chapter 3 and also on the potential safeguards presented in this chapter) in contributing to the body of knowledge. Lastly, this research is a ‘conversation starter’ that attempts to drag the issues of AD and dementia out of the ‘too hard basket’ exploring ways that may lead to new insights.

6.4 Limitations and future research

With regard to limitations, while my Delphi study (Chapter 3) reflects the views of experts on the primary issues and challenges for the provision of AD for individuals with dementia, it lacks the views of individuals who are diagnosed with dementia and their families/caregivers. Their expertise and experience by virtue of living with the day-to-day realities of dementia, are not captured. Further limitations are related to the issue of bias and selectivity of the populations studied in the Netnography (Chapter 4), and the feasibility research (Chapter 5). As to the Netnography research, the members who contributed to the online communities voluntarily chose to do so and may not be representative of the general public. For example, it is possible that they were potentially more inclined to express and defend their views than those who may have a positive experience or view about dementia and its related end-of-life options. Furthermore, it is predominantly an ‘outsider’ view of dementia and AD, which did not include the perspectives and insights from those living with dementia, who are facing their own challenges. The data were also gathered from a single platform (Facebook) which may have excluded data from other online social networking sites that could have complemented the views on my understudy topic. The feasibility study informed by the Netnography and Delphi findings was done by seeking the perceptions of a select group of New Zealanders who may have been influenced by societal discussions about assisted dying at the time of the study. Our participants from the informed group were representative members of an advocacy organisation who are actively seeking a change to the law and thus are potentially more supportive of assisted dying in principle. It is, however, not clear to what degree their support of AD in principle contributed to their view on their AD for people with dementia. These limitations represent opportunities and directions for future research. A comparison of the findings with a group with less supportive views concerning assisted dying and dementia is recommended for future research.

In order for safeguards to provide guidance in diverse societies they need to incorporate relevant and specific socio-cultural characteristics. One primary example of this relates to cultural traditions and the values of minority ethnic groups concerning death and end-of-life care. For instance, as quality of life at the terminal phase of an illness is important for many people in western countries, an AD may be an acceptable option when quality of life is no longer acceptable for an individual person. Conversely, for those from non-western countries, respecting the sanctity of life is often more highly valued than quality of life, and assisted dying is considered unaccepted (Buiting et al., 2008). Differences in religious beliefs, rituals, cultural norms, and the values of patients and their caregivers when faced with terminal illness, are also especially salient as they affect patients’ and HPs’ responses to illness, healthcare services and death (Gysels et al., 2012).

In looking ahead, it would be of immense value to research longitudinally the views of patients recently diagnosed with dementia who support assisted dying to identify whether their views change over time; and if so, what factors are associated with the change.

There is no doubt that we have a duty to care for our elderly, especially those who could not escape a diagnosis of dementia. It is also our duty to make their lives as good and comfortable as possible. I will close by quoting from one my participants. Their perspective illuminates the very human and devastating side of this issue, and grounds the necessity for my research:

> I have seen my mother, two sisters, and two uncles all died of dementia, some suffering up to 7/8 years before dying. I have one sister left who also has dementia. She is bed-bound and losing her sight. There is no dignity in any of it; and we, loved ones, suffer too of seeing them all become a shadow of their former selves. There is No Dignity in that.

APPENDICES

Appendix A – Delphi study

#1 Participant information sheet

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PARTICIPANT INFORMATION SHEET

Project title: Consensus view on euthanasia for dementia of people not opposed in principle: A Delphi study on key issues and concerns[15]

Name of Principal Investigator/Supervisor: Phillipa Malpas and Professor Glynn Owens

Name of Student Researcher: Aida Dehkhoda

My name is Aida Dehkhoda; I am a PhD candidate at the school of psychology, The University of Auckland. I am currently undertaking a doctoral project identifying major issues and concerns regarding assisted dying for people with dementia. This project is supervised by Professor Glynn Owens – School of Psychology, Professor Phillipa Malpas – Department of Psychological Medicine, and Professor Linda Cameron – School of Psychology.

You have been invited to take part in this study by sharing your thoughts and consideration about aid-in-dying for people with dementia as a person with expertise in social, psychological, biological, ethical, and legal aspects of dementia and aging or as an expert by virtue of taking care of a patient with dementia. You do not necessarily need to have experience of practicing euthanasia in any kind.

As a Delphi panel member, you will be asked to complete a series of questionnaires (a minimum of three rounds) using an online survey via Qualtrics Survey Software. It is envisaged that the first round should take approximately 30-60 minutes to complete. This time will be reduced to 10-20 minutes in the second and the following rounds. In these future rounds you would receive a summary of the group's responses and asked to assess your agreement with the responses and modify your answers should you wish through a further brief online questionnaire. This process would continue until a group

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[15] This title was subjected to some changes. In the thesis, the Delphi study is now presented with the title of "Conceptual framework for assisted dying for individuals with dementia: Views of experts not opposed in principle

consensus is achieved. In order to allow timely conclusion of the study we would respectfully request a response time of 3-4 weeks for completion of the first round and 2 weeks for the following rounds.

Considering the nature of the Delphi study and the few number of panellists participating it is impractical for responses not to be identifiable by the researcher; however, all responses received in the project will be strictly confidential, and your identity will not be divulged in any publication. Direct quotes to free-text answers may be used as part of the study report or later Delphi iterations, but these will be not be traceable back to you. Please note that this study may also be published in academic journals. You will be asked to provide your e-mail address to link your first response to the following ones in order to analyse them. These e-mail addresses are known only to the lead investigator and will be stored for a period of six years in a password-protected directory on an external hard drive to which only the lead investigator has access. After this the data will be deleted securely.

You have the right to withdraw from participation at any time; however, your commitment to complete the survey would be truly appreciated due to your critical role in this study, and we would like to offer you a $50 Amazon voucher for your time should you wish. At the end of the data collection process, a unique username/password of the Amazon website will be sent to e-mail address of those participants who wished to receive a gift voucher.

Thank you for reading this information sheet and for considering participation in this research. If you are happy to proceed please consider that you have implicitly given consent by completing the survey. If you have any questions or concerns, please do not hesitate to contact me.

Thank you very much for your time.

Please direct any queries to Aida Dehkhoda (a.dehkhoda@auckland.ac.nz).

PhD supervisor's contacts: Glynn Owens (g.owens@auckland.ac.nz), telephone: +64 9 373 7599 ext. 86845; Phillipa Malpas (p.malpas@auckland.ac.nz) telephone: +64 9 923 3776; and, Linda Cameron (l.cameron@auckland.zc.nz).

Head of the School of Psychology contact: William Hayward (w.hayward@auckland.ac.nz), telephone: +64 9 3737599 ext. 88516.

For any queries regarding ethical concerns, you may contact the Chair, the University of Auckland Human Participants Ethics Committee, the University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone: 0064 9 373 7599 ext. 83711. Email: ro-ethics@auckland.ac.nz.

Approved by the University of Auckland Human Participants Ethics Committee on 02-feb-2016 for three years. Reference number 016552

#2 Invitation e-mail

Dear ...,

We are writing to you as we understand that you are not in principle opposed to the general issue of euthanasia. We are in the process of conducting research looking at what special issues might arise when considering euthanasia in the context of people with dementia. We will be extremely happy if you would be able to take part in the research. If you think you might be interested in taking part, please read the attached PIS. If you feel you are unable to take part, we entirely understand. Any comments you may wish to send whether to take part or not would be grateful in received. Thank you for your attention.

#3 Questionnaire – Round one

Thank you for helping us with our research. By answering the following questions, you are deemed to have given consent to participate. We would respectfully remind you that you are free to withdraw at any time should you wish.

As you may know, laws which permit medical assistance in dying normally require that the patient be mentally competent to request such assistance and to receive it. This would typically exclude individuals with severe dementia whose mental capacity is lost. However, it is quite common for some patients to feel that if they were to develop severe dementia, they would not want their lives to continue.

This study focuses on the following classifications of end-of-life decisions that hasten death:

Physician assistance in dying is where a physician intentionally *provides* a patient with lethal drugs at their explicit request. The patient determines when or if they will self-administer the drug.

Euthanasia is where a physician *administers* the drug upon the explicit request of the patient.

These definitions exclude practices that may hasten death by withdrawal or withholding of life-sustaining treatments, non-resuscitation decisions, futile treatments, and the alleviation of pain and symptoms.

In this regard, we would be grateful for your considered thoughts on the following questions:

1) Is it possible to devise safeguards which would permit physician-assistance in dying and euthanasia for people with dementia?

2) If so, what form would you expect these safeguards to take?

3) Why do you think this would work well in practice?

4) Briefly summarise what you think would be the main concerns and issues regarding the possibility of physician assisted dying and euthanasia for people with dementia.

5) Please feel welcome to express any further comments on this topic.

#4 Questionnaire – Round two

I would like to thank you all for your thoughts and time, and also to remind you that you are free to withdraw at any time should you wish or to skip this round for any reason – but do please inform me so that I could circulate you into the next round.

I'd like to draw your attention to some points that will help you to complete the second round of this study:

- To facilitate the process this round will be presented in three separate sections: Question one; Questions two and three; and Question four.
- Please evaluate each item from the list of statements that were extracted upon first round. In the box directly below the statement, feel free to comment and/or revise your statements, or explain your choices if you so wish.
- Please note that your progress will be saved automatically: you can leave your survey and then re-enter where you left off when you click on the survey link again.
- For ease of use, please use your computer/laptop rather than a smart phone.
- Here is a list of acronyms that have been used throughout: Assisted Dying (AD) – Physician-Assisted Death (PAD) – Advance directives (ADs) – Advance Euthanasia Directives (AEDs) – Health Professionals (HPs), End of Life (EOL).

Q1. Is it possible to devise safeguards which would permit physician-assistance in dying and euthanasia for people with dementia?

While 6 experts believed that creating safeguards were possible, 2 experts said No, and the other 4 experts were unsure how safeguards may be devised.

Below are the main reasons that raised:

	Statements	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
1.	It is just a matter of establishing whether this is truly what society wishes from us.	○	○	○	○	○	○
2.	Instead of focusing on AD it is more helpful to work on education leading to advance directives, physicians' orders for life sustaining treatment (POLST), and what palliative care entails.	○	○	○	○	○	○
3.	Patient autonomy and consent until the moment of PAD is of the essence.	○	○	○	○	○	○
4.	I am uncertain whether adequate safeguards can be devised for PAD and Euthanasia.	○	○	○	○	○	○
5.	Evidence emerging form countries where AD practices are monitored like The Netherlands show how problematic these practices are in some cases.	○	○	○	○	○	○
6.	It is important for HPs to embed discussion about PAD/euthanasia within an overall	○	○	○	○	○	○

	understanding of what death means for society.						
7.	Deciding whether a patient's motivation to request an AD is objective, rather than coerced by internal fears or external worries, is not possible.	○	○	○	○	○	○
8.	The issue of patients with dementia and EOL options will become more and more relevant to public discussion as the population in most countries is growing older.	○	○	○	○	○	○
9.	This is an extremely complex area.	○	○	○	○	○	○
10.	It is not about living a year less or a year more per se, it is about how we value human life.	○	○	○	○	○	○
11.	It is of concern that caregivers and proxies may project their own wishes onto the patient.	○	○	○	○	○	○
12.	With PAD/euthanasia the urgency and creativity to look for other solutions to meet patients' suffering will be downplayed.	○	○	○	○	○	○
13.	Giving room to AD has an impact on our view about suffering, decline, willingness, and creativity to find other ways to meet the needs of vulnerable individuals.	○	○	○	○	○	○
14.	We need a system that lets people know that if they are sure that PAD and/or euthanasia is the right option for them, then their request will be taken seriously.	○	○	○	○	○	○

Q2. If so, what form would you expect these safeguards to take?

Q3. Why do you think this would work well in practice?

Please find below the forms these safeguards may take. A random number has been assigned to each one of the experts who advised safeguards.

Statements		Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
E1. Expert 1							
1.1.	Safeguards include that the patient should be demonstrably competent to decide whether PAD is what s/he wants.	○	○	○	○	○	○
1.2.	The physician must believe that PAD/euthanasia is the only means to address the suffering of the patient.	○	○	○	○	○	○
1.3.	Where a patient has lost capacity, the physician should be responsible for making decisions based on his/her knowledge and interpretation of the former and current wishes of the patient.	○	○	○	○	○	○

Practicality (1.1-3): Safeguards will work for patients with early dementia, not for patients in advanced stages who are incompetent.	○	○	○	○	○	○
E2. Expert 2						
2.1. Safeguards should include careful procedures within a regulatory system to protect those who are using it and acting within such a system.	○	○	○	○	○	○
2.2. Safeguards need to acknowledge the possibility of coercion and pressure on people by others (family and carers) to make an advance directive.	○	○	○	○	○	○
2.3. Preferences should be written/expressed in detail and must be very clear to follow so the decision cannot be doubted.	○	○	○	○	○	○
2.4. An ADs should be signed by the person prior to loss of capacity in order to prevent abuse.	○	○	○	○	○	○
2.5. The decision to enact an ADs should be made on the ground of patients'' previous and clearly stated wishes.	○	○	○	○	○	○
Practicality (2.1-5): These safeguards seek to protect the interest and will of the patient.	○	○	○	○	○	○
2.6. Safeguards should consider the views of all stakeholders involved in any request for PAD/euthanasia (family members, carers, and HPs).	○	○	○	○	○	○
2.7. In order to preserve their psychological wellbeing, HPs need to be absolutely certain (both from a professional and personal perspective) that the person with dementia actually wants to die in this current situation.	○	○	○	○	○	○
2.8. Safeguards need to protect HPs from prosecution when they are willing to assist a patient to die.	○	○	○	○	○	○
2.9. Safeguards also need to protect HPs from those in the community who are opposed to PAD/euthanasia who may seek to destroy the reputation and integrity of a HP.	○	○	○	○	○	○
2.10. There should be a robust reporting system for HPs involved in PAD/euthanasia.	○	○	○	○	○	○
2.11. There needs to be legal consequences for practitioners acting outside of the law.	○	○	○	○	○	○
2.12. There needs to be training for HPs.	○	○	○	○	○	○
Practicality (2.7-12): These safeguards will protect HPs involved in PAD/euthanasia by training them in the necessary skills, providing support, and in accountability processes	○	○	○	○	○	○
2.13. The State/regulator must ensure that there are strict accountability systems in place to monitor PAD/euthanasia.	○	○	○	○	○	○

Practicality (2.13): This safeguard will reassure society that AD practices can be carried out legally and ethically.	○	○	○	○	○	○
2.14. Ideally it is best if the patients who desire AD, inform their caregivers and loved ones about their decision so their wishes are clearly known, and AD is not a shock.	○	○	○	○	○	○
Practicality (2.14): No safeguards can completely mitigate the worry that a patient with dementia may be assisted to die without the knowledge of family and caregivers	○	○	○	○	○	○
E3. Expert 3 3.1. The ideal safeguards should prevent others making AD decisions for people with dementia. In other words, it can never be the decision of another person.	○	○	○	○	○	○
3.2. Patients need to clearly specify in their ADs what types of function must be lost prior to enactment of their end-of-life directives.	○	○	○	○	○	○
3.3. Educating patients about dementia would be helpful prior to them making an advance directive.	○	○	○	○	○	○
3.4. Regular updating of ADs would be helpful in protecting the person with dementia against the decision of someone with power of attorney over health who perhaps holds a different view or is only considering a view expressed perhaps 20 years ago.	○	○	○	○	○	○
Practicality (3.1-4): As dementia is a complex condition, it is hard to say how well these safeguards will work in within the context of PAD/euthanasia.	○	○	○	○	○	○
3.5. The only way PAD could be a viable end-of-life decision, is if it was carried out in the earliest stage of the disease, when people remained able to carry out a plan.	○	○	○	○	○	○
E4. Expert 4 4.1. PAD would have to take place when a person had capacity to decide they wished to have the lethal drug.	○	○	○	○	○	○
4.2. Safeguards should prevent the person taking the lethal medication in error at a point when s/he has lost capacity.	○	○	○	○	○	○
4.3. Safeguards should require patients to nominate someone who knows where the lethal medication is stored.	○	○	○	○	○	○
4.4. Some people may make an advanced statement asking for AD to be administered in particular circumstances based on future conditions. A helpful safeguard could therefore be for the person to communicate with HPs to uncover the fundamental	○	○	○	○	○	○

condition that they would wish to trigger euthanasia.						
4.5. Safeguards should prevent patients being persuaded or encouraged to request PAD/euthanasia by relatives or carers.	○	○	○	○	○	○
Practicality (4.1-5): Patients" needs and preferences would need to be discussed with a person when they had capacity which would require staff to be able to broach the topic. It would fit alongside considerations that are currently routinely addressed soon after diagnosis, for instance, whether to give up driving, whether the person has a will, whether they know about and would like to assign powers of attorney.	○	○	○	○	○	○
4.6. At the point of loss of capacity, the Community Psychiatric Nurse (CPN) or GP should take action based on their review appointments with patients considering their feeling about life and whether their views have changed.	○	○	○	○	○	○
Practicality (4.6): This safeguard would work if the person is being followed up.	○	○	○	○	○	○
4.7. Safeguards are needed to ensure that PAD/euthanasia was not carried out if the person was to indicate that they felt life was still worth living.	○	○	○	○	○	○
4.8. A scale like the Bradford Well-being profile or Dementia Care Mapping may be helpful to ensure a well-informed, nuanced, subtle, and thorough observation of the person's wellbeing.	○	○	○	○	○	○
4.9. An "advanced dementia" specialist team needs to assess the quality of care to make sure that poor care is not the reason for opting for AD.	○	○	○	○	○	○
Practicality (4.8-9): To ensure that safeguards about the quality of care and patients well-being would properly work, a periodic assessment and care review should take place by the GP in the home or care home setting.	○	○	○	○	○	○
E5. Expert 5 5.1. Safeguards need to assess whether the person has categorically expressed a wish for AD preceding their diagnosis then evaluating the authenticity of this expression based upon a thorough appreciation of their values and life lived.	○	○	○	○	○	○
5.2. Transparency, patient cantered communication, support for team members, and ongoing reviews should be integrated into the safeguards.	○	○	○	○	○	○
Practicality (5.1-2): It would take many years for any system and infrastructure to become	○	○	○	○	○	○

established, but it would eventually find the middle road balancing the various stakeholders’ perspectives.						
E6. Expert 6						
6.1. In order to safeguard people who might be pressured into opting for PAD/euthanasia against their will or who may change their mind as they adjust to living with their condition, patients should be required: To make a clear written request detailing their disinterest in alternative options and their desired time, situation, and method;	○	○	○	○	○	○
6.1.1. To make these interests/disinterests on at least 3 separate occasions during which symptoms have worsened;	○	○	○	○	○	○
6.1.2. To take part in recorded semi-structures interviews with a different doctor and psychologist without the presence of their family.	○	○	○	○	○	○
6.2. Three sets of doctors and a psychologist have to be satisfied that the request is an enduring and voluntary personal choice.	○	○	○	○	○	○
6.3. The recordings of the person's prior interview should be available on request to all HPs involved in the process.	○	○	○	○	○	○
Practicality (6.1-3): Having review meetings with different HP teams each time would reduce the chances of interviewers influencing the patient in undetected ways and it would spread the burden of authorizing the wish across a number of people.	○	○	○	○	○	○
Practicality (6.1-3): Having both a doctor and psychologist present each time would help determine any cognitive decline or coercion or other medical/psychological factors.	○	○	○	○	○	○
Practicality (6.1-3): These safeguards will facilitate the detection of coercion and uncertainty or instability regarding the patient's wish to choose AD.	○	○	○	○	○	○
6.4. As people with dementia may know that their future self may not necessarily follow their current preferences, PAD/euthanasia seem the only truly helpful methods to control the manner and timing of one's death.	○	○	○	○	○	○
6.5. If only PAD is on offer, then patients need to opt to die while their mental faculties are still intact.	○	○	○	○	○	○
6.6. Providing a stable and authentic personal request by patients throughout the whole period of decline suggests that it is their wish to proceed as requested and reflects an enduring personal approach to their situation. Even if we are concerned that a person may no longer feel this way having lost their	○	○	○	○	○	○

faculties, it is expected that until that happens they will be less distressed as they will feel more in control and not have to stress about all the things that lead them to prefer death over living with dementia.						
6.7. It should be up to patients to decide whether their desire not to be a burden is greater than their desire to live.	○	○	○	○	○	○
6.8. Doctors may find it distressing to have to administer a lethal dose to someone who does not currently seem to want that.	○	○	○	○	○	○
6.9. To reduce such distress (and ensure doctors are not coerced into such situations), only doctors willing to perform euthanasia should be expected to do so.	○	○	○	○	○	○
6.10. Immediately prior to assisted death, steps should be taken to reduce a patient's distress.	○	○	○	○	○	○
Practicality (6.1-10): These safeguards are easy to explain to everyone involved and to implement within the current health care system.	○	○	○	○	○	○
E7. Expert 7						
7.1. Safeguards need to include independent assessment for cognitive abilities, pain, medical condition, care environment, and suffering at different points in the person's un-wellness.	○	○	○	○	○	○
7.2. There needs to be video documentation of the consent interview.	○	○	○	○	○	○
7.3. There needs to be evidence of any legal written documentation specifying a patient's medical preferences.	○	○	○	○	○	○
Practicality (7.2-3): Having both written and video recorded documents would allow everyone involved to witness an individual's decision making, would balance legal and medical decision-making, and would put the person centrally into the decision-making process.	○	○	○	○	○	○
7.4. The "care environment" should also be included as a part of the decision-making process since the care environments in which people often have to endure their illness contribute a great deal as to why any one of us might choose to end our life, given the same circumstances.	○	○	○	○	○	○
E8. Expert 8						
8.1. Safeguards need to include as assessment of the patient’s understanding the typical course of their dementia.	○	○	○	○	○	○
8.2. Safeguards should include an assessment of the patient’s understanding that AD results in death.	○	○	○	○	○	○

8.3. There needs to be an assessment to ensure that the AD wish is persistent, clear, and repeatedly expressed.						
8.4. There needs to be a clinical judgment that the patient has no diagnosis of depression.	○	○	○	○	○	○
Practicality (8.1-4): This safeguard may work for individual cases in practice not necessarily for society as a whole.	○	○	○	○	○	○
8.5. The requirement of unboreable suffering would probably not work since it is not clear what suffering entails and what is unbearable.	○	○	○	○	○	○
E9. Expert 9 9.1. Safeguards will involve assessment of capacity, rationality, suffering, depression, and cognition.	○	○	○	○	○	○
9.2. A panel of experts with the following background: legal, medical, psychological, academic, and ethics should consider each AD request collectively.	○	○	○	○	○	○
9.3. This panel of experts need to consider the view of the community and cultural representations, people with dementia, and their families.	○	○	○	○	○	○
Practicality (9.1-3): Such an assessment process will ensure each request will be considered seriously.	○	○	○	○	○	○
E10. Expert 10 10.1. Safeguards need to include standard eligibility criteria, procedural guidelines, and post hoc monitoring.	○	○	○	○	○	○
E11. Expert 11 11.1. The cultural context needs to be taken into account.	○	○	○	○	○	○
11.2. It is important to study the evidence emerging from countries where these practices are monitored, like The Netherlands.	○	○	○	○	○	○

Q4: Briefly summarise what you think would be the main concerns and issues regarding the possibility of physicians assisted dying and euthanasia for people with dementia.

