Patient choice as illusion: Autonomy and choice in end-of-life care in the United Kingdom and New Zealand

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Abstract

Death is a reality of life as we will all die. Despite this inevitability, death in the twenty-first century remains unwelcome and has been sequestered into the enclaves of medical practice as a means of quelling the rising tide of fear it provokes. Using a narrative analysis approach to examine online social media commentary of personal experiences, this research explores the reality of patient choice at end-of-life in the United Kingdom (UK) and New Zealand. Specifically it examines the barriers encountered when individuals seek control of the dying trajectory and how this unfolds for the patient compliant with the medicalised 'good death' and for those seeking the right-to-die; contextualising these issues within the human rights framework.[1]

This research explores the means through which medical practice maintains power over the dying individual, actualised through the use of specialist knowledge and the medical vernacular. It compares the use of specialist palliative models of care with euthanasia and assisted suicide, and examines the selective collaboration between medicine and law as a means of subverting the individual who attempts to disrupt the contemporary accepted norms when dying.

My research suggests that patient choice when dying is an illusion in practice, despite individual choice being considered an essential component in clinical decision making. I highlight that those seeking the right-to-die disrupt the normative compliance expected in the doctor/patient relationship, thus, positioning them as deviant and other. I suggest that there is a potential weakness in the construct of medical power and is evidenced in the selective reliance upon law when clinical decisions are challenged by the deviant individual. Finally, I suggest that although the equity in the doctor/patient relationship remains unbalanced at present the right to choice at end-of-life remains a potent prospect; with the re-invigoration and re-presentation of the *Ars Moriendi* having the potential to reflect the self-centricity of the contemporary Western individual to access the 'good death' of choice.[2]

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[1] A 'good death' is suggested to be one that is pain free, dignified, and one in which active resuscitation never occurs (Jones & Willis, 2003).

[2] *Ars Moriendi*, translates from Latin as the 'art of dying' and refers to a literary narrative of the same name developed at the beginning of the fifteenth century.

In loving memory of my father

David John Johnstone

1939 - 2012

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Introduction

"It is necessary to meditate early, and often, on the art of dying to succeed later in doing it properly just once." (Eco, 1998, p. 132)

Introduction

Death is all around us, it pervades our daily existence, yet it is simultaneously invisible. It is the absolute consequence of living. Death is a known inevitability, yet it remains an unknown entity; it cannot be avoided in the long term, it will not disappear, and it will happen to every living, breathing creature, yet is 'swept under the carpet'. Death will come to us all, it is immutable, with only when, how and where as yet to be determined. However, through the contemporary self-centric need for control over the minutiae of life and the pursuance of a 'good death', the when, how and where of death have become subject to increasing scholarly, media and individual attention.

The construction of a 'good death' has transcended the religious prescription of how dying occurs, with the contemporary notion of a medicalised death now meeting this criteria. This move has witnessed the religious framework of the *Ars Moriendi* as being no longer relevant to the contemporary death, as medicine is portrayed as being able to meet the needs of the dying patient today. This is evident in the construction of specialist medical practices to care for the dying, under the global umbrella of palliation and the subsequent development of specific medical models of care to provide symptom relief for the dying individual.[3] However, in its guidance towards how the contemporary death may now appear, medicine overlooks the role of individual subjectivity and the preference for specific experiences at this life point. This is highlighted in the legal cases where individuals no longer wish to endure the suffering associated with incurable or degenerative conditions and seek an end to the prolongation of both living and dying, through pursuing the right to choice and death when their suffering becomes intolerable.

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[3] Medical models of care refer to the *Liverpool Care Pathway* or palliative sedation therapy, and will be discussed in detail in chapter two.

The role of intolerable suffering provides a focal point in the discussion regarding the trajectories available to individuals at end-of-life; as the compliant dying patient is offered symptom relief through the application of palliative models of care, but those seeking choice and individualism become constrained by their activism, with their preference of death being denied. This presents a juxtaposed situation for those towards death, as the medical models of care used in palliation are not dissimilar to the means through which assisted suicide is achieved, with the only differing factor appearing to be the lens of authority attached to each practice.

Palliation functions legitimately under the jurisdiction of medical practice; however, assisted suicide becomes entangled in legal doctrine, thus locating the self-determined dying individual within the boundaries of both medical practice and law. Clinical decision making for the dying patient, however, appears less resolute in the context of medicine's need to collaborate with law on occasions when challenged over care practices at end-of-life. More specifically, medicine relies upon legal statute when it wishes to conduct practices that patients do not consent with that may induce an early death, but simultaneously engage with law when individuals seek the right-to-die, which currently is illegal in many Western countries.