In this section, similar suggestions were merged into one statement that retained the intended meaning. Where there was any uncertainty about whether the comments were referring to the same thing, or there was a subtle difference, comments were kept as separate statements.

Statements	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
1. People with dementia are a vulnerable group because they are not capable of having and articulating a stable long-term request.	○	○	○	○	○	○

2.	People with dementia are capable of changing their mind on assisted dying.	○	○	○	○	○	○
3.	What a person believes would be an end point for them at the beginning of a disease can shift as they progress. A person with dementia may be unable to articulate that their current quality of life is tolerable and "good enough" for them.	○	○	○	○	○	○
4.	People with dementia may lose their sense of self or memory of their former preferences and thus may change their mind. It is important to determine whether these changes are due to cognitive decline or a conscious change in their perspective.	○	○	○	○	○	○
5.	It is unclear whether people with dementia are able to make an informed decision because many people who develop dementia go through a period of depression which may influence their decision about AD.	○	○	○	○	○	○
6.	It is hard to determine whether the statement regarding AD decision is one that truly represents an informed statement, in the sense of truly understanding what dementia and it stages is.	○	○	○	○	○	○
7.	There is chance that caregivers and proxies project their own fears of dementia into the situation.	○	○	○	○	○	○
8.	If people with dementia could trust they would be cared for with respect and love, maybe they would be less likely to be drawn to hastening their death.	○	○	○	○	○	○
9.	One issue relates to difficulty to determine when conditions set by individuals to trigger PAD/euthanasia have been met.	○	○	○	○	○	○
10.	Every single person with dementia has a different pathology which requires special needs at different stages of the disease.	○	○	○	○	○	○
11.	Although it is an irreversible disorder, dementia has a different time course from other life limiting conditions. Most people with dementia are not necessary suffering as such.	○	○	○	○	○	○
12.	At the stage of advanced dementia, the level and nature of suffering and preferences of patients are difficult if not impossible to establish.	○	○	○	○	○	○
13.	If we relax laws to allow PAD or euthanasia, then on a societal level we may come to think of those who expect good care as selfish and as costing the state and their families too much, thus increasing the pressures on people to agree to hastened death.	○	○	○	○	○	○
14.	Society places great value on having intact cognition and many people think a person	○	○	○	○	○	○

	without intact cognition is almost not a person.						
15.	People may not recognize that most individuals with dementia are still capable of a very wide range of feelings including experiences of joy, pleasure and peacefulness.	○	○	○	○	○	○
16.	If I knew I would still experience laughter, uplift and tranquillity maybe I'd not be as keen to hasten my death.	○	○	○	○	○	○
17.	There is misconception that life with dementia not being worth living.	○	○	○	○	○	○
18.	Another misconception is that people with dementia may no longer be seen as a unique individual person, but as someone with a disease that devalues life.	○	○	○	○	○	○
19.	Older people are prone to feel they are burden to others when they need help and are worried that they may cause trouble in terms of care needs and care costs. Thus, they may feel pressure to relieve the burden they put on others.	○	○	○	○	○	○
20.	There might a risk of state abuse in which the state would end the lives of patients who cost society huge sums of money and resources.	○	○	○	○	○	○
21.	This risk of the state abuse can be eliminated through an appropriate safeguards and guidelines as well as independent oversight and monitoring.	○	○	○	○	○	○
22.	There is risk of harm to HPs involved in AD.	○	○	○	○	○	○
23.	There is a risk to HPs psychological well-being if they are not sufficiently trained in this area.	○	○	○	○	○	○
24.	There is risk that HPs may not receive appropriate support from their professional body.	○	○	○	○	○	○
25.	There is also a risk that HPs may be harmed by those opposed to AD practices being available to patients with dementia.	○	○	○	○	○	○
26.	S26. Societies where old age is not valued tend to provide poor support and care for people with dementia.	○	○	○	○	○	○
27.	Physicians are known to be unwilling to have a role in such practices.	○	○	○	○	○	○
28.	Physicians would have to provide lethal medication to patients who do not understand their situation and what is happening, which seems to be at odds with dignified dying.	○	○	○	○	○	○

#5 Questionnaire – Round three

I would like to thank you for evaluating the statements and for your valuable comments. They are very much appreciated.

In round 3, the statements that did not reach consensus of opinion (40 out of 119) are presented.

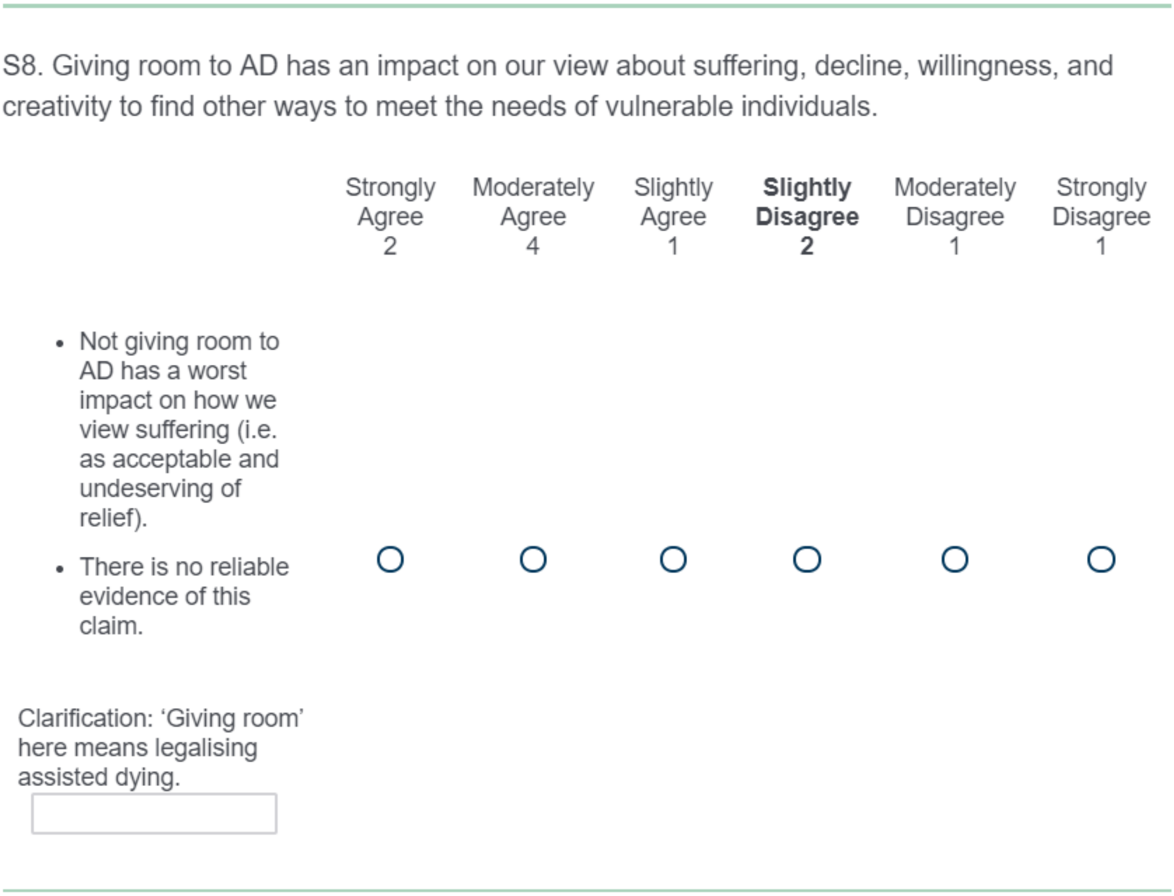
- Each statement is accompanied with the comments raised by other experts in **bullet points** and **extra explanation** if needed for those who required further clarification.
- The number of participants who chose each option appears on the **bottom row** of the scale points.
- The option you chose previously is highlighted in **Bold**. If no box is highlighted, then you did not previously respond to that statement but you may still do so in this round.
- Any statement that remains unranked in this round, will be considered as "neither agree nor disagree" and will be excluded.

For each statement, please indicate your level of agreement by choosing one of the responses (even if it remains the same as in the previous round); and, in the box directly below the comments/clarification, please feel free to comment or explain your choices if you wish to.

Please make sure you rate the statements NOT the comments

Figure 3.1

Extracted from Qualtrics Survey Software from Round 3 Delphi questionnaire showing how the individualised questions were presented to each participant.



S8. Giving room to AD has an impact on our view about suffering, decline, willingness, and creativity to find other ways to meet the needs of vulnerable individuals.

	Strongly Agree 2	Moderately Agree 4	Slightly Agree 1	**Slightly Disagree** **2**	Moderately Disagree 1	Strongly Disagree 1
• Not giving room to AD has a worst impact on how we view suffering (i.e. as acceptable and undeserving of relief). • There is no reliable evidence of this claim.	○	○	○	○	○	○

Clarification: 'Giving room' here means legalising assisted dying.

For ease of read, all round three statements are presented as follows. Each statement is accompanied with the comments raised by other experts and extra explanation if needed for those who required further clarification.

Statements	Experts' comments	Clarification
1. It is just a matter of establishing whether this is truly what society wishes from us.	• 'Just' is a term that makes it sound as if it is very straightforward once we know society's views, but it isn't. • Such a delicate issue can never be 'just a matter of'.	It is a matter of establishing whether AD is truly what society, including all the stakeholders involved, wish to have available to them.
2. Instead of focusing on AD it is more helpful to work on education leading to advance directives, physicians' orders for life sustaining treatment (POLST), and what palliative care entails.	• It does not need to be 'instead of advocating for legislation of AD'; it is Not either/or.	
3. Patient autonomy and consent until the moment of AD is of the essence.	• The person with advanced dementia would have neither autonomy nor capacity to give consent. So, if it is 'of the essence' this is immaterial since it is not possible to attain for anyone with advanced dementia.	In the case of advanced dementia, the patient's autonomy and consent can be preserved through adhering to their advance directives (if there is one).
4. I am uncertain whether adequate safeguards can be devised for AD.		
5. Evidence emerging from countries where AD practices are monitored, like The Netherlands, show how problematic these practices are in some cases.	• Problems are in how the law is drafted (objective standard) not the practice in principle. • Only some - but even so we need to think through how to manage those situations where problems arise.	
6. It is not about living a year less or a year more per se, it is about how we value human life.	• This should be about how the particular person, who is thinking about whether they would wish to have AD, values his or her own life.	This is referring to the differences between the quantity and quality of life.
7. With AD the urgency and creativity to look for other solutions to meet patients' suffering will be downplayed.	• Death is usually seen as a last resort and I don't see that changing (as long as there are some basic protections in place). • There is no reliable evidence of this claim.	
8. Giving room to AD has an impact on our view about suffering, decline, willingness, and creativity to find other ways to meet the needs of vulnerable individuals.	• Not giving room to AD has a worst impact on how we view suffering (e.g., as acceptable and undeserving of relief). • There is no reliable evidence of this claim.	'Giving room' here means legalising assisted dying.

9. The physician must believe that AD is the only means to address the suffering of the patient.	- This is not the physician's decision.	
10. Where a patient has lost capacity, the physician should be responsible for making decisions based on his/her knowledge and interpretation of the former and current wishes of the patient.	- Physicians shouldn't make the decision or interpret. The patient should make it through an advance request.	This safeguard is to be applied if a patient is no longer competent to make a decision about AD or to communicate about his/her degree and nature of suffering and there is no advance directives to follow.
11. Safeguards will work for patients with early dementia, not for patients in advanced stages who are incompetent.		
12. The only way AD could be a viable end-of-life decision, is if it was carried out in the earliest stage of the disease, when people remained able to carry out a plan.	- I am very much NOT in favour of this "protective measure" as it forces people to die before they are ready.	
13. AD would have to take place when a person had capacity to decide they wished to have the lethal drug.	- I am very much NOT in favour of this "protective measure" as it forces people to die before they are ready.	As it is not clear how and when a patient would decide to use the lethal medication when capacity is lost, this statement suggests that any assistance in dying ought to take place when patients are still competent.
14. At the point of loss of capacity, the Community Psychiatric Nurse (CPN) or GP should take action based on their review appointments with patients considering their feeling about life and whether their views have changed.	- Incapable views cannot override prior capable wishes.	
15. The above safeguard would work if the person is being followed up through review appointments.		
16. An "advanced dementia" specialist team needs to assess the quality of care to make sure that poor care is not the reason for opting for AD.	- It is not always necessary.	
17. Safeguards need to assess whether the person has categorically expressed a wish for AD preceding their diagnosis then evaluating the authenticity of this expression based upon a thorough appreciation of their values and life lived.	- Wish does not need to be expressed before the diagnosis.	

18. Safeguards would undoubtedly take many years for any system and infrastructure to become established, but it would eventually find the middle road balancing the various stakeholders' perspectives in equipoise.	- I don't think the 'middle road' is the goal.	Were AD to be legally available, over time such practices would be become accepted by the various stakeholders in society.
19. In order to safeguard people who might be pressured into opting for AD against their will or who may change their mind as they adjust to living with their condition, patients should be required to make a clear written request detailing their disinterest in alternative options and their desired time, situation, and method.	- I agree with need for clear written request but not the way the statement is framed re: pressure and changing minds. - This wouldn't solve the problem posed.	
20. Three sets of doctors and a psychologist have to be satisfied that the request is an enduring and voluntary personal choice.	- Two doctors and a psychologist are probably enough or two doctors and two psychologists. - It is overly restrictive.	
21. Having review meetings with different HP teams each time would reduce the chances of interviewers influencing the patient in undetected ways and it would spread the burden of authorizing the wish across a number of people.	- It would be a serious barrier to access. - There is no evidence of interviewers influencing patients.	
22. As people with dementia may know that their future self may not necessarily follow their current preferences, voluntary euthanasia seems the only truly helpful method to control the manner and timing of one's death.	- This depends on the view of personhood one holds, and the importance of psychological continuity it entails. One can also consider a person to be open for change.	
23. If only PAD is on offer, then patients need to opt to die while their mental faculties are still intact.		This statement should have been phrased as" if only PAD is available and voluntary euthanasia is not, then patients would need to opt to die while their mental faculties are still intact since they have to be active in the process.
24. Immediately prior to assisted death, steps should be taken to reduce a patient's distress.		A problematic concern is that by the time the procedure is carried out, it may be against the person's will (i.e. against the desire of who they have

		become); so, steps should be taken to reduce the distress of the patient.
25. Safeguards above - S19 to S24 - are easy to explain to everyone involved and to implement within the current health care system.	• There is more at stake than explaining: it is a moral issue that many HPs will disagree about.	
26. There needs to be video documentation of the consent interview.		
27. Having both written and video recorded documents would allow everyone involved to witness an individual's decision making, would balance legal and medical decision-making, and would put the person centrally into the decision-making process.	• Video may also make patients uncomfortable.	
28. Safeguards regarding PAD/euthanasia for people with dementia may work for individual cases in practice, but not necessarily for society as a whole.		
29. The requirement of unbearable suffering would probably not work since it is not clear what suffering entails and what is unbearable.	• The term "unbearable suffering" is subjective, which is the main point. It is about how the person feels about their situation. • It is for the patient to state in advance what she considers to be intolerable. • This requirement works in The Netherlands.	
30. A panel of experts with the following backgrounds: legal, medical, psychological, academic, and ethics should consider each AD request collectively.	• It is not always necessary or relevant and it would be a serious barrier to access. • Spirituality experts should be added and the psychological should be psycho social.	
31. This panel of experts needs to consider the views of the community and cultural representations, people with dementia, and their families.	• This would become too unwieldly. • This is the patient's decision.	
32. Such an assessment process – S29 and S30 – will ensure each request will be considered seriously.		
33. It is unclear whether people with dementia are able to make an informed decision because many people who develop dementia go through a period of depression which may influence their decision about AD.	• Someone could be "informed" and "depressed". They are not mutually exclusive. People who decide on all sorts of medical treatments may be depressed but they are still considered able to give	

	"informed consent". This may be an issue for AD but not necessarily more than any other major decisions. • Depression does not automatically mean lack of capacity.	
34. It is hard to determine whether the statement regarding AD decision is one that truly represents an informed statement, in the sense of truly understanding what dementia and it stages is.		
35. If people with dementia could trust they would be cared for with respect and love, maybe they would be less likely to be drawn to hastening their death.	• This may be right for some people; not for everyone.	
36. If we relax laws to allow AD, then on a societal level we may come to think of those who expect good care as selfish and as costing the state and their families too much, thus increasing the pressures on people to agree to hastened death.		
37. There might a risk of state abuse in which the state would end the lives of patients who cost society huge sums of money and resources.	• 'Voluntary' is the key word; and safeguards would need to ensure that AD is voluntary. • There is no evidence for this claim.	
38. This risk of state abuse can be eliminated through appropriate safeguards and guidelines as well as independent oversight and monitoring.	• One should not underestimate the slippery slope effect.	
39. Physicians are known to be unwilling to have a role in such practices.	• Some physicians are but some aren't. Some of them are also unwilling to participate in AD at all. However, it is not a reason to not allow it.	
40. Physicians would have to provide lethal medication to patients who do not understand their situation and what is happening, which seems to be at odds with dignified dying.	• To help eliminate this distress for the HP and patient, the patient should be put to sleep first and only then given the lethal dose. • I don't see it as "at odds"	

#6 Results – Rounds two and three

Overall concordance across all statements

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
Applicability of assisted dying (AD)				
1. It is just a matter of establishing whether this is truly what society wishes from us.	36.4%	No	33.3%	No
2. Patient autonomy and consent until the moment of AD is of the essence.	54.5%	No	50.0%	No
3. It is important for HPs to embed discussion about AD within an overall understanding of what death means for society.	81.8%	Yes		
4. The issue of patients with dementia and EOL options will become more and more relevant to public discussion as the population in most countries is growing older.	100.0%	Yes		
5. It is not about living a year less or a year more per se, it is about how we value human life.	72.7%	Yes		
6. We need a system that lets people know that if they are sure that AD is the right option for them, then their request will be taken seriously.	90.9%	Yes		
7. I am uncertain whether adequate safeguards can be devised for AD	45.5%	No	41.7%	No
8. It is of concern that caregivers and proxies may project their own wishes onto the patient.	90.9%	Yes		
9. Instead of focusing on AD it is more helpful to work on education leading to advance directives, physicians' orders for life sustaining treatment (POLST), and what palliative care entails.	63.6%	No	66.7%	No
10. Evidence emerging form countries where AD practices are monitored like The Netherlands show how problematic these practices are in some cases.	54.5%	No	58.3%	No
11. Deciding whether a patient's motivation to request an AD is objective, rather than coerced by internal fears or external worries, is not possible.	72.7%[1]	Yes		
12. This is an extremely complex area.	100.0%	Yes		
13. With AD the urgency and creativity to look for other solutions to meet patients' suffering will be downplayed.	45.5%	No	41.7%	No

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
14. Giving room to AD has an impact on our view about suffering, decline, willingness, and creativity to find other ways to meet the needs of vulnerable individuals.	63.6%	No	66.7%	No
Ethical Safeguards				
15. Safeguards include that the patient should be demonstrably competent to decide whether AD is what s/he wants.	100.0%	Yes		
16. Safeguards should include careful procedures within a regulatory system to protect those who are using it and acting within such a system.	100.0%	Yes		
17. Safeguards need to acknowledge the possibility of coercion and pressure on people by others (family and carers) to make an advance directive.	100.0%	Yes		
18. Safeguards should consider the views of all stakeholders involved in any request for AD (family members, carers, and HPs[2]).	81.8%	Yes		
19. In order to preserve their psychological wellbeing, HPs need to be absolutely certain (both from a professional and personal perspective) that the person with dementia actually wants to die in this current situation.	81.8%	Yes		
20. Safeguards need to protect HPs from prosecution when they are willing to assist a patient to die.	81.8%	Yes		
21. Safeguards also need to protect HPs from those in the community who are opposed to AD who may seek to destroy the reputation and integrity of a HP.	90.9%	Yes		
22. Ideally it is best if the patients who desire AD, inform their caregivers and loved ones about their decision so their wishes are clearly known, and AD is not a shock.	100.0%	Yes		
23. The ideal safeguards should prevent others making AD decisions for people with dementia. In other words, it can never be the decision of another person.	81.8%	Yes		
24. Safeguards should prevent the person taking the lethal medication in error at a point when s/he has lost capacity.	100.0%	Yes		
25. Safeguards should require patients to nominate someone who knows where the lethal medication is stored.	100.0%	Yes		

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
26. Safeguards should prevent patients being persuaded or encouraged to request AD by relatives or carers.	100.0%	Yes		
27. Safeguards are needed to ensure that AD was not carried out if the person was to indicate that they felt life was still worth living.	90.9%	Yes		
28. Providing a stable and authentic personal request by patients throughout the whole period of decline suggests that it is their wish to proceed as requested and reflects an enduring personal approach to their situation. Even if we are concerned that a person may no longer feel this way having lost their faculties, it is expected that until that happens, they will be less distressed as they will feel more in control and not have to stress about all the things that lead them to prefer death over living with dementia.	81.8%	Yes		
29. It should be up to patients to decide whether their desire not to be a burden is greater than their desire to live.	90.9%	Yes		
30. Doctors may find it distressing to have to administer a lethal dose to someone who does not currently seem to want that.	100.0%	Yes		
31. To reduce such distress (and ensure doctors are not coerced into such situations), only doctors willing to perform euthanasia should be expected to do so.	100.0%	Yes		
32. Immediately prior to assisted death, steps should be taken to reduce a patient's distress.	63.6%	No	66.7%	No
33. The cultural context needs to be taken into account.	81.8%	Yes		
Legal Safeguards				
34. Where a patient has lost capacity, the physician should be responsible for making decisions based on his/her knowledge and interpretation of the former and current wishes of the patient.	54.5%	No	50.0%	No
35. Preferences should be written and/or expressed in detail and must be very clear to follow so the decision cannot be doubted.	100.0%	Yes		
36. An advance directive should be signed by the person prior to loss of capacity in order to prevent abuse.	100.0%	Yes		

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
37. The decision to enact an advance directive should be made on the ground of patients'' previous and clearly stated wishes.	90.9%	Yes		
38. There needs to be legal consequences for practitioners acting outside of the law.	100.0%	Yes		
39. There should be a robust reporting system for HPs involved in AD.	100.0%	Yes		
40. The State/regulator must ensure that there are strict accountability systems in place to monitor AD.	100.0%	Yes		
41. The risk of the state abuse can be eliminated through an appropriate safeguards and guidelines as well as independent oversight and monitoring.	63.6%	No		
42. Patients need to clearly specify in their advance directives what types of function must be lost prior to enactment of their end-of-life directives.	90.9%	Yes		
43. Regular updating of advance directives would be helpful in protecting the person with dementia against the decision of someone with power of attorney over health who perhaps holds a different view or is only considering a view expressed perhaps 20 years ago.	100.0%	Yes		
44. The only way AD could be a viable end-of-life decision, is if it was carried out in the earliest stage of the disease, when people remained able to carry out a plan.	45.5%	No	50.0%	No
45. AD would have to take place when a person had capacity to decide they wished to have the lethal drug.	63.6%	No	41.7%	No
46. At the point of loss of capacity, the Community Psychiatric Nurse (CPN) or GP should take action based on their review appointments with patients considering their feeling about life and whether their views have changed.	45.5%	No	58.3%	No
47. In order to safeguard people who might be pressured into opting for AD against their will or who may change their mind as they adjust to living with their condition, patients should be required: To make a clear written request detailing their disinterest in alternative options and their desired time, situation, and method;	63.6%	No	66.7%	No

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
48. To make these interests/disinterests on at least 3 separate occasions during which symptoms have worsened;	45.5%	No	50.0%	No
49. To take part in recorded semi-structures interviews with a different doctor and psychologist without the presence of their family.	72.7%	Yes		
50. Three sets of doctors and a psychologist have to be satisfied that the request is an enduring and voluntary personal choice.	72.7%[3]	Yes	75.0%	Yes
51. The recordings of the person's prior interview should be available on request to all HPs involved in the process.	72.7%	Yes		
52. As people with dementia may know that their future self may not necessarily follow their current preferences, AD seem the only truly helpful methods to control the manner and timing of one's death.	45.5%	No	41.7%	No
53. If only physician-assisted dying is on offer, then patients need to opt to die while their mental faculties are still intact.	72.7%[3]	Yes	66.7%	No
54. There needs to be video documentation of the consent interview.	63.6%	No	75.0%	Yes
55. There needs to be evidence of any legal written documentation specifying a patient's medical preferences.	90.9%	Yes		
56. Safeguards need to include standard eligibility criteria, procedural guidelines, and post hoc monitoring.	100.0%	Yes		
Professional Safeguards				
57. The physician must believe that AD is the only means to address the suffering of the patient.	72.7%[3]	Yes	66.7%	No
58. There needs to be training for HPs.	100.0%	Yes		
59. Educating patients about dementia would be helpful prior to them making an advance directive.	100.0%	Yes		
60. Some people may make an advanced statement asking for AD to be administered in particular circumstances based on future conditions. A helpful safeguard could therefore be for the person to communicate with HPs to uncover the fundamental condition that they would wish to trigger euthanasia.	90.9%	Yes		

Statements	Round 2		**Round 3**	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
61. A scale like the Bradford Well-being profile or Dementia Care Mapping may be helpful to ensure a well-informed, nuanced, subtle, and thorough observation of the person's wellbeing.	72.7%	Yes		
62. An "advanced dementia" specialist team needs to assess the quality of care to make sure that poor care is not the reason for opting for AD.	63.6%	No	83.3%	Yes
63. Safeguards need to assess whether the person has categorically expressed a wish for AD preceding their diagnosis then evaluating the authenticity of this expression based upon a thorough appreciation of their values and life lived.	72.7%[3]	Yes	41.7%	No
64. Transparency, patient cantered communication, support for team members, and ongoing reviews should be integrated into the safeguards.	100.0%	Yes		
65. Safeguards need to include independent assessment for cognitive abilities, pain, medical condition, care environment, and suffering at different points in the person's un-wellness.	100.0%	Yes		
66. The "care environment" should also be included as a part of the decision-making process since the care environments in which people often have to endure their illness contribute a great deal as to why any one of us might choose to end our life, given the same circumstances.	90.9%	Yes		
67. Safeguards need to include as assessment of the patient's understanding the typical course of their dementia.	100.0%	Yes		
68. Safeguards should include an assessment of the patient's understanding that AD results in death.	100.0%	Yes		
69. There needs to be an assessment to ensure that the AD wish is persistent, clear, and repeatedly expressed.	100.0%	Yes		
70. There needs to be a clinical judgment that the patient has no diagnosis of depression.	81.8%	Yes		
71. Safeguards will involve assessment of capacity, rationality, suffering, depression, and cognition.	100.0%	Yes		
72. A panel of experts with the following background: legal, medical, psychological, academic, and ethics should consider each AD request collectively.	72.7%[3]	Yes	58.3%	No

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
73. This panel of experts need to consider the view of the community and cultural representations, people with dementia, and their families.	45.5%	No	33.3%	No
74. It is important to study the evidence emerging from countries where these practices are monitored, like The Netherlands.	100.0%	Yes		
Practicality of Safeguards				
75. Safeguard regarding the application of monitoring system will reassure society that AD practices can be carried out legally and ethically.	81.8%	Yes		
76. Safeguards will work for patients with early dementia, not for patients in advanced stages who are incompetent.	63.6%	No	66.7%	No
77. Training safeguards will protect HPs involved in AD by training them in the necessary skills, providing support, and in accountability processes.	100.0%	Yes		
78. Safeguards regarding the advance directives seek to protect the interest and will of the patient.	90.9%	Yes		
79. No safeguards can completely mitigate the worry that a patient with dementia may be assisted to die without the knowledge of family and caregivers.	90.9%	Yes		
80. As dementia is a complex condition, it is hard to say how well these safeguards will work in within the context of AD.	90.9%	Yes		
81. Patients" needs and preferences would need to be discussed with a person when they had capacity which would require staff to be able to broach the topic. It would fit alongside considerations that are currently routinely addressed soon after diagnosis, for instance, whether to give up driving, whether the person has a will, whether they know about and would like to assign powers of attorney.	90.9%	Yes		
82. Safeguard would work if the person is being followed up.	54.5%	No	41.7%	No
83. To ensure that safeguards about the quality of care and patients well-being would properly work, a periodic assessment and care review should take place by the GP in the home or care home setting.	72.7%	Yes		

Statements	Round 2		Round 3	
	Consensus ($\geq$70%)	Consensus Status	Consensus ($\geq$70%)	Consensus Status
84. It would take many years for any system and infrastructure to become established, but it would eventually find the middle road balancing the various stakeholders' perspectives.	45.5%	No	41.7%	No
85. Having review meetings with different HP teams each time would reduce the chances of interviewers influencing the patient in undetected ways and it would spread the burden of authorizing the wish across a number of people.	72.7%[3]	Yes	66.7%	No
86. Having both a doctor and psychologist present each time would help determine any cognitive decline or coercion or other medical/psychological factors.	81.8%	Yes		
87. Safeguards regarding the review meeting will facilitate the detection of coercion and uncertainty or instability regarding the patient's wish to choose AD.	72.7%	Yes		
88. Having both written and video recorded documents would allow everyone involved to witness an individual's decision making, would balance legal and medical decision-making, and would put the person centrally into the decision-making process.	72.7%[3]	Yes		
89. This safeguard may work for individual cases in practice not necessarily for society as a whole.	45.5%	No	66.7%	No
90. The requirement of unboreable suffering would probably not work since it is not clear what suffering entails and what is unbearable.	54.5%	No	41.7%	No
Ethical Issues				
91. There is chance that caregivers and proxies project their own fears of dementia into the situation.	100.0%	Yes		
92. If people with dementia could trust they would be cared for with respect and love, maybe they would be less likely to be drawn to hastening their death.	63.6%	No	58.3%	No
93. If we relax laws to allow AD, then on a societal level we may come to think of those who expect good care as selfish and as costing the state and their families too much, thus increasing the pressures on people to agree to hastened death.	54.5%	No	58.3%	No
94. Society places great value on having intact cognition and many people think a person without intact cognition is almost not a person.	72.7%	Yes		

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥70%)	Consensus Status
95. People may not recognize that most individuals with dementia are still capable of a very wide range of feelings including experiences of joy, pleasure and peacefulness.	100.0%	Yes		
96. If I knew I would still experience laughter, uplift and tranquillity maybe I'd not be as keen to hasten my death.	81.8%	Yes		
97. There is misconception that life with dementia not being worth living.	81.8%	Yes		
98. Another misconception is that people with dementia may no longer be seen as a unique individual person, but as someone with a disease that devalues life.	81.8%	Yes		
99. Older people are prone to feel they are burden to others when they need help and are worried that they may cause trouble in terms of care needs and care costs. Thus, they may feel pressure to relieve the burden they put on others.	90.9%	Yes		
100. There might a risk of state abuse in which the state would end the lives of patients who cost society huge sums of money and resources.	45.5%	No	58.3%	No
101. There is risk of harm to HPs involved in AD.	81.8%	Yes		
102. There is a risk to HPs psychological well-being if they are not sufficiently trained in this area.	81.8%	Yes		
103. There is risk that HPs may not receive appropriate support from their professional body.	72.7%	Yes		
104. There is also a risk that HPs may be harmed by those opposed to AD practices being available to patients with dementia.	72.7%	Yes		
105. Societies where old age is not valued tend to provide poor support and care for people with dementia.	72.7%	Yes		
106. Physicians are known to be unwilling to have a role in such practices.	54.5%	No		
107. Physicians would have to provide lethal medication to patients who do not understand their situation and what is happening, which seems to be at odds with dignified dying.	45.5%	No		

Statements	Round 2		Round 3	
	Consensus (≥70%)	Consensus Status	Consensus (≥75%)	Consensus Status
Assessment Issues				
108. It is unclear whether people with dementia are able to make an informed decision because many people who develop dementia go through a period of depression which may influence their decision about AD.	63.6%	No	50.0%	No
109. It is hard to determine whether the statement regarding AD decision is one that truly represents an informed statement, in the sense of truly understanding what dementia and it stages is.	54.5%	No	50.0%	No
110. One issue relates to difficulty to determine when conditions set by individuals to trigger PAD/euthanasia have been met.	100.0%	Yes		
111. At the stage of advanced dementia, the level and nature of suffering and preferences of patients are difficult if not impossible to establish.	72.7%	Yes		
Pathological Issues				
112. People with dementia are a vulnerable group because they are not capable of having and articulating a stable long-term request.	81.8%	Yes		
113. People with dementia are capable of changing their mind on assisted dying.	81.8%	Yes		
114. What a person believes would be an end point for them at the beginning of a disease can shift as they progress. A person with dementia may be unable to articulate that their current quality of life is tolerable and "good enough" for them.	100.0%	Yes		
115. People with dementia may lose their sense of self or memory of their former preferences and thus may change their mind. It is important to determine whether these changes are due to cognitive decline or a conscious change in their perspective.	90.9%	Yes		
116. Every single person with dementia has a different pathology which requires special needs at different stages of the disease.	90.9%	Yes		
117. Although it is an irreversible disorder, dementia has a different time course from other life limiting conditions. Most people with dementia are not necessary suffering as such.	72.7%	Yes		

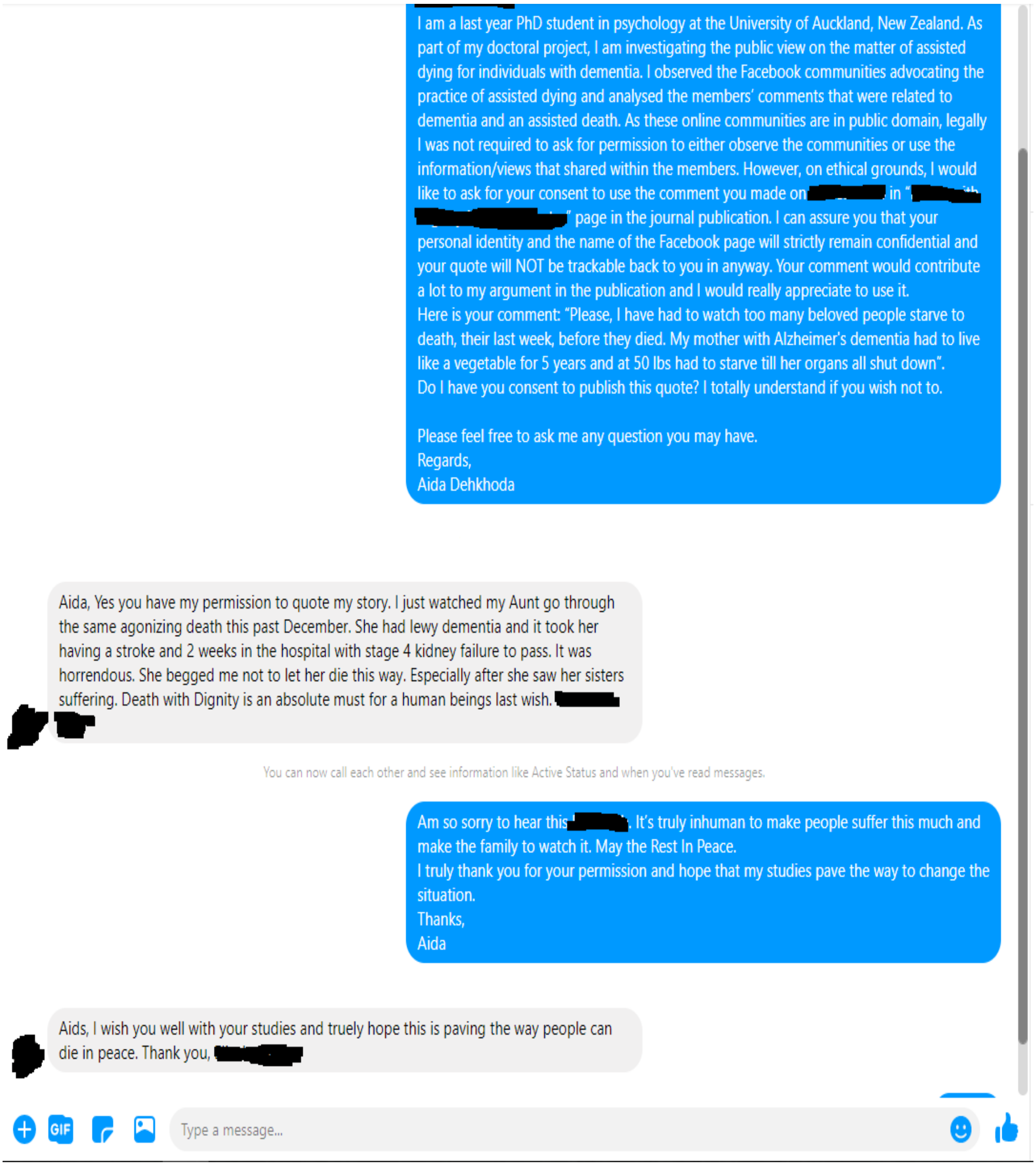
#7 Methodology reporting checklist

Guidance on Conducting and REporting DElphi Studies

Transparency and quality of reporting		Purpose and number of Delphi rounds		Feedback and design of next round(s)	
Purpose well defined	✓	Identification of issues; generation of items	✓	Statistical group response	✓
Rationale for Delphi	✓	Development of a draft document		Summary of qualitative comments	✓
Selection of experts clearly justified	✓	Rating/evaluation of statements/document	✓	Inclusion of items newly generated/added by experts	
Clear description of methods	✓	Ranking/selection/ prioritisation		Modification of items	
Flow chart		Qualitative responses/ comments/feedback	✓	Selection/reduction of items	✓
Clear definition of consensus	✓	Review/approval of (final) framework		Presentation of final document for approval	
Pilot test of instruments	✓	Not reported/not entirely clear		Not reported/not entirely clear	
Transparent reporting of results	✓	Numbers of rounds	3		
Data analysis clearly justified and reported	✓	**Selection criteria expert panel**			
Information of rounds	✓	Member of organisation			
Discussion of limitations	✓	Recognised authority	✓		
Adequacy of conclusions	✓	Relevant clinical academic expertise	✓		
Definition of consensus		Geographical scope	✓		
Round 2: ≥70% of experts either agree or disagree		Setting/work field			
Round 3: ≥75% of experts either agree or disagree		Profession/stakeholder			

Appendix B – Netnography study

#1 A sample of members’ consent for direct quotes



[redacted]

I am a last year PhD student in psychology at the University of Auckland, New Zealand. As part of my doctoral project, I am investigating the public view on the matter of assisted dying for individuals with dementia. I observed the Facebook communities advocating the practice of assisted dying and analysed the members’ comments that were related to dementia and an assisted death. As these online communities are in public domain, legally I was not required to ask for permission to either observe the communities or use the information/views that shared within the members. However, on ethical grounds, I would like to ask for your consent to use the comment you made on [redacted] in “[redacted]” page in the journal publication. I can assure you that your personal identity and the name of the Facebook page will strictly remain confidential and your quote will NOT be trackable back to you in anyway. Your comment would contribute a lot to my argument in the publication and I would really appreciate to use it.
Here is your comment: “Please, I have had to watch too many beloved people starve to death, their last week, before they died. My mother with Alzheimer’s dementia had to live like a vegetable for 5 years and at 50 lbs had to starve till her organs all shut down”.
Do I have you consent to publish this quote? I totally understand if you wish not to.

Please feel free to ask me any question you may have.
Regards,
Aida Dehkhoda

[redacted]

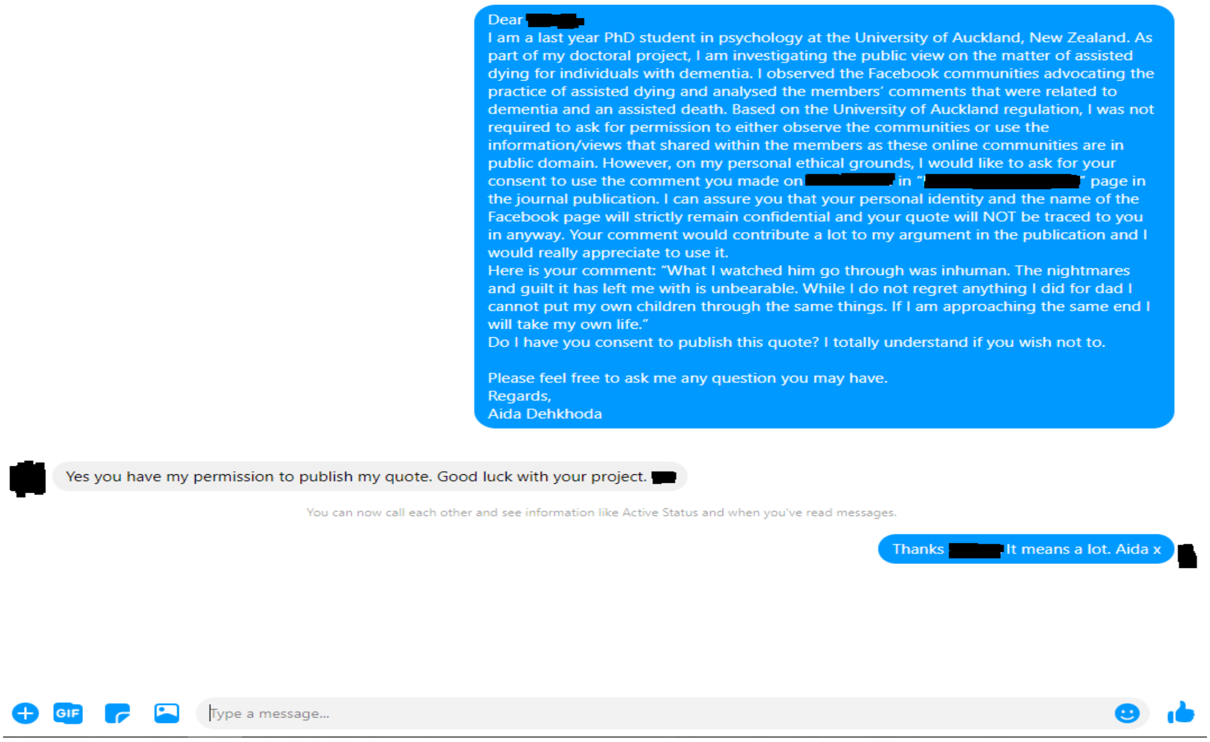
Aida, Yes you have my permission to quote my story. I just watched my Aunt go through the same agonizing death this past December. She had lewy dementia and it took her having a stroke and 2 weeks in the hospital with stage 4 kidney failure to pass. It was horrendous. She begged me not to let her die this way. Especially after she saw her sisters suffering. Death with Dignity is an absolute must for a human beings last wish. [redacted]

You can now call each other and see information like Active Status and when you've read messages.