The collaboration of medicine and law produces a powerful resource with which the self-determined individual must engage if true choice and equity in decision making is to be achieved at end-of-life. The right to choice and right-to-die discourses dominate contemporary social mediums of communication in Western cultures, but remain elusive in reality, despite individual choice being the product of much marketing. Medicine is a curative field of practice and to accept that death is inevitable proves problematic for many practitioners and is evidenced in both the prolongation of living and dying. That clinicians may not be able to meet the needs of the dying, or those experiencing intolerable suffering produces a reflexive abhorrence in that their expertise is insufficient to quell the rising storm of those seeking control as they move towards death through methods that do not align with medical care.

It is, therefore, this contemporary desire for control of the self at end-of-life that is proving problematic within the context of the medical narrative of care. To consider death as preferable to that of life produces a subtext of otherness for the individual involved.[4] It locates the self-determined individual outside the boundaries of the contemporary medicalised 'good death'. To be other, however, does not quell those seeking the right to choice and the right-to-die, as such individuals remain resolute to their beliefs that control of the self should be attainable in death as it is in many other spheres of life; and that the right to choose one's dying trajectory, whether medicalised or not, should not be contained and constrained by the powerful expert, but be attained in a similar manner to lives led. This research will, therefore, address these issues to ascertain whether such concerns are a reality for those seeking such autonomy of the self.

There is, however, already an extensive and rich field of sociological literature available on death and dying, suicide and medical law, engaging with a diverse range of perspectives, documenting the historical significance of rituals and customs associated with death, the social construction of death, medicalisation of the dying and the social anxieties death imposes on cultures. Notable authors include Allan Kellehear's *A social history of dying* (2007), Phillipe Ariés and *The hour of our death* (1981) and Ivan Illich's *Medical nemesis* (1974), which is closely aligned with the medicalisation critique, for example. More specifically, and in relation to the sociology of palliative care, the works of Camilla Zimmerman, *Death denial: obstacle or instrument for palliative care? An analysis of clinical literature* (2007) and *The denial of death thesis: sociological critique and implications for palliative care* (2004) are significant contributions to the denial of death discourse and the effects this may have on effective care at end-of-life, together with Clive Seale and his research into continuous deep sedation, euthanasia and physician assisted suicide, exemplified in *Hastening death in end-of-life care: a survey of doctors* (2009) and *Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes* (2009a). Pertinent, however, to the notion of patient choice, but related to the ageing individual more specifically, the work on palliative care issues of Jane Seymour

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[4] 'Other' or 'otherness' refers to the social identities of those individuals who sit outside the cultural boundaries of what it perceived as being 'normal' practices (Ryan, 2012; Okolie, 2003).

(2007) enhance the debate on the suffering individual; together with Annemarie Jutel (2015) and her work on the relevance of clinical diagnostics.

In acknowledging the existence of such wide-ranging fields of research, however, it is notable that a gap exists in the literature, whereby the selective collaboration between medicine and law in limiting individual patient choice at end-of-life, thus, controlling the way we die in the UK and New Zealand is absent. More specifically, this research will consider the patient choice and right-to-die discourses through the lens of the human rights framework as a means of self-actualisation; within the context of the roles played by medicine and law in denying individuals the right to control the demise of the self at this time.

In reviewing the literature on death and dying, and due to the expansive nature of the topics it is impossible to navigate a means to encompass it all within this research. In considering this, I have carefully selected a number of key works through which to explore these issues. In utilising, therefore, Ivan Illich's *Medical Nemesis* (1974), together with the work of Peter Conrad on medicalisation, it provides a foundation upon which to build the research argument. In supporting this, I also engage with the many works of Michel Foucault as a means to develop the argument regarding the monitoring, surveillance and expected compliance of individuals with powerful institutions and the potential inequity in such relationships.

Furthermore, I utilise Foucault's *Birth of the Clinic* (1973) and his development of the *medical gaze* as a means to both macro and micro analyse the clinical situation dying patients find themselves in.[5] In developing the argument I also use the works of Brian Turner in relation to the sociology of human rights and medical power, Foucault's work on knowledge and power and introduce Pierre Bourdieu's work on social, symbolic and cultural capital in relation to the expert knowledge of the clinician, to provide a depth of analysis as a backdrop to the issues at hand.

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[5] The *medical gaze* (Foucault, 1973) was conceptually perceived as being used at a macro level in relation to the subjectivity of the human body; however, for the purpose of this research, and in addition to the original usage of this concept, I take the *medical gaze* and consider its usefulness at a more micro level as a means of analysis.