Am so sorry to hear this [redacted]. It’s truly inhuman to make people suffer this much and make the family to watch it. May the Rest In Peace.
I truly thank you for your permission and hope that my studies pave the way to change the situation.
Thanks,
Aida

[redacted]

Aids, I wish you well with your studies and truely hope this is paving the way people can die in peace. Thank you, [redacted]



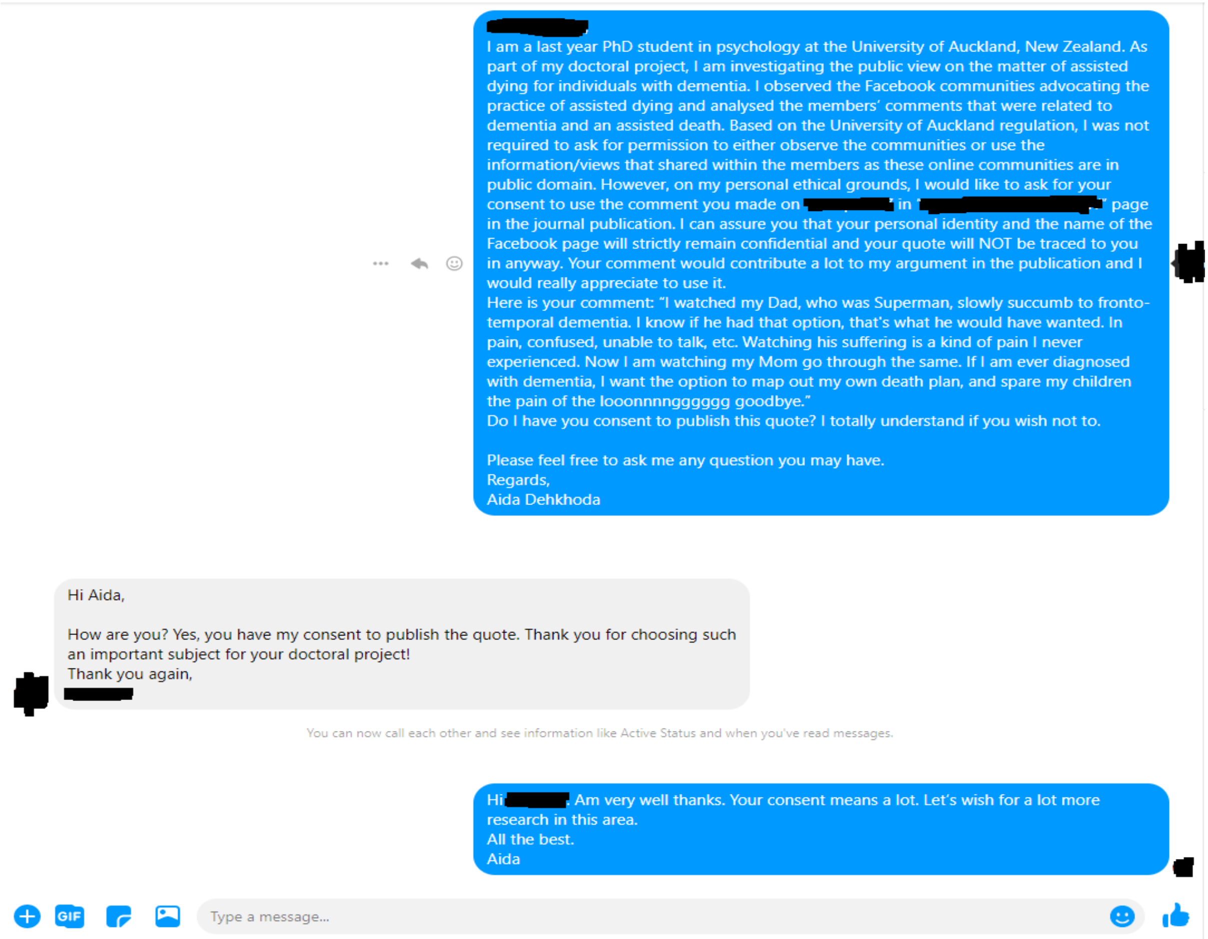
Dear [redacted]
I am a last year PhD student in psychology at the University of Auckland, New Zealand. As part of my doctoral project, I am investigating the public view on the matter of assisted dying for individuals with dementia. I observed the Facebook communities advocating the practice of assisted dying and analysed the members' comments that were related to dementia and an assisted death. Based on the University of Auckland regulation, I was not required to ask for permission to either observe the communities or use the information/views that shared within the members as these online communities are in public domain. However, on my personal ethical grounds, I would like to ask for your consent to use the comment you made on [redacted] in “[redacted]” page in the journal publication. I can assure you that your personal identity and the name of the Facebook page will strictly remain confidential and your quote will NOT be traced to you in anyway. Your comment would contribute a lot to my argument in the publication and I would really appreciate to use it.
Here is your comment: “What I watched him go through was inhuman. The nightmares and guilt it has left me with is unbearable. While I do not regret anything I did for dad I cannot put my own children through the same things. If I am approaching the same end I will take my own life.”
Do I have you consent to publish this quote? I totally understand if you wish not to.

Please feel free to ask me any question you may have.
Regards,
Aida Dehkhoda

[redacted] Yes you have my permission to publish my quote. Good luck with your project. [redacted]

You can now call each other and see information like Active Status and when you've read messages.

Thanks [redacted] It means a lot. Aida x [redacted]



[redacted]
I am a last year PhD student in psychology at the University of Auckland, New Zealand. As part of my doctoral project, I am investigating the public view on the matter of assisted dying for individuals with dementia. I observed the Facebook communities advocating the practice of assisted dying and analysed the members' comments that were related to dementia and an assisted death. Based on the University of Auckland regulation, I was not required to ask for permission to either observe the communities or use the information/views that shared within the members as these online communities are in public domain. However, on my personal ethical grounds, I would like to ask for your consent to use the comment you made on [redacted] in “[redacted]” page in the journal publication. I can assure you that your personal identity and the name of the Facebook page will strictly remain confidential and your quote will NOT be traced to you in anyway. Your comment would contribute a lot to my argument in the publication and I would really appreciate to use it.
Here is your comment: “I watched my Dad, who was Superman, slowly succumb to fronto-temporal dementia. I know if he had that option, that's what he would have wanted. In pain, confused, unable to talk, etc. Watching his suffering is a kind of pain I never experienced. Now I am watching my Mom go through the same. If I am ever diagnosed with dementia, I want the option to map out my own death plan, and spare my children the pain of the looonnnngggggg goodbye.”
Do I have you consent to publish this quote? I totally understand if you wish not to.

Please feel free to ask me any question you may have.
Regards,
Aida Dehkhoda

[redacted]

Hi Aida,

How are you? Yes, you have my consent to publish the quote. Thank you for choosing such an important subject for your doctoral project!
Thank you again,
[redacted]

[redacted]

You can now call each other and see information like Active Status and when you've read messages.

Hi [redacted]. Am very well thanks. Your consent means a lot. Let's wish for a lot more research in this area.
All the best.
Aida

[redacted]

#2 A sample of initial qualitative codes of online members' comments

Name	Coded Text
Advance Directives - Living wills	The other is a dementia illness. These times with scans now that can detect early signs within the brain that then begins a journey into "Dementia" a neurological cell death journey. However first diagnosed, brain capacity is working on a level that a DR can view and accept your able to make decisions about this need of future choice, This is when a legal "end of life choice is made before the time arrives that dementia has destroyed brain cells for then not to capable of decision making. Dementia's can take many years to overtake the victim. so dementia's people when first diagnosed can and should have the choice of free will to end their lives once they are bed ridden and have to enter into the wretched nursing dementia wards "secured" environments. Imprisoned until they die. MY two real frustrations, and it is all lack of true facts and knowledge. I have a terminal neurodegenerative disease, which will take me into dementia. I desperately would not "ever" want to be in one of those secured dementia wards. I wrote my legal document 5 yrs ago, My brain capacity accepted by my Dr to make this type of decision. More knowledge is needed re" dementias. That a diagnosis is only the beginning of its wrath not the ending of it.
Advance Directives - Living wills	Thank you for this simple, honest, open account of life in LTC for these precious souls. I too worked several years with people with dementia in LTC and absolutely share your story. My own mom succumbed to dementia after 11 years at home (my dad was her tireless caregiver) before her final 15 months in LTC. She would have wished she'd had the chance to give her advance directives...and dying with dignity at the time of her choosing would have been her wish.
Advance Directives - Living wills	2 years ago I took my old cat to the vet to be put to sleep. My mother in law had just died and my father in laws dementia had rapidly deteriorated. I was with my husband and apologised for crying over the cat when his mum had died. He said I wish we could do this for my dad this disease is cruel. 2 years later his dads is still alive. Lost all ability to recognise his family he has moved nursing homes three times is a frail old man who has to have everything done for him. If he knew he would hate it. I think everyone should be counselled on this before they get to a stage where they just exist. Let them make an informed choice of when and how they want to go.
Advance Directives - Living wills	A heartbreaking tragedy sparks debate in Quebec over allowing patients with dementia to make advance requests for assisted dying.
Advance Directives - Living wills	Absolutely. My mother has an advanced written request. Now she has severe dementia and is spending five hours a day crying, calling out senselessly, shaking with fear and anxiety and we have no choice but to let this go on possibly for years. I am prepared to arrange my own demise if it appears nobody can carry out my final wishes!
Advance Directives - Living wills	Advanced directives should be part of the law. Period.
Advance Directives - Living wills	Advanced request must be included in our doctor assisted end of life practice, law. To disallow this is unconstitutional. Why should someone be deprived of this assistance because they are not capable of speaking for themselves? This means that the only course for them to take is early suicide, depriving them of precious time with their family.
Advance Directives - Living wills	All these people who oppose are not in the position to judge because when you're in that much pain or your terminal and know it's going to be torture why would you want a loved one or yourself to suffer like that just because you think it's morally wrong. Who made you the morality police? Yes high medical bills you can't pay you can't get the treatment are you to suffer because you don't have that money. Family take advantage not if the decision is down to the person whose life is affected. Watch a parent die of cancer or dementia and see them starve themselves to death it takes days and days. That is morally wrong watching them suffer when there is no hope.
Advance Directives - Living wills	Although I totally believe in assisted dying and am in fact a member of FATE (Friends at the End) when I joined this organisation over fifteen years my husband and I had a long discussion about it. He made it clear that he would never ever help me to die and that under no circumstances

	was I to help him to die. My husband is in the advanced stages of dementia and has not recognised me for a few years. Even if I could help him to die I could never do it because I know what his wishes were. This is why everyone should have a Living Will / Advanced Directive.
Advance Directives - Living wills	And I also think you should be able to leave a letter signed by a Dr or solicitor if you think you have start of dementia so they can end your life I don't want to lose my dignity and my family know that I'm 73 and in good health now but you don't know what tomorrow will bring
Advance Directives - Living wills	How can we make it happen? No one wants to go through this Hell before they die. A merciful release should be offered to those who request it. And people should be able to request it before dementia sets in and before they are too confused. I have written an Advanced Directive stating that if I no longer recognise the ones I love I do not wish to be fed, just water until the end. I would prefer a lethal injection. We should be able to demand one.
Advance Directives - Living wills	How incredibly sad! This Lady's wishes have not been honoured! While everyone struggles to make a point this Lady suffers- this is abuse on all sides of the fence. Absolutely unforgivable!!
Advance Directives - Living wills	I believe they should have the right to choose when they die and those that those who help them should not be blamed before the person is unable should be allowed to make a legal declaration first
Advance Directives - Living wills	I 100% agree with allowing assisted death for those with dementia if they have advanced directives. I do! I also want whoever I give the right to decide my medical care to have this option. If I trust them enough to give them that power in case of accident they should know me well enough to know what I want in case of a life robbing illness.
Advance Directives - Living wills	I agree we should be able to decide BUT we also need to be sure not one of us is pushed into that decision by someone who is tired of caring for us or who will inherit a lot if we are out of the way. We need to be sure it's not just depression affecting our thought process....depression can and should be treated. So we need the process for protection but our decision should be respected. I do fail to see what's undignified about going through the process.
Advance Directives - Living wills	I agree with end of life choice but dementia is the most difficult one as to know what point is right to end that life
Advance Directives - Living wills	I cannot believe that the people that make up the law saying we cannot have assisted dying in this country. They obviously haven’t had a close member of their family with Alzheimer's or Vascular dementia, they would soon change their minds, no one should go through this, I feel if we're of sound mind to write a will. Then we should be able to add it that is our wishes
Advance Directives - Living wills	I have dementia, before I get really bad, I think I should be able to make that decision.
Advance Directives - Living wills	I have looked after so many people with no quality of life waiting for their bodies to give up; often in pain and in distress. There is no way I want that for anyone I care for, or indeed myself. I have lodged an Advance directive with my GP which at least means I will not be given life extending treatment (analgesia is permitted) in the event of getting dementia and being unable to live independently.
Advance Directives - Living wills	I have nursed people with dementia you lose all dignity I think we should be able to make a will or statement to our family and doctor about our wishes I have seen some terrible cases ,it was heart breaking
Advance Directives - Living wills	I quite agree with this, I think everyone should have a say in what happens to them. No one wants to suffer at the end of their lives, Everyone should be allowed to write down what they wish for should they have no quality of life i.e. dementia, MS, cancer etc.
Advance Directives - Living wills	I think this option should be available to us all. As many of us get dementia and age related problems later in life should all able minded people not be given the choice in our forties? We could make a living will which could be registered with our doctors while we are still in sound mind.

Name	Coded Text
Alzheimer's	"I don’t want to suffer with Alzheimer’s and be reduced to a completely helpless bag of bones, wishing she were anywhere but where she is."
Alzheimer's	I don't understand why access to MAID is denied to people who draw up an Advance Care Directive regarding Alzheimer's. Truthfully at 72, it is my greatest fear and I don't wish to live when I've lost my memory and can only look forward to sitting in wet diapers in […] with no quality of life. But of course that would affect the nursing home profits.
Alzheimer's	I have a good chance of getting Alzheimer's I have no children or partner would sign right now would much rather be dead than scared and neglected I truly hope I can.
Alzheimer's	I have Alzheimer's and I already have a DNR notice. I'm also writing an advanced directive stating that I don't want to go into care and outline what treatments I don't/do want. I'm doing this in conjunction with my next of kin and my GP will be signing it. It will be a legally binding document , of course this does not include assisted dyeing and the reason we need a wider criteria ✌
Alzheimer's	I think it all depends on the individual and what stage they're in. If they're having difficulty eating or swelling or if in pain due to a physical condition, then yes I'd consider it. However, even a patient in the last stages of Alzheimers may still be able to eat, drink and walk. Although extremely confused and maybe periodically aggressive, if they're able to try to sing and still laugh (for example) then they should have the right to live. I consider late stages of Alzheimers like a 12 month old baby. Although we have to literally do everything for these babies and they can exhaust us, we love them and continue to care for them because to me in the end, seeing them smile makes it all worth it.
Alzheimer's	I totally agree. My aunt basically starved to death because her right to choose was taken away due to her Alzheimers. And then the Supreme Court said if the family took her home they would be charged. You can follow that in the news. Check out […].
Alzheimer's	I watched my dad basically starve to death with metastatic lung cancer that went to his brain. Now my mom is in a nursing home with Alzheimer's, she has been in the nursing home for 3 years, will be 78 in December, has no idea who anyone is, and has NO quality of life! My chocolate lab had osteosarcoma and I was able to humanely euthanize him once he was in too much pain. What the hell is wrong with us?!?!?
Alzheimer's	I watched my gorgeous mam suffer as a result of Alzheimer's had she known what was coming she would of been devastated at how bad it got I am adamant I am not going to go through what she did and I am not going to let my children see me suffer hopefully this becomes legal in our country to allow everyone the choice of dying with dignity I'm still heart broken and still can't get the images of my gorgeous mam suffering out of my head x
Alzheimer's	I work at a long-term care facility and this is why I support advance consent for assisted dying.
Alzheimer's	If you or hubby have any control over what happens to you before this awful disease takes him over then do it, please do not hesitate for long. Mum Alzheimer’s was so so rapid. We never had time to even have those conversations.
Alzheimer's	I'm a Christian. OK, that's the three words. But many will say because I'm a Christian I should NOT support it. It's God's privilege to take back his gift. Er....but a loving father would not want his child to suffer, would he? After all, Christ died the most awful death - so terrible that the means of it was never spoken about in polite Roman society. When he was actually crucified, he died within hours. People are being crucified on a bed of pain not just for hours, or days, but weeks, months and years. I am a Christian who watched her mother died from Emphysema, her stepmother from breast and bone cancer, and her father with Alzheimer's disease, who was lucid enough to refuse food, drink and medication in his last hours. I don't want my family to go through that torment with me should I be diagnosed with any of those diseases. And I want to die at home, in my bed, at peace, not in some overcrowded hospital, waiting for someone to notice that I have died.
Alzheimer's	It's a kindness we can show our pets but not our loved ones.

	My mother died of Alzheimer after 9 long years of suffering. She would have been horrified to see what she became. I was horrified with what she went through, broke my heart. Why should so many people suffer because someone might take advantage? Those who would take advantage probably already are in one way or another.
Alzheimer's	I've seen two aunts, one on each side of the family, languish for years with Alzheimer's before they died. I only can hope that if it happens to me, there is an assisted death protocol in place for such situations.
Alzheimer's	Late stage Alzheimers shuts down the part of the brain that instructs digestive processes. These poor souls can often eat like horses but they still lose weight.
Alzheimer's	Mum had Alzheimers and was in a home for 8 yrs she couldn't do anything herself she would not have wanted this. She got an infection and a couple of days later they said they would Fast track her death it too 2 weeks it was terribly cruel. If you did this to a pet you would end up. In prison, this horror should be stopped.
Alzheimer's	My dad had Alzheimer's for ten years. Even at the beginning he didn't want to be here but it was too late. We just managed to get a power of attorney signed so that we could have a say in what happened to him. A horrible ten years for him and devastating for our family. I wish you and your husband didn't have to go through this.
Alzheimer's	My mom passed away 2 years ago after suffering from Alzheimer's disease for more than 15 years. Even though she had a signed card for euthanasia, they would not do that for her. She did not understand why they would not end her suffering (her words). Even though we lost her physically in 2014 she was gone long before that. It takes a while to remember her the way she used to be and I miss that person every day!
Alzheimer's	My mother has Alzheimer's and lives with me, my husband and our daughter. Seeing my mum slowly degenerate is utterly heart breaking, I know the time will come soon when she doesn't even recognise me. She/we should have a right to say when then time has come, enough is enough. When quality of life has totally gone and she is just a body, but no comprehension of life itself then why make her live when she/ our family should have a choice whether she to lives or dies? When I told mum her diagnosis she said, right I'll kill myself. She hasn't because of her family. It is so bloody unfair and undignified to wait for death when you have such a degenerative illness. It should be decided on an individual/medical basis. Sorry, rant over.
Alzheimer's	My mother is 68 and has Alzheimer's. She was diagnosed several years ago. She doesn't want this life. Living in a facility. In a lucid moment, she said - if I had known, I would have killed myself in 7th grade. Yet, here she is- stuck and unable to speak her own wishes and has no options on a death with dignity.
Alzheimer's	My mum in law had Alzheimer's and she decided in her lucid moments that she didn't want to be a burden and didn't want to put us through the pain of watching her decline so she committed suicide which to a church going lady must have been such a brave painful decision to take.
Alzheimer's	My story is so close to yours it's scary. I would not wish Alzheimer's on my worst enemy. My mother weighed 74 lbs when she died because her mind forgot how to eat. We had no dying with dignity laws and we really still don't here in Ontario even if we have living wills in place. I am terrified that I will suffer the same way. I have left instructions to everyone I know to pull the plug but I have no children who will comply.
Alzheimer's	The minute I develop Alzheimer's I am booking my flight to Switzerland. I'm not taking any chances. What a bloody disgrace to allow this. My heart goes out to the family who are already going through hell and have been for six years. I'm so sorry you have to go through this. DWD I would really like to know what we have to do with our POAs to make sure this doesn't happen. Please help us.
Alzheimer's	TV shows, movies and the media try to make Alzheimers look like it's nothing but charming forgetfulness. The medical industry only looks at physical health and wants to keep bodies alive to make their numbers look good. Certain religions think suffering is beautiful and enjoy watching it happen. As a result only sane people who actually have to deal with the late stages know what it really means.

Name	Coded Text
Assisted dying law - requirements & importance	I believe that anyone who doesn't wish to live a diminished life (decrepit old age/ dementia) should be allowed to leave it at any time they wish, with their family around them. It should not just be for people dying & in pain!
Assisted dying law - requirements & importance	I totally agree with the decision. I want the choice to leave orders for when to check me out if I develop dementia too
Assisted dying law - requirements & importance	Agree fully, but would add to your comment "should they wish." We need the legal choice and those who disagree may assume we want all terminal folk be supported to die.
Assisted dying law - requirements & importance	Alzheimers and dementia patients aren't classed as terminal so a living get will make little difference.
Assisted dying law - requirements & importance	Anyone who has ever sat with a loved one of any age and watched them die would know what a must this is. Be it someone with a terminal illness, someone in terrible pain or in my case sitting with my beautiful mother for over a year, losing her first to dementia, watching her suffer terribly sometimes, and finally losing her all over again until we meet in the next life. Everyone deserves this respect and dignity. The only consolation is In a lot of circumstances Doctors are able to speed people on their way at the end of their journey, but of course they do so at great risk to themselves and in the case of people in pain or with terrible illness they shouldn't have to suffer until their last breath before they can be helped.
Assisted dying law - requirements & importance	As health care assistant working with dementia care, palliative care and end of life's, my dear friend you have my support 100%, I signed and shared from the first post a read about you, if there's more than share and sign we could do please just say, if the high court needs hear from people like me please contact me I would be grateful to help with change the low! Lots of courage and lots of love to you and your family and loved ones
Assisted dying law - requirements & importance	Assisted dying bills usually only consider the physically ill whose disease is terminal What about mental illness, and what about dementia? do we end up in the situation of making when well an advance declaration covering at what point, though we may be mentally incapable at that point, we want to die? Just a thought for when we get our assisted dying bill here
Assisted dying law - requirements & importance	But please include patients with dementia. Their medical position can be monitored by two doctors and the patients can elect early enough to elect when they can choose to go
Assisted dying law - requirements & importance	A natural death does not include all kinds of measures to extend life in those who have absolutely no quality. And Canada's MAID laws do not currently include dementia despite living wills or wishes expressed while if firm mind.
Assisted dying law - requirements & importance	Congratulations for getting this far. The other States must follow suit. Consideration must also be given to very advanced terminal dementia patients, experiencing severe pain, which is difficult to manage, and no quality of life. Otherwise it is a cruel and undignified way to end what was an amazing life. It is inhumane and there should be no need for anyone to suffer. It is just prolonging the inevitable.
Assisted dying law - requirements & importance	Dying With Dignity Canada called on the province to show "a clear commitment to respecting the end-of-life rights of Quebecers with dementia.”
Assisted dying law - requirements & importance	Dying with Dignity NSW Within 12 months, really? It’s a start I guess, but what about people facing death by Dementia....that can be years and years of extreme suffering
Assisted dying law - requirements & importance	Dying with dignity should include Alzheimer and Dementia patients. I've been watching my dad die for almost 10 years. He lost his dignity years ago and would be modified if he knew how his life has turned out. It's miserable to watch him suffer. Besides all of that, my mother is losing everything she has just to keep him in a nursing home because they don't qualify for any state benefits leaving us with no money to take care of her. Unreal.
Assisted dying law - requirements & importance	Everyone has the right to die with dignity without pain and the prolonged dying within palliative care. Everyone should have that choice with the end of life with a terminal disease. And this should include advanced dementia.

Assisted dying law - requirements & importance	Everyone should have the right to die with dignity I watched my mum destroyed by cancer it broke my heart & I’ve lost aunties who have suffered dementia they suffered for years so I think that assisted dying should be made legal it is in other countries y not here
Assisted dying law - requirements & importance	Extreme physical pain, with no hope for improvement, warrants dignity in dying. What about mental pain, including, but not limited to Alzheimer's , dementia, etc.
Assisted dying law - requirements & importance	HERE IN THE USA...... we should decide how we want to end our lives we should have dignity in dying....what is the purpose of letting someone suffer ...for weeks or months. Or even days........this should be my choice...no one else's.......we need Switzerland’s. Plan it covers all long term illnesses...not only ...having 6 months to live...some of these illnesses like dementia....Parkinson’s is very cruel and the list goes on...why should we be housed in assisted living or nursing homes...why....is it for money???? The end is going to be the same...not fair ......animals have it better than we humans do...
Assisted dying law - requirements & importance	Patients with dementia would not be eligible under the law. Assisted dying would only be accessible for terminally ill, mentally competent adults in the last six months of their lives. Also, assisted dying is not something you can request in advance. Further, no one has to take the medication, even if they have been granted access to it. For example, in Oregon, 39% of people who have access to life-ending drugs choose not to take them. This shows that the law brings them comfort and reassurance and that they don't feel pressured to end their lives. I hope this helps.
Assisted dying law - requirements & importance	Under the law, people with dementia would not be eligible for an assisted death, as the person must have full mental capacity. However, you can make an Advance Decision now, which means that you can refuse treatment ahead of a time when you might lose capacity.
Assisted dying law - requirements & importance	How does assisted dying work for Dementia patients who have made their wishes clear whilst of sound mind but when the time comes, are incapable of making a decision? Thousands of Dementia patients in the latter stages of the disease are left lying in sedated limbo despite stating (in writing) that they do not want their lives prolonged if there is no quality left. They have no voice, no life. How can they be helped?
Assisted dying law - requirements & importance	How dreadfully shocking. I am so sorry for your loved ones enforced suffering. We really do need a more compassionate way to allow such horrors to stop now, for those who want a more dignified end. The problem for me is that how would the proposed law help those who have been ill for a long time and are no longer capable of expressing their desire to die? My father in the UK had Parkinson’s Disease. We have come to realise that he had been masking his own failing health for at least a couple of years while looking after mum (with lots of family help) who had Alzheimers and heart disease. When she died in 2010 he really did fall to pieces and if he could have got in the coffin with her, I believe he would have. He died last year 6 years after mum and although he did enjoy moments of happiness and joy in reality his world had gone and for the final 18 months or more could do nothing for himself and his ability to communicate diminished hugely in his own dementia.
Assisted dying law - requirements & importance	I agree that it shouldn't be just about the terminally ill with 6 months left. The long term physically incapacitated also need to be able to choose for themselves. But mental incapacity is more difficult. I might as a healthy person think that "x" (lack of mobility, dementia) would make my life not worth living. But I might change my mind when I actually had "x" and find that, surprisingly, I still had enough quality of life to prefer it to dying, limited though that quality might be. Still my choice. Set it up in advance, by all means, but unless you are in a vegetative state, it's your choice on the day that counts. "It's just that life is a habit that's hard to break...” […]. And we should continue to have a choice as long as we are mentally capable of making it.
Assisted dying law - requirements & importance	I agree with you wholeheartedly. For those who don’t choose this, and before dementia causes the person to lose all dignity, there is so much more that can be done. I’ve seen how well dementia patients respond to music, singing and special attentions from staff who have been well trained.

Name	Coded Text
Carers' experience & opinion - families & nurses	Every family and person will have tragedy in their life. My sister died when a drunk driver hit her car at the age of 21. I'm caring for my mom with severe dementia. I trust God for all answers for all suffering. And when I do, he brings me great relief. When he stands with you, nothing can stand against you. Take a chance and open up the Bible. It might change your whole life. It did mine.
Carers' experience & opinion - families & nurses	Good Luck, we are going through the ~EOL motions with my FIL, He has Vascular Dementia and has had a massive stroke and just lying there waiting for his turn to come. It's so distressing, from and lovely caring man to a very sick poorly withering man. No way to go. Dignity in Dying has succeed 100%.
Carers' experience & opinion - families & nurses	Having spent 14 years working as a carer within the community and then a senior carer in a disability nursing home I have seen IMHO a lot of unnecessary pain and suffering not only for the person that had the long drawn out illness but for their families too. I am now watching my father go through terminal throat cancer and I'm the main carer for my mil who has mixed dementia. It is going to be a bad end for both unfortunately but I will do my very best to make sure they do not suffer. We treat our animals better than we do our humans when it comes to knowing when the time is right.
Carers' experience & opinion - families & nurses	Having worked in care for 14 years and seen lots of IMHO unnecessary stress and suffering from people and now Benin full time carer for my mil who has mixed dementia and is disappearing daily it is soul destroying to know how bad she will get. We put our fur babies to sleep to avoid unnecessary pain and suffering, how come we can be more loving and compassionate towards them but not our fellow human beings. I have now also got to watch my dad suffer from terminal throat cancer. I know if I get any illness I will decide when enough is enough not anyone else.
Carers' experience & opinion - families & nurses	I don't want any one changing my ass my mum was the proudest person I know when she had dementia. I felt that we had let her down so badly the way she had to end her life she had. Overcome so much mental trauma from the ww11 and she had to end her life the way she did, she didn't ask any one for anything she over cone a great deal to live a normal life and to bring up two strong daughters and a strong grandson and granddaughter she was the most amazing woman in my life she gave me and my sister our strengths there's not a minute in the day that I pray we done the most for our mum, and if I can be half the mum or grandmother she was I could rest hopefully. Easy love you mum you didn't deserve the way your life ended, the cruel unjustified and the just doesn't make Sense the illness dementia
Carers' experience & opinion - families & nurses	I had same ordeal with my mum but a different hospital so I understand what you're going through so very heartbreaking that nobody seems to care
Carers' experience & opinion - families & nurses	I have lost people I love to both cancer and dementia. There was no hope in the cases and we were forced to watch them in pain, or unable to remember their children or spouses.
Carers' experience & opinion - families & nurses	I have volunteered with dementia patient as a friend/assistant for 18 years and can attest to their quality of life. If I could change it I would do that in a min. But with the way things are they have to just go on in their terror of what is happening to them. IT IS TIME TO CHANGE THE LAW. We must make that happen for them, and those of us that may face a similar fate. Please dare.
Carers' experience & opinion - families & nurses	I know how you feel It's the worst thing to have a loved one being there in Body but not in mind. I remember going to see Auntie Eve on the Nursing Home and her screaming get this woman out of my room I don't know her. I left and cried my eyes out When I went after that I always went with Les
Carers' experience & opinion - families & nurses	I pray that Massachusetts & New York pass the Death with Dignity law. Watching my mother slowly painfully decline from an early onset Frontotemporal Dementia & Primary Progressive Aphasia, as well as her caregivers- my brother & myself, is the torturous destruction of multiple lives.

Carers' experience & opinion - families & nurses	I really feel for you […] it is a dreadful dilemma I had a friend who died with MND & know another who has it. I lost my Dad aged 92 in January not from that but he did have dementia I have made my friend promise if I get it she will take me to Switzerland Sending you every best wish x
Carers' experience & opinion - families & nurses	I see people die at work a lot, working in dementia geriatric care isn't just wiping bottoms as a lot of one eyed public see it. We are the eyes ears and mouths of those who are old, frail and coming to the end of their lives. The pain and suffering people for through is simply inhumane. We do not treat animals that way so who should we treat our peers in such a barbaric manor
Carers' experience & opinion - families & nurses	I was in this position but for someone with dementia and not in constant terrible pain or with something like motor neurone disease so I couldn't. I don't think any of us can say for definite until we are actually face to face with the decision for an individual we love... and I can't say the decision would be the same every time.
Carers' experience & opinion - families & nurses	I watched my awesome dad go down with dementia it was very cruel and sad I know it's wrong but say yes do not let them suffer it's not fair and its cruel to see the person that you love go through bloody hell it should be the law to die
Carers' experience & opinion - families & nurses	I watched my Mamma die from cancer and my Daddy from dementia. No one should be forced to suffer the way they did. Cruel is an understatement. But more than that it's the memories and guilt that burden the loved ones left behind. I would hate for my daughters to have to bear the grief of watching me die slowly, the torture of wondering if there was more they could have done or guilt of not having ended my suffering sooner. So my three words would be: REMEMBER ME BEAUTIFUL!
Carers' experience & opinion - families & nurses	I watched my mum suffer with Parkinson's for 11 years the last two years she had dementia and finally last year was diagnosed and died within 5 weeks with cervical cancer she was my mum, my best friend, my enemy, my shoulder to cry on and my cheerleader I watched her for those five weeks and felt so helpless as there was nothing I could do for her but make her comfortable the answer to the question YES I would go to prison because I loved her enough to say goodbye and that she would be at peace only people who have stand/stood in my shoes can honestly comprehend the pain of watching someone slowly slipping away my blessing was that she was never in pain. The government need to do the right thing and change the law.
Carers' experience & opinion - families & nurses	I work on a 30 bed dementia unit n trust me! If these people had an insight to how this cruel disease ends their life! Trust me! They would be mortified and wouldn't want to die this way.
Carers' experience & opinion - families & nurses	I've looked after a dying man whose face couldn't be recognised due to cancer, lost his nose, one ear and eyes. A woman who had end stage dementia and died starved, skin and bones. Also a man who had metastatic cancer and was wailing in pain up to the last few hours of his death. All of them died in suffering. All that they had left was the ability to breathe. There was no other indicator of life let alone dignity. I'm just busy at the moment but I won't let the first week of November end without me handwriting our local MP- to tell him or her of the countless stories I have of people dying an awful and painful death because they didn't have a choice.
Carers' experience & opinion - families & nurses	I'm an RVN and people say to me 'I don't know how you can do your job' because of euthanasia. In reality it's one of the kindest and the bravest things you can do for a beloved pet (hell, I don't even refer to my dogs as pets as they're family) that is suffering. Yes, it's sad, and I know the day when it's my turn I will be a wreck, but I will be thankful that my dogs don't have to be in pain or have a poor quality of life. Previous to my career as an RVN I was a carer for those with dementia, and you are literally nursing them to death. To lose all cognitive and physical ability and dignity because of such a progressive condition, it's damn right unfair to know it's going to happen and you have to just accept that. I wouldn't want that for me or anyone.

Name	Coded Text
Competency	....such a brave lady but an even braver spouse. To be able to give that 100% solid support right thru to the end of her life, knowing it would be his greatest most significant loss ever and his only to bear. I fully support any legislation that brings about greater dignity in dying. It is so very hard to watch people sink into indignity and to be living a life they would not have wanted to live themselves. Thank goodness she stayed of sound mind and able to convey her own thoughts clearly and without hesitating. For those with dementia it is a different story and one I hope is addressed before my time comes!
Competency	Alzheimer's and dementia would be a difficult one to use end of life services. An argument could be made that they weren't of sound mind when they made the decision. So then people could say let the family make the decision and there lies the start of complicated issues. There would have to be a ton of legislation and constant amendments upon hitting unforeseen issues. I am avid supporter of dying with dignity. I do hope that one day we give people the same respect we give our pets.
Competency	And non compus mentus too... with an advance directive signed of course... dying from end stage dementia is pitiful and pointless...
Competency	At the moment it's not allowed to leave directions. You must be of sound mind and able to verify that you still want to go. Leaving directions, they say, does not allow for changing your mind. I'd like dementia to come into play.
Competency	Certainly in my case you would be understood, certainly not demonised but I have an awful feeling if you're not considered of 'sound mind' I don't think you have a chance of an assisted death. Is your husband still of sound mind? Worth phoning Dignitas and asking them for information on this. Best wishes and good luck
Competency	End stage Dementia is particularly cruel and torturously slow. I'm so sorry for you Tracey. Of course this proposed change to the law wouldn't be of benefit to him due to "capacity" to make informed consent.
Competency	Every adult person reserves the capacity to suicide at any time, using any method they so choose right throughout their lives ... and NOBODY can stop them. Why does this change when incapacitated ... and who says it has to??? It really is just as simple as that.
Competency	I feel sorry that there are restrictions for those who have lost the capacity to take the medication themselves. My mum lived long enough to endure her worst nightmare and I would hate to outlive my useful capacity.
Competency	I totally agree that the person suffering pain and loss of dignity should be the one to make the decision to end it when they can't take any more, but they must be in a fit state mentally to be able to make that decision. Those suffering dementia and similar and are not able to make that conscious decision cannot be believed. Then it should be decided by the Doctor responsible for that patient and the immediate family members in a consultation. Then and only then should the patient be allowed to die with dignity
Competency	I would think that if you combine it with an ACP (Advance Care Plan) and an Advance Directive - both of which can be done before a degenerative state then you will have that base covered.
Competency	It's shameful that we are so backward about this issue! Even several American states allow it! The person involved has to be completely compus mentus, otherwise it can't go ahead, so there is no room for devious deeds!
Competency	My dear husband died earlier this year of young onset Alzheimer's, he drowned in his own secretions, it was an awful death. From the day we met, over 40 years ago, he always said that he wanted to be injected if he ever became unable to make informed decisions. The problem with dementia is that you don't know when capacity ends. Please change the law. My last memories of him are harrowing, he was the best and did not deserve to die the way he did.
Competency	My mother died of early onset dementia, the last 2/3 years of her life was pointless. I never want to put my children through it. An injection to end your life if you have made the decision whilst in a sound mind would be much more acceptable for the family and much cheaper for the country

	and family. Like many say...... We put animals to sleep instead of going through pain.
Competency	People with dementia are ineligible. Mental health reasons. Cannot give informed consent.
Competency	Read the bill which is pretty self-explanatory except for my queries below. If the person has to have competency to understand what ending their life means then what occurs when the person's mental ability has been eroded by their disease? Can I make a decision (if this bill is enacted) in advance that states my wishes in the event of incompetency in the later stages of my illness? Competency to decide in the broader sense is vital but I shudder to think that mental incapacity would prevent me receiving the choice I wish. My son is my medical proxy so what decisions would he be able to make?
Competency	Reps don't have the right to request you be allowed an early exit. The request has to come directly from you and at this moment you cannot request in advance because that does not allow for you to change your mind. You must be of sound mind and able to make that request in person and at the time it is administrated.
Competency	So very sad. Each and every one of us should have the choice on how we want to end our days - if at all possible. It is cruel to enforce someone to continue living if they have neither dignity nor quality of life. If they have made a conscious decision and are fully in control of thought processes, then they should be permitted a dignified release from this World. There are ways and means. It's a difficult, emotive subject but there should be legislation in place to assist those who need assistance in their end of life. I can only imagine the pain the Lady and her family are going through. My mum has suffered from dementia for seven long years, so I can appreciate to extend their feelings. Be brave dear family. My thoughts are with you.
Competency	The trouble with dementia is that you would lose the capacity to decide for yourself
Competency	Those diagnosed in the early stages of Dementia are just as responsible as the rest of us. They should not be denied making the decision for themselves down the line when they will be unable to speak up.
Competency	To watch my dear mum go through the painful journey of Dementia and Alzheimer's was devastating for not only Mum, but the whole family. Such a wicked disease. Perhaps if more people were aware we wouldn't allow people to go through this. We wouldn't allow an animal to suffer. I believe we should be able to state our wishes whilst we still have mental capacity.
Competency	Watched my Mum vanish over 5 years with Dementia. Never want my life prolonged beyond point of losing my mind thanks. That's inhumane. Only preserving pain & helplessness; & big Pharma profits.
Competency	Watching my mother suffer from the torment of dementia is the real world, Paul Burrows. It is because of witnessing her senseless suffering (and the slaughter of innocent people in wars by Christian lead nations) I no longer believe in a God but I do believe that euthanasia should be an option for someone capable of making the choice.
Competency	We choose the way we live our lives, and wherever possible - and while still of sound mind - we should be able to choose the manner and time of our death if we should be gravely ill. Both my parents had dementia and were in nursing homes - where, I might add, they were treated with kindness and dignity. But they were no longer recognisable and my siblings and I were strangers to them.
Competency	We choose the way we live, for better or worse (because we're only human after all)... I believe that while we're still sound in mind and body we should be able to make plans - via a Living Will or similar - to determine the way we die IF we are suffering, whether it be from cancer, dementia, MND or any of the other illnesses that diminish us day by day, week by week and sometimes year after year (as with both my parents who had Alzheimer's).
Competency	Yes it's a decision to be made before the person succumbs to dementia. We all need to make the decision when we are still of sound mind. Euthanasia should definitely be legal.

Name	Coded Text
Dignity in Dying	I saw my grandma not recognise her own daughter, being tormented by her own mind, pissing in a chest of drawers, slowly decaying with no dignity left. She had dementia. No cure. Just slow terrifying deterioration. The worst bits were when she had semi-awareness. We wouldn't force animals to live that way. So why make our loved humans suffer? Dignity! I ask for dignity!
Dignity in Dying	I saw my Mum not recognise her own daughters & grandchildren being tormented by her own mind, slowly decaying and disappearing with no dignity left. She had dementia and Alzheimer's No cure just slow terrifying deterioration an horrible situation and soul destroying disease to watch anyone go through No one should have to go through that why shouldn't they be allowed some dignity if that's the last thing they can choose so so cruel .
Dignity in Dying	I support this cause after sitting with numerous family members waiting to go to sleep for the last time. Dementia runs in my family and seeing two family members die with this disease is terrible, it takes away all of a person's dignity. I for one will be signing up for Dying with Dignity.
Dignity in Dying	I totally agree that people in the U.K. Should be given the chance to die in dignity. My grandad suffered from dementia for 10+years and knowing the proud man that he was he would not have wanted to spend his last years being cared for and losing himself along the way.. very sad xxx
Dignity in Dying	I understand how you feel Jennifer Price I specialise with dementia... hate to say this but with some people near the end stage they forget how to eat and drink. That is sheer torture them and their loved ones to witness as they see their mum /dad... slip away in a painful confused state with no dignity or hope of recovery
Dignity in Dying	I want to choose how I end my life. I may have a quick heart attack like both my parents in which case that's fine. No long drawn out illness. However, I am a diabetic and may develop complications or have terminal cancer or dementia like some of my relatives. I am single with no children and live alone. I do not wish to be a burden to my friends and remaining family or the NHS. Everyone deserves to die with dignity and minimal pain. As someone said, we wouldn't let a beloved animal suffer, why humans. Death is easy, the process of dying is not
Dignity in Dying	I want to go before I lose my dignity, and that means the first time someone else has to wipe my butt. Has to wipe my nose, dry my body after bathing me. I ask you set me free...
Dignity in Dying	I was an RPN on a locked unit for a number of years. I adored my residents, no matter what behaviours were caused by Alzheimer's and related dementias. I worked with irreplaceable PSW"S/HCA's. We cried for all our resident's when they died, in relief that this horror was over for them and because we loved them unconditionally. I absolutely believe that the majority of these souls would have chosen a dignified way out, had it been available to them.
Dignity in Dying	I would like to die with dignity even with dementia. If I don't know who I am or who my love ♡ ones are what life is that. That's my right. Mona
Dignity in Dying	If we treated an animal like this we would rightly be prosecuted. I have so much sympathy for you all. There needs to be a dignified end of life process.
Dignity in Dying	It's a right to die with dignity and not having someone else make that choice for you! Ask anyone whose parent is suffering with Alzheimers or Dementia...it's a slow painful death...for the parent & the caregivers
Dignity in Dying	It's an absolute necessity to allow people to die with dignity. If you are unsure about this issue I suggest you go and watch someone die of this illness and then you will have your answer.
Dignity in Dying	My mum was a psychiatric nurse for over 20 yrs. and she had seen first-hand what these kind of diseases do to people and their families and she always said that if she had one of these diseases she would commit suicide. When she was due to be tested for dementia 3 yrs. ago I asked her to promise not to do anything stupid if she didn't like the result, she was diagnosed with vascular dementia and she kept her promise. This yrs. she died of a major stroke. We were at the hospital day and night for 10 days before she passed, it was only during those days that I fully

	understood her position, she supported assisted dying or dying with dignity and even though she didn't get her wish to die in her own home she still got to die with dignity.
Dignity in Dying	My Mum who has dementia, mentioned Dignitas to me but by that time, she had lost ‘capacity’ ... sad fact is, even though she had dementia, at that time she was lucid.. She wanted dignity in her death, she’s still with us ♡ but sadly, the dignity is being eroded. it’s devastating and heartbreaking that we don’t have a choice... the law has to change
Dignity in Dying	My nan was terrified of getting Alzheimer’s but she did and "lived" with it for ten years in a nursing home, mistaking my dad, her son for her husband, using her bedroom drawers as a toilet and many more degrading things that she would have been horrified about pre dementia before deteriorating to a skeletal figure in a chair, we had to watch our beloved, sparky lady with a wicked sense of humour become a living corpse and it was heartbreaking, living in limbo until eventually her heart stopped beating, we couldn't really grieve as we'd lost her years ago. Absolutely assisted dying with dignity should be an option, my heart goes out to you and everyone who has commented on your post x
Dignity in Dying	Nobody should have to suffer such indignities as your mother has. Basic management of pain should be a patients right
Dignity in Dying	No-one should have to suffer great pain or the loss of dignity in any way, shape or form. I lost a brother to cancer and my mother has dementia, which is demeaning.
Dignity in Dying	Now mum at to go into a home with dementia watching her is terrible. So sad we need to do what we want. We are human for God's sake... DIE WITH DIGNITY... BRING IT IN THE UK...
Dignity in Dying	OMG what a horrible and painful tragedy. Compassion certainly is a word not in their dictionary. Dignity has been stripped away from her and no one knows what her true suffering is. Shame on them
Dignity in Dying	On 2 Sept we were able to perform this in our home in Sussex, to the most beloved member of our family. As she had got to her grand age, she was unable to toilet properly, bouts of dementia were more frequent, her blindness, arthritis and heart murmur were causing more problems for her. Thankfully, the law in the UK does not cover animals, this was our most beloved BB who reached nearly 15 years old. It was the most painful thing we have ever done. Make the decision (have felt like a murderer ever since) even though the attending vet advised she would have only lasted a few more (painful) months. I WHOLLY believe in “Dignity in Dying”, don’t any politician or religious leader suggest we take it lightly. We want it because we love the person and don’t want them to experience a painful end. They want to be remembered in a certain way. I only wish my mother’s end could have been more dignified. Our memory of her last days will never leave us, she had wanted to go weeks and months before, but it was not allowed. That memory is still deeply inset 13 years later. Anyone who has taken the trouble to read this so far, keep supporting the cause!! I may need your support soon
Dignity in Dying	Only those of us who have to care and watch our parent go further and further down and have to feed and change their shitty pants can understand this and realise that maybe it is a good thing they do have dementia as they could never forgive themselves and die of embarrassment
Dignity in Dying	Set the record straight. Dying a death from Dementia/Alzheimer's. I is not dying with dignity.
Dignity in Dying	So very sorry for all of your pain and suffering. Everyone should have the right to die with dignity, pain free and in comfort. End of life care needs to dramatically improve and given the choice I don't believe any of us would want to linger or suffer. We allow him and to suffer yet would be prosecuted if we treated an animal in this way. I hope the care improve quickly for all of you
Dignity in Dying	The people who are against dignity in dying are cruel heartless people with no idea of the pain upset one has to go through to die.
Dignity in Dying	It's an absolute necessity to allow people to die with dignity. If you are unsure about this issue I suggest you go and watch someone die of this illness and then you will have your answer.

Name	Coded Text
Fear of having the same destiny	Anne I to nursed my mum with dementia at home every day for years, my mother two weeks before she died was completely lucid and asked me to not end up like her, it was the second thing my mother had asked of me in my life. The first was not to come home and tell her I was pregnant I easily fulfilled that as I knew I never wanted children, this last request I hope I can fulfil her and myself. Cancer hit me but thank goodness my mother never knew. Heart felt wishes are with you.
Fear of having the same destiny	because of sharing an unbearable dying process with both of my parents and" ahead" a neurological terminal disease which takes me into a vascular type-of dementia. I am still traumatised by my parents dying procedures. AND despair that this could be my barbaric ending. IF "end of life choices" were legalised. I could live out the remaining of my life knowing "ahead" I would be spared such disgrace.
Fear of having the same destiny	Def the screen. Must be the tightening of ligaments. Hell of a shock and still haunts me. Not cancer but dementia. Skeleton. Don't want to go that path myself. Scared.
Fear of having the same destiny	Definitely happy. Exits watch mum and dad suffer when dying now watching my sister with dementia God bless her .She has a way to go yet but what her ending will be. I love her to bits .I'm 78 myself I'm worrying what my ending be I want euthanasia to be legal
Fear of having the same destiny	Dignity in death My mother had dementia end in the end she was a nothing lying in a bed they don't know if they suffer Where is the dignity I don't want to be like that for my family I would rather be dead
Fear of having the same destiny	I am caring for both my parents with dementia and staring my future in the face. I don't want my children to have the same with me. Have already lodged my living will with the GP and hope the law will change by the time I need it.
Fear of having the same destiny	I am so afraid I will have a stroke and end up without any control over my life and death. Or get Dementia and be consigned to the hell of a care home, trapped in a room, staring into space, with a TV I can't get away from blaring out.
Fear of having the same destiny	I am sorry I was unable to join you on the boat. I support Noel. Personally I watched my Dad die from dementia and my Mum die from respiratory failure. She repeatedly asked to be allowed to die rather than keep on having intervention. More recently I watch Roy my brother in law die from cancer. It has taken me a long time to get over their deaths. Now I can say I am not frightened by death but I am frightened by the possibility of dying slowly in prolonged agony, unable to communicate, feed myself, etc. I want to have the option of assisted dying available to me so should I need it.
Fear of having the same destiny	I am terrified of this myself. It is beyond horrible to make someone suffer like that. How can anyone be this inhumane? People should be picking in from of this nursing home...
Fear of having the same destiny	I had a dementia test and passed with 9/10 so pleased about that as dementia is my worse fear of dying I'm 73 and it quite good health apart from arthritis and spinal problem x
Fear of having the same destiny	I have a greater than 50% chance of getting dementia, and it would be soon...I don't want to be living in diapers like a vegetable for 8 years like my mother did. But how to get anyone to end it?
Fear of having the same destiny	I have a rare gene called C9ORF72 discovered in 2011 causing frontotemporal dementia and Motor Neurones Disease at the same time. My dad has had it for 4 yrs and diagnosed at 57. Seeing what my dad goes through I have already put some plans in place to do the same before it takes me beyond control. We shd have the human right to decide whether we live or die in our own home. Not travel the world and pay thousands for it to happen.
Fear of having the same destiny	I have early onset Dementia and I really do not want to end up like that. It must be so difficult for you to have to watch this happening. God bless you and your family xx
Fear of having the same destiny	My dad has just been diagnosed with vascular dementia and he is slowly disappearing before our very eyes. He wouldn't have wanted to end his life like this. Neither would I if I ended up in a similar position. I hope by

	then the laws will have been changed. An animal gets more dignity in dying than we presently do.
Fear of having the same destiny	My father died at the age of 55 due to a heart attack and it was a massive shock to me, I was only 20 years old, my mother died of early onset dementia, it started when she was in her late 40's and she died at the age of 60, the last 5 years were spent in a care home and the last 6 months she was fed through a drip, looking back even though it was a shock I'd rather die like my father did, we wouldn't allow animals to be dragged through a pointless life. And I'd rather leave the money spent whilst in a care home to my children.
Fear of having the same destiny	My father had dementia. I personally don't see the point of living like that, and don't wish to if I get dementia. I don't believe he was enjoying any part of living like that. Even though he didn't seem to know what was going on.
Fear of having the same destiny	My heart goes out to you, for the torture of the way your wife died & for what you fear. I have sat with both parents dying, one from cancer & one from Dementia with physical problems he couldn't understand. I was privileged to hold their hands after all they had done for me, but it was awful and I wish I could have made it easier. I also fear I will inherited either condition or want to control my end.
Fear of having the same destiny	My mother had dementia for over 12 years. I never, ever want to be like her!!! If I get dementia, I want to be euthanized!!!!!
Fear of having the same destiny	My mother has been lying in a bed, not knowing anyone since 2013. Fortunately, she is peaceful. I have resigned myself that there is no alternative and she will have to die by inches in indignity. Luckily, she has wonderful caregivers. However, there is no way I am going to have the same fate myself if that time comes for me. My family and friends are well aware that I fear this fate much more than mere death. The thought of putting the people I love through the same torture is unbearable. I'd go now if it were the only choice to prevent that from happening. I am utterly disappointed in the Trudeau government for their legislative failure and this, for me, is a key political issue.
Fear of having the same destiny	My one fear is getting Dementia or Alzheimer's. Then all rights are took away from you.
Fear of having the same destiny	My sister in law has vascular dementia. She is 61 now but was diagnosed 5 yrs. ago. I've made it perfectly clear to my family that I would not wish to be dependent on others. I hope in the next few years that our law changes and gives a person the right to die with dignity. I have been a nurse for over 40 yrs. and have had many patients begging me to help them "end it". It should be an individual's choice.
Fear of having the same destiny	My thoughts are with you and your family and I totally agree with this cause. I work with people who have varying degrees and types of dementia, which is also a terrible debilitating progressive disease. I am certain that I would not want to live like this or see any of my family suffering in this way and I myself would choose to die before I reached a certain stage. Good luck
Fear of having the same destiny	The law needs to change. The world would be a different place. My Mum had Dementia. I NEVER want my boys to go through that. It's so cruel.
Fear of having the same destiny	This is heart breaking, what that poor man and his family have went through is cruel, UK laws need to change, I can say I truly believe people with terminal illnesses should be allowed to die with dignity when they choose to is have vascular dementia and know my day when care homes and being unable to care for myself will be in the near future, I think it's a disgrace that animals are shown more sympathy and compassion than we are.
Fear of having the same destiny	This is so sad. We must get the law changed. My biggest fear is to end up with Dementia and be a burden to my loved ones.
Fear of having the same destiny	My father had dementia. I personally don't see the point of living like that, and don't wish to if I get dementia. I don't believe he was enjoying any part of living like that. Even though he didn't seem to know what was going on.

Name	Coded Text
Hospice - PC - EOL care	They shouldn't be using jobs as a reason, There are not enough nursing home places, so how dare they, I hope when/if I get Dementia, this law has been changed also.
Hospice - PC - EOL care	Dignity in Dying Dad, Mum and Step-Mum all vegetated suffering from Alzheimer's and Dementia. My late husband died of lung cancer. All 4 believed in Dignity in Dying but were left to suffer. My darling husband wasn't even allowed to die in a care home of his choosing even though they knew him well and had a room for him next to his beloved Mother in Law!! Instead he was placed in the next town 10 miles away making it difficult for us all to be with him 24/7. My step daughter was heavily pregnant and my other daughter lived 40 miles away and relied on public transport with 3 babies. The local authorities were told my husband only had a few days and yet he/we were denied precious time and he died on 29 December 2011. I regret not keeping him at home with me. Something I will have to live with for the rest of my life.
Hospice - PC - EOL care	Do you live in NZ? I want to break down a misconception. I am a nurse that works for the part of a district health board that assesses people for rest home care. NOONE can be forced to live in a rest home, unless you are lacking mental capacity due to a condition such as dementia and then when you can no longer safely live in your home, your enduring power of attorney can make that decision for you only after you have been deemed incompetent by a GP. Our main job is to support people to live independently in their own homes for as long as possible, with care givers assisting. Please don't worry about being thrown in a rest home x
Hospice - PC - EOL care	Greedy nursing home! You don't let animals suffer like this! That poor woman and her family having to see her like this! She made it so clear and did her best to make sure her wishes were clear and they were simply ignore them! It all comes down to money instead of respecting her wishes!!
Hospice - PC - EOL care	Hi […] very sorry to hear that. I have a similar story, my mum had a stroke and then dementia. She had 2 desperately sad and difficult years followed by a coma, denied water we had to wait, it was cruel and I want a change in the law.
Hospice - PC - EOL care	Unfortunately hospices don't always have space or people are too I'll to be moved. Nurses in hospitals should be equally capable of offering care and the issues with drugs should not arise anywhere so that someone is left on pain. Lucky for us we are now at the hospice but after 9 days of suffering even the hospice can't assist with what is really needed to end that suffering.
Hospice - PC - EOL care	I cannot believe that they are leaving dementia sufferers off the list. They should be the first on. They are never going to get better and just deteriorate. It is extremely scary for them. AND they cannot even get palliative care because it is not regarded as a terminal disease. But no, let’s let the nursing homes who take them for respite feed them incorrectly and let them aspirate alone in a room. No longer supporting any euthanasia groups now until they put dementia on the table
Hospice - PC - EOL care	I feel we should be actively campaigning for an end of life ward in every hospital as the availability of hospice beds cannot meet the demand. Having been with friends and family who have been transferred from hospital to hospice the contrast in care and pain control could not be more striking.
Hospice - PC - EOL care	I have been in this situation exact situation. My mother was in the same condition and luckily, laws are a bit different in Ontario. After numerous mtgs with doctors, we put my mom in palliative care and kept her sedated so she could pass peacefully.
Hospice - PC - EOL care	My Father was in the […] nursing home at Welshpool and had Lewy Body Vascular Dementia, he was very poorly and had to be admitted to the Royal Shrewsbury hospital and I can tell you that it was the worst place on earth for him he was tutted at and laughed at by staff, patients and visitors and i even heard people say "why don’t they shut him up" .Our family did all we could to get him out of there and he was sent back to The […] with his end of life package .It was down to the love and care of the staff at The […] that my father improved from the minute he got

	back and he lived his life for another 12 months before passing away last year.
Hospice - PC - EOL care	This treatment is absolutely disgusting and inhumane. Force feeding is torture and abuse and should not be allowed. I spent 12 years working in health care and I have seen people like this. It's time to start respecting people's wishes. Glad this photo is being shared. For those offended, too bad. It's not the image that should offend you. It's the way in which this poor woman is being treated and the way her family struggles that should offend you.
Hospice - PC - EOL care	If u ever worked in a dementia ward u would feel even more strongly. Watching people go through pain and suffering unnecessarily is hard. Sitting in a fallout chair, plonked in front of a TV with nothing worth watching and no one interacting with you is just a horrible existence. It is not living. It is not quality of life. Families rarely visit. When they do it is too hard to see their loved ones as they now are. Most of the time they recognize the staff more. It's kind of ghoulish to visit someone who doesn't realize how bad they look. Some staff try to make their day a little better. Almost no one has enough time to do it properly. You can spend all day just changing continence pads. Assisted feeding never happens like they say in the Cert III training: often you multitask multiple feeds and serving others. Eating is not pleasurable or social. It's a task that you have to get through before its back to toileting. And even worse when someone combines the two and you can't stop feeding others to clean them up. Mandatory staffing ratios need to be set.
Hospice - PC - EOL care	None of the dementia patients in the LTC facility of my church's seniors' complex where I live in the Independent Living sector, are tube fed. If they refuse food at meals, they will be offered more lately at snack time. Volunteers like myself, help those who have physical difficulty feeding themselves. We have found that often, once other persons in the dining room begin eating, that a dementia patient will then also do so. But at a certain point, they just can no longer remember what to do with food. And if we try to encourage them to eat, and they refuse, nobody forces them.
Hospice - PC - EOL care	Thanks, my mum was in the same nursing home under the same Doctor. She had dementia we were worried she would have a Bad Death as well. She was too sick to move so we changed Doctor's. The new one was so different, he listened to what mum wanted in her Health Care Directive and made sure it was done. She fell and fractured her pelvis, came back from hospital into High Care with Palliative Care already in place. Doctor was great, she died 3 weeks later. We saw how Palliative Care works when you have a Doctor makes sure his patients Die with Dignity. Surely everyone is entitled to this.
Hospice - PC - EOL care	The current Reality is that pain meds cannot ease all suffering. Many don't realise that-they think that hospice care means the patient doesn't suffer. When circulation is poor the medication can't circulate and work. As circulation slows so does the effect of the meds. Howling agony is the result. That's for those who can get the breath to scream. Personally, I can't speak for longer than five minutes in one day without ending up curled in a knot, just trying to take the next breath because the pain is unbearable. There are illnesses people have never heard of that cause suffering that is unknowable till you feel it. They cause a downward spiral in to Hell. Many sick/dying people don't fear death-because they are already in Hell. Their bodies are torture chambers and they have no dignity, self-respect, or semblance of the person they once were. Many, however, fear the dying part. The complete and utter lack of dignity, peace and closure that Euthanasia could allow. I can't make that choice for someone else. So it is wildly cruel that others-without knowing the suffering or endurance it takes to fight- make that choice for me. That is how it stands. Legally. Morally, I find that horrendous. Physically and emotionally, I find it horrific.
Hospice - PC - EOL care	My mum didn't and i certainly don't after caring for her for years. Also seeing how they are treated in the health care system ... nope

Name	Coded Text
Quality of life	I have watched my parents, sister and other family members suffer cancer and dementia/Alzheimers and not be able to endure the pain and confusion with fear that was forced upon them. When there is no quality of life and you are only enduring mindless pain we should all have the choice to die (or when one cannot speak for themselves but medical science agrees there will be no quality of live ever again, a medical proxy decision must be made). We allow our pets and insured animals to be put out of their misery, why can't humans have the right to die with some dignity. I would like that choice.
Quality of life	I hope they soon realise we treat our pets better than fellow humans... I said this to several Drs, nurses and consultants recently when my mum finally reached the end of life after a long battle with Parkinson's, no quality of life for 5 years... No dignity in dementia, no mobility, no speech and no control of her own body functions... How can this be right! The whole family suffers
Quality of life	I totally agree. I am going to my husband's funeral today after virtually watching him starve to death. He had Parkinson's disease and Lewy body dementia. This not only affected him but the rest of our family which was so undignified all round - something needs sorted as he didn't even look like the beautiful man he was - he had no quality of life for the past five years - How can this be right...
Quality of life	I watch with great heartache my 94 yrs. old mum in torment every day from dementia I do not want or wish to have to live my last days like she is, she is demented tormented and unhappy she cries daily her eyes are red from crying it is cruel and unnecessary she is on antidepressants but they do not help her body is slowly giving up but her brain is in torment it is cruelty on a daily basis. I wish you well with your petition
Quality of life	It is a disgrace that within today's "forward" thinking society, such old fashioned laws are still in place. It's a tough line between treating a patient and actually prolonging the suffering of the patient and there family. 100yrs ago if someone was terminally ill and they then got an infection they were given pain relief and left to let nature take its course. I sometimes wonder, as hard as that would be to see, if it actually was kinder in away.
Quality of life	It must be more people seem to be getting it dementia is a slow death so sad to watch a loved one slowly not knowing anything or anyone anymore, going through this now with my sister it's so sad. Something must be done when quality of life is no more!!!!
Quality of life	I've seen my nan over the past year with dementia. To see her the way she is today is horrendous but the main issue is the effect it has on my grandad living with her it is destroying him and my nan has no quality of life. It would be a lot easier if she was put to rest peacefully.
Quality of life	Our choice, our way, personally, a celebration of life whilst living, then Fentanyl which is used for quick, pain free end of life, why wait until we are ridden with pain, endure treatments, lose our decision making due to dementia etc., our quality of life is the issue.....
Quality of life	Quality of life should be the main focus not quantity.
Quality of life	They will not recover from dementia. They lose all quality of life. They become a shell, a walking skeleton. They only eat when forced. It is degenerative with no cure. It is effectively the UK's biggest killer but people usually die of complications as opposed to the illness itself.
Quality of life	Totally agree, my Father diagnosed with dementia Seven years ago now in a care home, if he knew how he was living he would have made arrangements. My 83 yrs. old Father in law was diagnosed with cancer of the oesophagus a month ago, he was the carer of my mum in law until recently, today when visiting he said to his son (my husband) and I he needs a cyanided pill. ! He knows he is dying, I always thought dementia was worse than cancer, no more, my Dad does not have a clue, for the last seven years my father in law has been more of a Dad to me and has enjoyed the arrival of two great grandsons courtesy of my daughter and son in law, he knows he is dying and leaving us all, how cruel.

Name	Coded Text
Right to die - Right to choose	I went through the same nightmare when my husband was at the end of his life with Parkinson's disease and dementia. I swore then that I would never endure that and pray that laws will be changed to give people a choice which should be their right.
Right to die - Right to choose	I totally agree with you & it should be our choice what we decide & the right not taken out of our own hands.
Right to die - Right to choose	I totally support the right to die, with great control obviously. We wouldn't let a dog suffer like that, in fact would be prosecuted, but we are not allowed to let our loved ones go with dignity
Right to die - Right to choose	"HUMAN RIGHT" If we could see the future who of us would wish to live with a terminal illness or fade away with dementia. Or be old ailing and alone......we should all make our own choice and that should be respected.
Right to die - Right to choose	After watched my mother die a slow death with dementia. I do not ever want my children to have to cope with my slow death heart breaking. I want to have the choice to die peacefully
Right to die - Right to choose	Assisted dying should be everyone's right and a matter of choice and nothing to do with religion. More a case of quality of life. I am watching my mum die a slow death and other people seem to think they know what's in my mum's best interest ,she's 94 and in later stages of dementia.
Right to die - Right to choose	Because I've seen my gran suffer through vascular dementia, forgetting everyone she ever knew and loved, becoming a different person and wasting away in a care home. She would never have chosen the ending she got, and neither would anyone she loved. I want to know that when and if I need the choice, that it will be mine to make.
Right to die - Right to choose	Because my mom had dementia and if I get it later in life I do not want to put my wife and children through what I went through and I want the right to end my own life if no chance of getting better why put humans through all that pain if they want to die
Right to die - Right to choose	Dignity in Dying I actually cried, that poor lady End of Life dementia and treat like that. We must get this law passed, so we can make our own decisions.
Right to die - Right to choose	Done, this is a fundamental human right. You are an inspirational man and I dearly hope you succeed. My children of 18 and 16 know my wishes should I become terminally ill. We have a right to determine our own fate. I watched my father with dementia. The last six months of his life was sheer purgatory for him.
Right to die - Right to choose	Each of us should have the choice of when and how we wish to leave this life. This lady has suffered so much. Animals are not treated this badly. We all say, of our beloved pets, "It's better for them to be put to sleep, as it will end their pain and suffering".
Right to die - Right to choose	Every person who is either terminally or has severe dementia should have the right to die in a painless and dignified manner. Surrounded by love ones.
Right to die - Right to choose	Everyone should in this day and age have the right to die with dignity and pain free....
Right to die - Right to choose	feel I'm a great believer in assisted dying having watched my mother and brother go through a slow painful death in this day and age we should all have the choice if we can't be helped and our pain can't be managed
Right to die - Right to choose	Having sat with my mum in her last week with lung cancer I completely sympathise and agree with you that if someone wants to choose when to say goodbye then that is their choice to make.
Right to die - Right to choose	Having seen my dear, wonderful, Mum, die with dementia and the indignities and fear she suffered in that time I do so agree that we should all have that choice, that right. We wouldn't dream of putting an animal through such suffering yet we are still barbaric enough to allow our fellow human beings to go through it. How we die is so important. My love and thoughts to all who have or are experiencing this

Right to die - Right to choose	Having supported loved ones through cancer, Parkinson's and dementia I have held their hands and been helpless while witnessing their immense suffering. I would like to think that if my life followed a similar terrible journey, I would have the right to say 'enough' and have the choice to die with dignity and without unnecessary pain and suffering.
Right to die - Right to choose	Having watched my Grandmother die earlier this year, spending 3 weeks in hospital slowly fading away, as she could not eat or drink, then my mother (for whom I was primary carer for the last 2 years), waiting to see which was going to get her first, the rare form of dementia or aggressive cancer, I can honestly say, hand on heart, THIS NEEDS TO CHANGE...NOW! I have had the same conversation with quite a few medical personnel recently, and all I can say is, vets have the right idea. At least my Mum and Nan are both no longer suffering. RIP both xx
Right to die - Right to choose	Humans are encouraged to take that difficult decision to end their pets suffering so I find it perverse in the 21st Century that we are prevented from taking that ultimate act of compassion for a fellow human being. I would wholeheartedly support a change in the law
Right to die - Right to choose	I agree with what you are saying everyone should have this choice it's their life
Right to die - Right to choose	I agree. I only hope that eventually one can choose whether you want to have a quick injection if you are dying and in agony, but also if you just being kept alive like a living vegetable. Surely it is not too much to ask?
Right to die - Right to choose	I am getting older and now have to worry about how I will die. Why can't I know that when I have had enough I can just have a quick injection? Why should my family have to perhaps watch me for years should I get dementia and also lose the money I would rather they had, and not a nursing home. I believe in God but feel he has given man the knowledge to help people with an injection; why can't I have one if necessary?
Right to die - Right to choose	I feel for you Your views should be heard. We have to give individuals the choice. Your life your body. Behind you with this. Governments and Dr's should not play god. My dad has dementia and has had for the last 10 years. He is on the last leg and it is horrible to watch. If I get it I want to have the freedom to leave this life peacefully and knowing I have my family around me rather than looking blankly at walls and eating pureed food and not being able to walk. We would not treat animals in the same way so we should treat humans with respect and decency. Change the law.
Right to die - Right to choose	I find the statement that people would end their lives on a financial or care burden value incredibly insulting. I'm 35 and as someone who plans ahead for my life I would very much hope that by the time and if I am lucky enough to reach old age that this barbaric biblical law be changed. It truly is ridiculous. At this stage in life I can plan for so many things. I can have a funeral plan, an accident/illness insurance cover plan but to say I cannot have a plan in place if I were to say become a "vegetable" or immobile or lose my senses. If in 30 years-time there is no cure for illnesses that are put on the backbone, I would like this option. For example there are 100 types of dementia and the only one people know about is Alzheimers! And even that is underfunded. I know when I reach my 60's it is highly unlikely we would have a cure. There are many other terminal illnesses with the same outcome. I don't want to be penalised for thinking ahead. It would be the parliament's job to ensure that laws are put in place to make sure it is not abused. It is a shambles that dignity in dying is a privilege for the rich. It is a shambles that it is muddled with suicide or depression. It is an incredibly courageous thing to step up to parliament to ask for permission to die in a dignified manner. That is not mentally ill and an insult to the welfare of individuals who wish to do so. It is also an insult to the carers who stand by. I think the option should be there for natural endings and assisted. I do not want my last days to be watching my friends and family looking on at me whilst I am unable to speak, eat or move. I don't want them to look on at me frightened. I don't want anyone to have to go through that suffering if they don't need to. The implications of a change in law are scary and case studies from other countries need to be assessed. But please do and please do maturely and without insult.

Name	Coded Text
Slippery Slope - Opposition - Concerns	A wonderful and very moving goodbye. We should all be entitled to this but not all friends and relatives are motivated by love and there's the rub. I've seen it work the other way and that is what we must guard against especially with an aging population and the accompanying dementia issues. There's no easy answer but I'll say it again - John was a fortunate man to die with such clarity and love.
Slippery Slope - Opposition - Concerns	According to statistics there are more than 8 suicides a day in Australia. People can and do suicide without help if they really wish to die. Personally, if someone really wanted to die, then it is their own decision, but it should strictly be by their own hand....no doctor or nurse should be involved. In my opinion, this is killing! We would be horrified if someone helped a mentally ill person to suicide...and rightly so. Everyone keeps saying that the bill has strict safety guidelines, but so did the abortion bill when it was first introduced. Termination in the first trimester was only allowed if a life (mother or baby) was at risk or in the case of rape for the mental wellbeing of the mother. The abortion laws today allow for terminations almost to the point of birth, no questions asked...in fact, we have people using it as a method of birth control! There have been cases in other countries of people requesting assistance to die because they are mentally ill (I note one person here has given that as a reason for wanting assistance) or being killed against their wishes because they suffer from dementia and cannot speak for themselves! There are no guarantees that this bill will not be modified in the future. Too dangerous for the old, the sick and the vulnerable at the mercy of governments who say aged care is too expensive and want to cut funding for it!!
Slippery Slope - Opposition - Concerns	Assisted suicide is such a complicated subject, who decides and when? Working with dementia patients as I do it gives you a lot to think about .So many lose their will to live, it's painful to be with them day after day when they are so miserable, not just dementia patients, but others who feel they have lived their lives and are now just existing. Some are in a lot of pain. But to make that decision, I think that it should not be up to just one person .The family and the doctors need to make it together. The patient also should be aware of the option while they are still able to make such choices for the long term.
Slippery Slope - Opposition - Concerns	I do not believe the dying with dignity bill is designed to terminate the lives of people with Dementia or old age while still lucid. I hope it isn't - I thought this was designed to allow a choice to those who are terminally ill and suffering from terrible pain. I am a cancer survivor and hope to have this choice if it comes back but can't get my head around it for elderly as in my Mum who died 4 days off 99. When she first said "I'd rather be dead", I said "then why are you taking all those multi vitamin?" and she laughed out loud.
Slippery Slope - Opposition - Concerns	I don’t see these people as worthless , how dare you suggest that , I’ve seen behind the scenes you are suggesting that people are ruthless when it comes to having to make a choice have you not thought they don’t want to see loved ones suffer , you were lucky your dad still had some enjoyment plenty don’t.
Slippery Slope - Opposition - Concerns	I know what you are talking about but do not agree that dementia is a reason for this Bill. They do not know what they are doing but will eat, drink, sleep etc. so not a terminal illness in terms of a person of sound mind with a terminal illness making that decision for themselves.
Slippery Slope - Opposition - Concerns	I'd worry if the dementia tax and other Tory policies come in. I'd hate to see older people making this choice to protect their families. I know there are strict processes in Switzerland but it's a real consent for me
Slippery Slope - Opposition - Concerns	I've worked in care, I'm watching the man I knew as Dad disappear to Dementia, I've watched relatives and friends lose their lives in misery and pain to Cancer and I'm an advocate for Dr's being allowed to help those with a terminal illness find comfort and peace at a time of their patients choosing. However, I think the crimes of Harold Shipman are still too fresh in the memory of many and have hampered any progress. Even with stringent rules and regulations in place any system can be abused. Shipman managed to abuse the system and his position for decades killing hundreds. I suppose there's an underlying fear in parliament that murder could be easily hidden.

Slippery Slope - Opposition - Concerns	I have an Auntie that is in a vegetative state due to dementia, she is doubly incontinent, tube fed, has no speech or recognition but still feels pain. Absolutely no quality of life whatsoever. You're happy to keep her alive? Also the argument that vulnerable people would be put at risk is absolutely nonsense as a decision to end someone's life would have to be approved by 2 independent doctors and a High Court Judge.
Slippery Slope - Opposition - Concerns	The opposition to assisted dying is not about the example of your mum. I'm sure that was a terrible time for all concerned. The problem is the unscrupulous families and of course there will be some unscrupulous medical practitioners as well. The whole concept relies on people doing the right thing. Some don't. My son died by assisted suicide. He was only 26 and suffered from depression. The doctor involved was completely unremorseful. In fact he was proud he had helped my son to die. This particular Dr will continue ignoring the law and will continue to run a very profitable suicide business. This is the coal face of assisted suicide. It will become an industry with ever-expanding borders.
Slippery Slope - Opposition - Concerns	People with Dementia are not capable of making this decision for themselves. Who is going to PLAY GOD and make a decision for others. Be very careful people for the doors you are opening.
Slippery Slope - Opposition - Concerns	That's a nonsense, that it has no impact on anyone else. Of course it will. It will impact the whole society. Firstly, it will decriminalise assisted suicide. So there will be plenty of opportunity for those with bad intent. This Bill will be impossible to enforce and safeguards will be ignored or watered down. If you think it is only about the terminally ill, gasping their last breath-then you have been seriously misled. (Deliberately I'd say). And it's not about murdering the dementia patients either.
Slippery Slope - Opposition - Concerns	There is no slippery slope! The bill is extremely clear that the person themselves must make the decision as described above. Though I personally believe that everyone should be able to make an enforceable living will or advanced care directive so that their wishes re their death can be taken into account if they lose the ability (either physically or mentally) to make that decision at any time (accident i.e.).
Slippery Slope - Opposition - Concerns	This choice and decision can be made before hand, in case this happens. It is not playing god. This door needs to be opened as it is cruelty keeping someone alive after they have left and a shell remains.
Slippery Slope - Opposition - Concerns	Well, I think that is exactly why the law should not be changed. Would you have all people in Nursing Homes killed off? My father had dementia and was almost like a baby towards the end, but he still smiled and took pleasure from seeing his great grandchildren and from simple pleasures, just sitting holding my hand. I have seen many other people suffering from dementia who, when well cared for, still get pleasure from life, but different pleasure. It breaks my heart to think that someone might have thought my Dad's life was worthless and should have been ended sooner. I can see that if someone with an unbearable illness, who is fully compus mentis would feel they have the right to end their life if they so choose, but if the law were changed, it could put vulnerable people at great risk, when other people see those lives as worthless.
Slippery Slope - Opposition - Concerns	You are very very wrong and I would think not had to stand by someone you love dearly and watch them die a horrible and unnecessary distressing death. Our beautiful mother took four days to die with pneumonia. She was extremely uncomfortable, restless, so congested that the fluids kept coming up through her mouth. She had dementia and had not known any of us for about four years. She was our Mum. She did not deserve to die like this. She believed totally in euthanasia. Walk in her shoes and ours. See what it is like.
Slippery Slope - Opposition - Concerns	This could potentially protect the most vulnerable. Robust legislation would ensure that the person’s wishes were paramount and protected from family interference. Relatives wouldn't have the right to make this decision for someone who doesn't have the capacity to make their own decisions and dementia would come under this. People can make advanced statements regarding their care while they have the capacity. The advanced directive would take precedence.

Name	Coded Text
Suffering	Absolutely. Same with my mother with Alzheimer's dementia. 5 horrendous years and had to starve to death at 50lbs. Broke my heart.
Suffering	After watching my dear sweet mother in law starve to death in an induced coma after Parkinson's and dementia took her mind and body, I do not want to see the same thing happen to my recently diagnosed Alzheimers Mom. It is cruel to make someone die that way. I treat my pets better by giving them a dignified death....why can my loved one not get the same dignity in dying?
Suffering	Almost identical situation, my mother passed away 10-9-17, Would have been 92, 10-11-17. Many years of watching her Struggle was heartbreaking enough, Her last 4 months were agonising for both of us. I would not wish that on my "Worst Enemy ". Best Wishes to you and your Mum!
Suffering	And yet.... and yet they will dose elderly dementia sufferers with morphine until it suppresses their breathing and they have a peaceful death....peaceful? What about the 4 days she spent screaming until the dosage 'kicked in'? Euthanasia is here, just completely unregulated
Suffering	I lost my dad twice, first with dementia then watched him as his body slowly gave up, organ by organ. His heart and lungs were healthy and kept him going while his liver, kidney, bowels, bladder and brain packed up. They kept giving him anti biotic for a chest infection till we begged them to stop. He was a skeleton in the bed. He finally died on 14/12/2005, 2 days before his 79th birthday. When you reach the point of no return you should be able to decide when it ends, not keep giving treatment for no reason other than "it's the law".
Suffering	I support assisted death. I watched my mother slowly die it took a horrible 3 weeks after being taken off all medication. At first when she was taken medication her awareness and health stabilised but because she had vascular dementia she did not know how to swallow. It took another long and painful two weeks to finally pass away. To make it even worse we were offered by Drs to put a feeding tube in her. What for???? She was dying. So sad to think people want to delay someone's pain and suffering longer than it needs to be.
Suffering	I watch my dad suffer with dementia it was cruel it broke my heart and very sad to watch my beautiful dad slowly die
Suffering	I watched both my parents die in pain my dad with cancer my mum had vascular dementia and at the end I had to fight with doctor as he said she didn't appear to be in pain he wasn't the one cleaning her two or three times a day and screaming in pain eventually he said ok but it hurt that she was in pain when there was no need
Suffering	I watched my brother suffer with pro frontal dementia for over a year.
Suffering	I watched my Dad suffer through the last weeks of his life. It wasn't just the pain. The cancer in his neck had become so bad he couldn't swallow any more. Half his neck was missing. He couldn't communicate what he needed anymore because of his dementia. That distressed him and the people who loved him. I wouldn't have put one of my animals through it. In the end he had a do not feed order, so he starved to death. Why should anyone have to die this way!!!? Horrific
Suffering	I wholeheartedly support you, and I wish with all my heart it would become part of our choice when told how you're going to die, my husband had Motor Neuron Disease and unfortunately got dementia with it, six months after diagnosis he died the most horrendous death you can imagine, in the last week's he was just a shell of the man I used to know, his body was just a twisted wreck, and the pain, just a sheet on his body hurt, he didn't recognise anybody or anything, (so can you imagine how frightening that must have been for him)it took him all his effort to try and speak as he'd almost lost his power of speech altogether, and he asked for anybody to kill him, it was devastating knowing that all me and my daughter could do was hold his hands try and comfort him and just hope he knew we were there with him all the way till the end, those last few weeks will be stuck in our minds forever, this is the most horrendous disease ever so please listen to how people want to end their lives in situations like this no matter what terminal illness it is, they

	deserve some dignity and peace of mind that their loved ones will not have to see them suffer x
Suffering	I/we went through the same horror with my dad too Debs...it haunts me...my poor dad, we had to sit by & watch him starve to death...it's inhumane, it's horrific...
Suffering	If animals are allowed to be put down instead of suffering then why aren't we..... My mother died of early onset dementia at the age of 60 but had suffered from her early 40s......she was in a care home for 5 years and then in hospital for 6 months being fed through a stomach tube, for what reason??
Suffering	If I could have done this for my Mam who passed away in June 2017, I would have. Instead I had to watch her be slowly starved to death for a week before she passed away. She, nor anyone else alive, deserves such a torturous undignified death after suffering with Dementia for seven years. It broke my heart to see her in unimaginable pain and discomfort, alleviated only by morphine. Inhumane is the only way to describe it.
Suffering	If we treated an animal the way some people are treated, we would be prosecuted. My Dad died of vascular dementia, he was a skeleton covered in skin at the end. Even though we had a DNR notice on his notes, the care home ignored it, he would have been at peace sooner if they'd left well alone.
Suffering	I'm completely behind this campaign No person should have to suffer, my Father died from cancer and Mum from Dementia both had months of unnecessary and cruel suffering.
Suffering	'I'm with Noel' Watching our loved one suffer and slowly fade away from us is gut wrenching! This is NOT how our loved one wants to be!!Parkinson's disease AND dementia, no one deserves to suffer this way
Suffering	I'm with you. My Mum SUFFERED whilst suffering from dementia. She was soooo totally confused and angry.
Suffering	It shouldn't have to come to this. It's about time that the British government passed the bill for assisted dying. It is heart breaking to see people be made to suffer in their final days. I see this first hand as a dementia Care worker and it breaks me in two to see their suffering.
Suffering	It was similar when my sweet Dad passed away. Tiny bit of dementia there but everything except his strong heart gave up. He was on morphine and poor love hadn't eaten when they put that sign up "Nil to mouth" for 10 days!, it was so sad to watch him. They also wouldn't increase the drugs, kind of weird really.
Suffering	Kathy I had the exact same my dad had dementia and I sat holding his hand for 4 days before he died little did we know then that my mom was riddled with cancer and just a couple of months later I went through the exact same thing again with her. She was in so much pain at the end. I feel your pain.
Suffering	Life can be so unfair, no human being should be made to suffer like your Mum and family have . My dad has Parkinson's and vascular dementia and also attends the Uplands day centre twice a week where the staff are lovely, kind & caring. I can only imagine how distressing this must be for you all .
Suffering	Lindsay Whittam I understand this now to. What the doctor said would be 48hours for her passing lasted 8 days. It was awful for her as she was aware even though she had dementia. I just think it's barbaric to do this to a human being
Suffering	Me too it gives me a huge sense of peace. My own mother is 96 and living in the hell of dementia.
Suffering	Mum passed away last year dementia and multiple health problems, blind, nearly deaf, couldn't eat, barely able to swallow tiny amounts of fluid. They were still trying to shove medication into her as she lay dying. I was with her when she died and her body had deteriorated very badly. I can't go into it too much because it still haunts me. A once proud smartly dressed lovely lady reduced to a physical and mental wreck. Cruel beyond words.

Name	Coded Text
Suicide - thoughts & assistance	363 days ago I watched my beloved dad pass away after a period of dementia followed by cancer. What I watched him go through was inhuman. The nightmares and guilt it has left me with is unbearable. While I do not regret anything I did for dad I cannot put my own children through the same things. If I am approaching the same end I will take my own life. I would prefer however that instead of being on my own to save any prosecutions I would like it to be legal with my family around me. Compassion is sadly missing in this society
Suicide - thoughts & assistance	And/or Dementia. At the onset of this diagnosis, I will be taking care of business so it is not prolonged and I must suffer all the crap in an LTC plus having my family see me deteriorate to the point of me not knowing who they are plus the anger that goes with this illness. I certainly would not want this afflicted on my loved ones.
Suicide - thoughts & assistance	As someone who spent 12 years working with the elderly before going back to school to change careers and as someone who has a grandpa suffering from Alzheimer Disease and an uncle who suffered with Parkinson's and saw no other option but to jump into the river to stop the endless torture, I fully support assisted dying. If you don't like it, don't do it. Simple!
Suicide - thoughts & assistance	Everyone should have the choice to end their life with either assistance at their chosen time or continued suffering if that is their chosen wish. My mother has had dementia now for 12 years. Apparently most dementia sufferers die choking to death which takes quite a while and is extremely distressing to watch. If I end up with dementia (high chance) I will be organising my own death alone to save my family before it comes to that.
Suicide - thoughts & assistance	Fully agree - for me. Thinking seriously of having a lights-out pill to take somewhere along the line before my memory light fades completely. Just need to remember Where the heck I put it - as I don't want to put that kind of responsibility on anyone else.
Suicide - thoughts & assistance	Having nursed my husband with vascular dementia for eleven years in his head he died the day they took him into care. It took him a year and eight months to die in this place he hated. The sad thing was I am a qualified nurse and could have stopped this happening. He could have died in my arms at peace with the world. But I loved him too much to do it. So want our right to die allowed over here. Its time now we should be able to do it. Another beautiful man having to die too soon in Switzerland because of our rules. It's wrong....
Suicide - thoughts & assistance	Having worked for years with elderly people right to end of life, I only knew one who didn't beg to die at the end, and she was very religious and had dementia. I had a gentleman beg me to put him against the wall and shoot him, ladies tended to the pills and injections route, men to pills and drinks. It's also distressing for carers having these conversations virtually daily, much better for there to be an active and positive choice!
Suicide - thoughts & assistance	I wish we had a euthanasia law here in US. Hope ahead and yell all you want if you don't want you use it just become a vegetable if you want but don't make me either go to Switzerland or do it myself.
Suicide - thoughts & assistance	I admire both of them. I have just watched my mum die with vascular dementia another awful illness. I wish I could have helped her but didn't have the courage
Suicide - thoughts & assistance	I agree that we must have a choice, and Dying with Dignity should be that choice. For over a year I have seen my husband suffering in pain and unable to speak, to walk and hard to hear even though he using his hearing aids, he cannot eat properly as he can't remember how to do it. He has dementia and brain damage. Therese I know every life is sacred but I'll like to see you seeing a love one every day and not wishing to be able to help that person terminate their life.
Suicide - thoughts & assistance	I am frisking family that's what makes me angry those poor individuals have no dignity left and I know my father has said many times in the past 20 years of I ever get like that end it well he's there and my hands are tied That's my point it's elder abuse

Suicide - thoughts & assistance	I am so sorry for your loss. I am care-taking my 87-year-old mother who has dementia and know that I will be facing that shortly. While she has no desire to die early, any death of a loved one is distressing and painful. I know that should I come to a place where living is more painful than the idea of dying, I know what I will do.
Suicide - thoughts & assistance	I disagree as well If I am diagnosed with dementia or Parkinson’s I will euthanize myself very quickly because you do not know when you will lose your facilities to make choices. Wanting control over your own death is not a mental illness. I work in aged care and I know how death is for those with these types of diseases and I would rather cut my life short than be forced into the existence they have in their final years. You would have to be mentally ill to think that dying slowly from dementia or Parkinson’s or Huntington’s is ok
Suicide - thoughts & assistance	I think the argument about being pressured into euthanasia is rubbish and actually insulting to the majority of caring relatives who only wish the best outcome for their beloved relative. Shame on you for suggesting otherwise. People are often far more damaged by having to watch their relative suffer for every last breath while they beg for release. It would be carefully counselled and monitored and not just a case of rocking up at the GP and asking to have your relative put down. I think denial will encourage more early suicides while people still have enough physical control to do it themselves. My mother has dementia and if ever I am diagnosed with it then I will take my own life immediately even if I could still have a few decent years left rather than end up like she has and unable to get out of it. From what you say above I suspect you are religious and you have every right to your beliefs but you do not have the right to impose them on others and deny them a choice.
Suicide - thoughts & assistance	I was discussing this with a friend over lunch, yesterday. Her mum has been bed bound for several years following a fall. She also has dementia and is in her late 80's. Her mental and physical health has deteriorated to the extent that she is no longer able to give voice to her wishes, but when she could, she said that she would rather be dead. She is now on constant morphine due to pain from old injuries, has to be fed liquidised food, is bed bound and even has to have bed baths as she is now too frail to carry to the end- suite bathroom. She doesn't always know her own daughters. Quality of death as well as life is essential. People must be given a choice as to whether or not they wish to carry on in this situation. People must be given an option of assisted dying in this country. Safeguards must be put in place. My personal choice is in this situation. If the legal situation is unchanged, I would kill myself whilst still able to do it... but I hope that I would have the courage to go through with it.
Suicide - thoughts & assistance	I watched my mother die from cancer n my dad from dementia and if at any point either one would have asked me to help them end it, I would of no question
Suicide - thoughts & assistance	I watched my mum begin to succumb to dementia, be admitted to hospital where she ripped out her feeding tubes and starved herself to death
Suicide - thoughts & assistance	I wish my grandma had done this. It’s heartbreaking to watch her decline and hate the state she’s in but she doesn’t know why. She was a vibrant, life loving woman who had become an empty shell. This is not living, it’s hell.
Suicide - thoughts & assistance	In and when you are on the way to dying and you know you will reach a point where you will be helpless either physically or mentally to even instigate your own death, i would consider Robin Williams, he knew and he acted while he could, he was intelligent enough to know that he would be unable to choose. I admire him so much for his foresight and courage x ok so hanging there is suffering, but dementia is unrelenting for years and years.
Suicide - thoughts & assistance	It always takes that one person to start the ball rolling. My heart goes out to that man If that was me, I would want MAID, or my kids to end my existence. However, I wouldn't want them to be in trouble. If I am ever diagnosed with a mind destroying disease, I will choose my own way out before I can't. This should be in MAID!

Name	Coded Text
Wish to die - patients & carers	I totally agree with the decision. I want the choice to leave orders for when to check me out if I develop dementia too
Wish to die - patients & carers	After seeing my father wilt away from dementia it made me realise how important having a choice in death was. He wanted to go when he still had a mind and knew what was going on. I totally support having a choice when the outcome of an illness can't be changed. We don't make animals suffer so why must we be made to suffer to the bitter end?
Wish to die - patients & carers	Diane Woods I feel exactly the same. I was asked by someone who has dementia to help them to die and it breaks my heart to see them suffering
Wish to die - patients & carers	FB isn't a priority to either of you? Yet you both found time to leave a response to my post. Ali I appreciate your professional explanation and words of comfort but yes your right our experiences are engraved in our minds forever. I must point out that when you speak of Advanced Planning with the patient, when the patient has Dementia then them being able to make an informed decision is much more difficult. I agree you're speaking on behalf of your own professional postcode area and I'm not speaking of my own postcode area, because my parents lived in a different Primary Trust Area to me. I'm sure they're not all the same. As Dad became more exhausted by his illness, there were so many times he expressed that he just wanted his suffering to end
Wish to die - patients & carers	He is still aware enough to know he no longer wants to be here and that is his only option ... but I will contact Dignitas I think and ask!
Wish to die - patients & carers	How sad I'm so sorry My mum has Parkinson's and dementia but before the dementia got worse she use to ask for a gun or a knife to kill herself she's now been bed ridden for 3.5 yrs and just exists doesn't open her eyes any more can't communicate other than moaning it's so hard and I know she hates it and there's not a thing I can do to help her if my mum was a dog I'd be prosecuted but the law lets us get away with this for humans
Wish to die - patients & carers	I said to a doctor when my father was in last stages of dementia couldn't they quicken it up, I said we would be arrested if we treated animals like this! Obviously he was a bit shocked, why they are only delaying the inevitable and in pain!
Wish to die - patients & carers	I had to watch my mum suffer for months with Vascular Dementia crying every day wanting to die. She was 95 and the last year of her life was hard to deal with but far worse for her. I wouldn't let my dog suffer like that so why should my mum?
Wish to die - patients & carers	I know the feeling. My Mama had dementia and much of her suffering was in her own mind. It killed me every time I would get called to the nursing home because she was out of control for whatever reason. Sometimes she didn't know where she was or who I was and she wanted to go home. Sometimes she just lost it and was acting absolutely crazy. One of the worse things I have ever had to endure.....I can't imagine what it must have been like for her, tormented by her own mind. Ended up she fell and broke her hip. Choices were to have surgery which was high risk or take her back to the nursing home to be bed bound until she passed. We opted for surgery and she made it through but she never came back, she ended up passing away several days later. Makes me so sad that this is what my Mama had to endure. She was ready to pass long before any of this happened. She would beg me to give her enough pills to make it all end. This is not something I want my children have to go through with me/ It was hard enough for them to see their Grandma go through it.
Wish to die - patients & carers	I watched my mother slowly suffer with altimeters and dementia for ten years, every time I saw her, her voice was telling me, "don't let them do this to me", and there is nothing you can do about it.
Wish to die - patients & carers	I watched my mum suffer for a year with Vascular Dementia and she cried every day and just wanted to die.
Wish to die - patients & carers	I watched my mum with various illness and dementia, loss of her dignity and telling me every day she didn't want to be here she wanted to be with my dad, it should be down to the individual I have told my kids that if I become like it I want to be taken to Dignitas, would rather it be in my own home and own bed but my choice
Wish to die - patients & carers	I would not think twice for myself or any of my loved ones my mom has suddenly developed Dementia and I have just the day walking her round

	her home explaining what room is what and taken her outside to show her where the doors are to get in and out I have done this about 6 times and had to show her where her clothes are 2 months ago she was fine. She had lived in her flat for 5 years approx. she is 91 and dying with dignity to mom is taking your own life so would never be an option for whatever the law was. We are keeping everything crossed that as it has happened so quick it could just be a water infection we can but hope x
Wish to die - patients & carers	If you get dementia you are unlikely to be able to sequence sufficiently to take steps of your own accord to end your own life. I lost my mother to Alzheimer's last year and while she was sufficiently aware to know she didn't want to live any more she was not able to do anything about it. When she was able to do so she was quite happy in her world and did not want to. In reality what people also want is the ability to access the drugs and support necessary to reliably end their life when they choose, as most people do not have access to means to do so quickly and reliably.
Wish to die - patients & carers	My mum was diagnosed with Alzheimers and Vascular Dementia 18mths ago at 68yrs old. She often asks to be put down. I would love to talk to my family about this. I live interstate from them so it’s hard me not seeing them regularly. But I don't want her to suffer and I know she doesn't want to
Wish to die - patients & carers	Now, my mom is 86 and suffering from dementia. She is doing well but it would be nice to have this option when things get worse. Her biggest question is, when she will die. She's not afraid. I pray she goes quick and doesn't suffer for years.
Wish to die - patients & carers	Parkinson's with Palsy and dementia over 15 years. He begged to help him go but no help. If I'd helped I'd be in prison and children no parent/grandparents. Terrible bed bound for last 2 years. He lost half his bodyweight and body rigid as drugs stop working towards end. Even carers found it hard to see his suffering. Been a dog etc. the country would have been up in arms.
Wish to die - patients & carers	My nana was the same. I will never forget before my nana had dementia she said "if I ever get like my mother was, please help me go" It was heartbreaking watching her leave us although she was still physically there she hadn't actually been with us for so long. Not being able to give her wish was heartbreaking. I feel now I let her down when she needed me most. So sorry for your loss Rachael xxx
Wish to die - patients & carers	See […] is against. What a surprise. Bet he's never had a sick relative or friend who would have longed for this. I have already told my daughters and husband that they are to complete a DNR form on my behalf should I be diagnosed with dementia or Alzheimer’s and can't do it myself. It's the best I can hope for. I never let my pets suffer and I don't want to either. It's disgusting treatment for those of us who have had enough of a serious illness. Get with the times please.
Wish to die - patients & carers	Simply because a person has dementia does not mean that he or she does not feel. My mother wanted to die when she had advanced dementia as she was unhappy with the way she was deteriorating. She asked me to help her and I had to refuse for obvious reasons, a horrible decision to make either way.
Wish to die - patients & carers	This is disgusting my heart goes out to you why aren't they listening the only sure thing in this life is death so please please listen to us I watched my mum in law slowly die with dementia asking me to help her die up to the end that's all she knew was wanting to die this must stop how ignorant are these judges on human need
Wish to die - patients & carers	Well done you. How very brave. I wish my lovely Dad could have chosen his time rather than suffer the end-of-life hell known as dementia

Appendix C – Confirmatory study

#1 Participant information sheet

School of Psychology
Room 233, Level 2, Building 301
23 Symonds Street
School Reception Phone: +64 9 373 7599
Ext. 88413 or 88557

The University of Auckland
Private Bag 92019
Auckland 1142, New Zealand

PARTICIPANT INFORMATION SHEET

Project title: Safeguarding the provision of assisted dying for individuals with dementia: A pilot study exploring the views of an informed group

Name of Principal Investigator/Supervisor: Phillipa Malpas and Professor Glynn Owens

Name of Student Researcher: Aida Dehkhoda

Research introduction

My name is Aida Dehkhoda, and I am a PhD candidate in the School of Psychology, The University of Auckland. I am currently undertaking a doctoral project identifying the applicability of assisted dying for individuals with dementia, the issues raised, and ways forward. This project is supervised by Associate Professor Phillipa Malpas – Department of Psychological Medicine, and Professor Glynn Owens – School of Psychology.

Project description and invitation

My doctoral project has looked into the views of national and international experts on the major issues and concerns regarding assisted dying for people with dementia. I have also explored the views of the public through several social media communal groups. This project sets out the central findings of the experts and publics' views on assisted dying for people with dementia. You have been invited to take part in this project sharing your thoughts on the findings thus far, indicating your level of agreement or disagreement with a number of statements. You may have experienced or have expertise in caring for someone living with dementia although this is not required. As you are a member of the End of Life Choice NZ (EOLC), you have thought about assisted dying and have a view on it. Participation is completely voluntary.

Project Procedures

The survey will be conducted online using Qualtrics Survey Software. You will be provided with the link to the online questionnaire via the EOLC electronic newsletter and/or your email – sent to you by the EOLC organisation. You will be asked to rate each statement based on your level of agreement/disagreement to that statement on a 7-point Likert scale. It is estimated that the questionnaire should take approximately 10-20 minutes to complete. At the end of questionnaire, you will be invited to enter yourself into a draw – using your email – to receive one of five $20 Countdown vouchers for your time should you wish. Your responses to the statements and your entering into the draw will not be linked to your email address.

Data storage/retention/destruction/future use

All anonymised responses will be stored for a period of six years in a password-protected directory on an external hard drive to which only the lead investigator has access. After this time the data will be deleted securely.

Right to Withdraw from Participation

You have the right to withdraw from participation at any time without giving a reason however you will be unable to withdraw your answers to the survey once you have submitted them as we will not know who has participated.

Anonymity and Confidentiality

The questionnaire is anonymous and the Qualtrics website will not collect any personal information such as IP and email addresses. Thus, the identity of participants remain unknown to the researcher(s) or any other person. In addition, all responses will be treated confidentially. This study may be published in academic journals or presented in conferences. The committee board of EOLC Society has given their permission for the name of the organisation to be identified in any related publication or presentation.

Thank you for reading this information sheet and for considering participation in this research. If you are happy to proceed to the questions please click on the link below. If you have any questions or concerns, please do not hesitate to contact me.

Survey Link: https://auckland.au1.qualtrics.com/jfe/form/SV_02FZ2TC2YrCo9yB

Thank you very much for your time.

Please direct any queries to Aida Dehkhoda (a.dehkhoda@auckland.ac.nz).

PhD supervisor’s contacts: Phillipa Malpas (p.malpas@auckland.ac.nz), telephone: +64 9 923 3775; and Glynn Owens (g.owens@auckland.ac.nz).

Head of the School of Psychology contact: Suzanne Purdy (sc.purdy@auckland.ac.nz), telephone: +64 9 923 2037.

For any queries regarding ethical concerns, you may contact the Chair, the University of Auckland Human Participants Ethics Committee, at the University of Auckland Research Office, Private Bag 92019, Auckland 1142. Telephone: 09 373 7599 ext. 83711. Email: ro-ethics@auckland.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on 13 March 2019 for three years. Reference number 022679.

#2 Invitation e-mail to the EOLC Society committee board

Dear […],

My name is Aida Dehkhoda, and I am currently undertaking my PhD at University of Auckland, under the supervision of Phillipa Malpas and Glynn Owen. My thesis is exploring the issue of assisted dying for individuals with dementia; specifically, theoretical and practical guidelines to safeguard practice and application. I have carried out two studies so far: one seeking the views of national and international experts on the feasibility of assisted dying for individuals with dementia, the second, exploring the views of online communities (such as Facebook) in relation to assisted dying and dementia.

I have analysed the results and combined the findings, and now would like to elicit the views of an informed and interested group on the level of importance and applicability of these findings. I believe members of the End-of-Life Choice Society would provide my research with an informed and valuable perspective on this important area. Thus, I would be extremely grateful if the End-of-Life Choice Society were supportive of my study and be able to extend an invitation to all members to participate in this study via the Society's electronic newsletter, and / or by email contact.

The survey is anonymous and conducted online via Qualtrics survey software. The survey asks participants to indicate their agreement or disagreement with 21 statements (i.e.: the combined findings from the two previous studies). It should take no longer than 15 minutes to complete. Participation is voluntary and no individual (or their IP address) would be identifiable by the researchers, thus participants can be assured of confidentiality of their responses.

Currently I am applying to the University of Auckland Human Participants Ethics Committee for ethics approval to conduct this study. Could you please let me know if the End-of-Life Choice Society would be prepared to send out, to its members, an invitation to participate in my research?

I have taken the liberty of attaching the Participant Information Sheet, and the 21 statements for further information.

If you have any queries, please feel free to contact me (a.dehkhoda@auckland.ac.nz) or Phillipa Malpas (p.malpas@auckland.ac.nz, or (09) 923 3775) to discuss.

I appreciate your time and support in this request and look forward to hearing from you.

Regards,

Aida Dehkhoda

Doctoral Candidate
School of Psychology | Faculty of Science | University of Auckland
Private Bag 92019 | Auckland 1142 | New Zealand
Email: a.dehkhoda@auckland.ac.nz

#3 Invitation e-mail to the EOLC Society members

Subject heading: Invitation to participate in a survey about assisted dying and dementia

Dear End-of-Life Choice member,

My name is Aida Dehkhoda, and I am currently undertaking my PhD at the University of Auckland, under the supervision of Phillipa Malpas and Glynn Owen. My thesis is exploring the issue of assisted dying for individuals with dementia; specifically, theoretical and practical guidelines to safeguard practice and application. I have carried out two studies so far: one seeking the views of national and international experts on the feasibility of assisted dying for individuals with dementia, the second, exploring the views of online communities (such as Facebook) in relation to assisted dying and dementia.

I have analysed the results and combined the findings, and now would like to elicit the views of an informed and interested group on the level of importance and applicability of these findings. I believe members of the End-of-Life Choice Society would provide my research with an informed and valuable perspective on this important area.

Title of study: Safeguarding the provision of assisted dying for individuals with dementia: the views of an informed group

The survey is anonymous and conducted online via Qualtrics survey software. The survey asks participants to indicate their level of agreement or disagreement with 21 statements (i.e., the combined findings from the two previous studies). It should take no longer than 15 minutes to complete. Participation is voluntary, and no individual (or their IP address) would be identifiable by the researchers; thus, participants can be assured of the confidentiality of their responses. In addition, participants have the right to withdraw from the survey at any time.

This email is being sent to you by the EOLC Society, inviting you to participate in my study. The EOLC Society has kindly given permission for this email to be sent to you.

If you are interested in finding out more about the study, please read the Participant Information Sheet (PIS) attached in this email. It provides information about the project's description and procedure, data storage and usage, right to withdraw, and anonymity and confidentially.

Please use the survey link that is provided in the PIS or simply click on the link below to take you to the survey:

'By completing and submitting the survey your consent is assumed'

Link: Survey

Thank you for considering this,

Aida Dehkhoda

#4 Questionnaire

Thank you for helping me with my research. You are free to stop the survey at any time, but once you have clicked on the “Submit” button you cannot withdraw your comments as the survey is anonymous. This is because there is no way to link your comments to you.

As you may know, laws which permit assisted dying normally require that the patient be competent to request such assistance and to receive it. This would typically exclude individuals with dementia whose mental capacity is lost. However, it is quite common for some patients to feel that if they were to develop dementia, they would not want their lives to continue in certain circumstances.

This study focuses on the practice of ‘assisted dying’ that captures two end-of-life practices that bring an intended end to the life of a competent patient at her/his explicit request:

Euthanasia: the administration of a lethal dose of medicine by an authorized practitioner.

Aid-in-dying: the prescription or supply of a lethal dose of medication by an authorized practitioner.

These definitions exclude practices that may hasten death by withdrawal or withholding of life-sustaining treatments, non-resuscitation decisions, futile treatments, and the alleviation of pain and symptoms.

Advance assisted-dying directive: a written instructional directive requesting an assisted death in the future event that the individual has lost competency to make an informed request.

Link: Participant Information Sheet

‘By completing and submitting the survey your consent is assumed’

Statements	Strongly Disagree	Disagree	Slightly Disagree	Do not have knowledge	Slightly Agree	Agree	Strongly Agree
1. Assisted dying laws should include dementia.	○	○	○	○	○	○	○
2. The provision of clear advance assisted-dying directives, written by competent persons, would safeguard their instructions in the future.	○	○	○	○	○	○	○
3. Only individuals should choose an assisted death in advance; no one else should make the choice for them.	○	○	○	○	○	○	○
4. The provision of assisted dying for people with dementia is essential as it would protect them and their carers/families from unnecessary suffering.	○	○	○	○	○	○	○
5. When competency is lost, health professionals should NOT have authority to make assisted dying decisions based on their interpretation of the former and current written wishes of the patients.	○	○	○	○	○	○	○

6.	Controlling their end of life through an advance assisted-dying directive may decrease the psychological and existential suffering/distress of the patient.	○	○	○	○	○	○	○
7.	Competency should be confirmed at the time of completing the advance assisted-dying directive, rather than at the time of assisted dying administration.	○	○	○	○	○	○	○
8.	The classification of ‘terminal illnesses’ in assisted dying laws should be changed to cover all debilitating and irreversible illnesses including dementia.	○	○	○	○	○	○	○
9.	There is a need to improve the quality of end-of-life care tailored to the unique needs of each individual with dementia.	○	○	○	○	○	○	○
10.	A regulatory system that monitored assisted dying practices for individuals with dementia, would mitigate abuse.	○	○	○	○	○	○	○
11.	If the previously expressed assisted dying request of a competent individual conflicted with their current (incompetent) desire, assisted dying must NOT be carried out.	○	○	○	○	○	○	○
12.	Having depression and making an assisted dying request are NOT mutually exclusive.	○	○	○	○	○	○	○
13.	The current wishes of now incompetent patients with dementia must not override their prior competent wishes.	○	○	○	○	○	○	○
14.	A health professional should act upon the competent advance assisted-dying request even when the patient can no longer confirm those previous wishes.	○	○	○	○	○	○	○
15.	Patients must clearly state in their advance assisted-dying directive what they mean by ‘unbearable suffering’.	○	○	○	○	○	○	○
16.	There is a need for more information and education about the role of dementia and assisted dying on a societal level.	○	○	○	○	○	○	○
17.	Having video recorded interviews with patients would increase the validity of their advance assisted-dying directive.	○	○	○	○	○	○	○
18.	When competency is lost, family/carers should NOT have authority to make assisted dying decisions based on their interpretation of the former and current wishes of the patient.	○	○	○	○	○	○	○
19.	Patients should decide what unbearable suffering means for them.	○	○	○	○	○	○	○

Health professionals need to be trained in:							
20. (20a). Initiating conversations about assisted dying and conveying relevant information	○	○	○	○	○	○	○
21. (20b). Providing an assisted death service	○	○	○	○	○	○	○
22. (20c). Providing support to other professionals involved in the process and to the patients as well as their families/carers	○	○	○	○	○	○	○
Families/carers of people with dementia are more likely to desire access to assisted dying for themselves if they have: 23. (21a). Feelings of guilt and/or uselessness when they can't assist their loved ones to die as they wished.	○	○	○	○	○	○	○
24. (21b). Difficulty witnessing their loved ones' 'pointless suffering'.	○	○	○	○	○	○	○
25. (21c). Suffered the distress of watching their loved ones die and do not want to burden their family if they developed dementia.	○	○	○	○	○	○	○
26. (21d). A fear of following the same path as their loved one.	○	○	○	○	○	○	○
27. (21e). Thought they might end their life while they were still able to do so.	○	○	○	○	○	○	○
28. (21f). Experienced a tension between helping a loved one to die illegally as they had wished or watch them suffer at the end of life.	○	○	○	○	○	○	○

Demographic questions

1. What is your gender?	Female	○
	Male	○
	Gender diverse	○
2. What is your age?	18 - 44	○
	45 - 54	○
	55 - 64	○
	65 - 74	○
	75 - 84	○
	≥ 85	○
3. What is your highest educational qualification?	Primary school	○
	Secondary school/college or equivalent	○
	Bachelor's or Graduate	○

	Postgraduate or Bachelor’s Honours	○
	Master’s	○
	Doctorate (PhD)	○
	Medical Doctorate (MD	○
	Other (please specify)	☐

#5 Results

Categories – Statements	Means	Medians	SDs[1]	Min	Max
Inclusion criteria					
1. Assisted dying laws should include dementia.	6.47	7.00	0.990	1	7
8. The classification of "terminal illnesses" in assisted dying laws should be changed to cover all debilitating and irreversible illnesses, including dementia.	6.58	7.00	1.029	1	7
4. The provision of assisted dying for people with dementia is essential as it would protect them and their carers/families from unnecessary suffering.	6.28	7.00	1.240	1	7
12. Having depression and making an assisted dying request are NOT mutually exclusive.	5.50	6.00	1.443	1	7
Drafting criteria					
5. Only individuals should choose an assisted death in advance; no one else should make the choice for them.	6.42	7.00	1.191	1	7
6. Patients should decide what unbearable suffering means for them.	6.49	7.00	0.895	2	7
7. Patients must clearly state in their AADs what they mean by "unbearable suffering".	5.95	6.00	1.329	1	7
8. Having video-recorded interviews with patients would increase the validity of their AADs[2].	6.08	6.00	1.122	1	7
Implementation criteria					
9. If the previously expressed assisted dying request of a competent individual conflicted with their current (incompetent) desire, assisted dying must NOT be carried out.	4.29	5.00	2.015	1	7
10. When competency is lost, health professionals should NOT have authority to make assisted dying decisions based on their interpretation of the former and current written wishes of the patients.	4.35	5.00	2.276	1	7
11. When competency is lost, family/carers should NOT have authority to make assisted dying decisions based on their interpretation of the former and current written wishes of the patient.	4.94	6.00	2.095	1	7
Harm/abuse mitigation criteria					
12. The provision of clear AADs, written by competent persons, would safeguard their instructions in the future.	6.55	7.00	0.909	2	7
13. Competency should be confirmed at the time of drafting AADs, rather than at the time of assisted dying administration.	6.62	7.00	0.702	2	7

14. Controlling their end of life through AADs may decrease the psychological and existential suffering/distress of the patient.	6.54	7.00	0.886	1	7
15. The current wishes of now incompetent patients with dementia must not override their prior competent wishes.	5.18	6.00	1.781	1	7
16. A health professional should act upon the competent AADs even when the patient can no longer confirm those previous wishes.	6.09	6.00	1.344	1	7
17. A regulatory system that monitored assisted dying practices for individuals with dementia would mitigate abuse.	6.13	6.00	1.194	1	7
Prerequisites for optimum practice					
18. There is a need for more information and education about the role of dementia and assisted dying on a societal level.	6.52	7.00	0.748	3	7
19. There is a need to improve the quality of end-of-life care tailored to the unique needs of each individual with dementia.	6.23	7.00	1.076	1	7
20. Health professionals need to be trained in:					
20a. Initiating conversations about assisted dying and conveying relevant information	5.54	6.00	1.430	1	7
20b. Providing an assisted death service	6.34	7.00	0.950	2	7
20c. Providing support to other professionals involved in the process and to the patients as well as their families/carers.	6.55	7.00	0.657	2	7
Contributor factors to desire for an assisted death					
21. Families/carers of people with dementia are more likely to desire access to assisted dying for themselves if they have:					
21a. Feelings of guilt and/or uselessness when they can’t assist their loved ones to die as they wished.	5.54	6.00	1.430	1	7
21b. Difficulty witnessing their loved ones’ “pointless suffering”.	6.03	6.00	1.201	1	7
21c. Suffered the distress of watching their loved ones die and do not want to burden their family if they developed dementia.	6.08	6.00	1.093	1	7
21d. A fear of following the same path as their loved one.	6.15	6.00	1.083	1	7
21e. Thought they might end their life while they were still able to do so.	5.89	6.00	1.277	1	7
21f. Experienced a tension between helping a loved one to die illegally as they had wished or watch them suffer at the end of life.	5.94	6.00	1.188	1	7

[1] Standard deviation

[2] Advance assisted-dying directives

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