The works of Martin Heidegger in *Being and Time* (1962) together with *The Humanism of Existentialism* and *Being and Nothingness* by Jean-Paul Sartre (1946; 1977) provide a useful background in the need for a contemporary engagement with the reality that death will occur; and the works of Zygmunt Bauman and the contemporary anxieties of death and dying. The *Letting Go* narrative of Atul Gawande (2010) moves us forward from the fear of dying through his promotion of the need to let go of the dying individual, although this is written from a medical perspective. Finally, I move forward and engage with contemporary literature, obtained through the online social media means of communication, and capture the essence of blogging in the writings of Kate Granger (2012) and her perception of the role of the clinician in end-of-life decision making, together with the findings of the *Neuberger Report* in the UK (2013), which relates specifically to the misuse of medical models of palliation in the UK in the past decade.[6][7]

Finally, there is an interesting selection of literary narratives produced regarding the role of the *Ars Moriendi;* however, much of this literature is written from a historical or medicalised perspective and not that of sociology. It is notable in particular, through the works of Atul Gawande (2010), and his 'letting go' discourse that the re-framing of the art of dying remains firmly contextualised within the medicalised model of dying. In acknowledging this literature, it is evident that there is a further gap in the body of work on the *Ars Moriendi*; with this research considering the futural role of this literary framework as a means to engage the contemporary Western individual in the dying trajectory, but locating it outside the boundaries of medical practice.

Research objectives

The objectives identified for this research are produced through the consideration of the current situation in end-of-life care in both the UK and New Zealand in relation to the gap in the literature previously identified. The primary objective is to consider how the constructs and constraints of medicine and law influence the notion of patient

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[6] The *Neuberger Report* refers to the *More care, less pathway: review of the Liverpool Care Pathway* (2013): An Independent Review of the *Liverpool Care Pathway.*
[7] Kate Granger is a 35 year old Medical Registrar (a senior clinician within a hospital setting), who has sarcoma (a cancer of the bone).

choice for the dying individual in the UK and New Zealand. Specifically I compare the legal implementation of palliative models of care for the dying with the illegal acts of euthanasia and assisted suicide, thus, examining the experiences of those who pursue the right to choice and control of the self at end-of-life, to determine whether choice is a reality at this time.

A further objective is to explore the consequences, if any, for those individuals who rally against the accepted norms in terms of acquiescence with medical practices at end-of-life, and the repercussions of such actions. Specifically I consider the dissemination of medical and legal knowledge as a means of power and authority over the self-determined dying individual.

The final objective of this research is to examine how the dying process in the UK and New Zealand can become an inclusive process in order to meet the needs of the contemporary self-centric individual. Specifically, I explore the potential re-invigoration of the *Ars Moriendi* as a vehicle to produce a new narrative of an artful death that embraces and accepts the individuality of personal choice at this life stage.

A personal perspective

My fascination with death stems from an early age, but my interests were merely in the solemnity and peacefulness of cemeteries. To walk among the tombstones of those who had lived their lives provided a stillness in our hectic world. Reading memorials scripted by those left behind provides a poignant reminder of the transience of our existence. To this day, cemeteries and burial grounds provide me with a tranquility that I find hard to pinpoint anywhere else. My first experience of death was personal, my maternal grandmother which, in retrospect, may have been the point at which my fascination with graveyards turned into a motivation to transform my interest into a professional career; not so much a mortician or forensic scientist, but a role supporting the transition from life to death.

Throughout my 25 years as a registered nurse I have encountered death in all forms from murder, suicide, accidents, through to degenerative conditions or a slow death from cancer in both the UK and New Zealand. They are all different except for the inevitable ending of existence as we currently understand it. Today I work in

specialist palliative care in New Zealand, a role that is both challenging and often misunderstood. The challenge is bringing the reality of death into peoples' homes in an acceptable format, as evasion of death remains a prominent discourse.

My professional work, as well as my personal experiences are, therefore, relevant to this work, but are utilised through the engendered practice of reflexivity actualised over the many years of my nursing practice and academic study. I use this experience, therefore, not to influence the direction and outcome of my research, but to allow an academic engagement relative to the encounters I have experienced, to produce viable and valuable outcomes for future research, clinicians and patients.

Research structure

This thesis comprises of nine chapters and is focused upon the contemporary dynamic of the right to choice and the right-to-die in relation to end-of-life care in the UK and New Zealand. As such, the first chapter will provide a brief history of dying and the human understanding of death together with the changes in attitudes and practices that have occurred over the centuries in Western societies; with this framework underpinning the development of contemporary anxieties regarding the death of the self.

Following on from this, the second chapter is dedicated to addressing the theoretical, cultural, medical and legal issues that arise when dying patients seek the right to individual choice at end-of-life. This chapter specifically examines the construction of palliative medicine and the prolongation of death discourse contextualised in relation to the notion of patient choice and the relevance of human rights in clinical decision making, and the inherent subjectivity of such practices. It also considers the selective collaboration of medicine and law and individual resistance to this. This is examined within the framework of ethical practices relating to end-of-life decision making, the positionality of law with regards to how palliative models of care differ from that of assisted suicide and euthanasia; together with discussing the ways in which medicine and law approach the contentious issue of having the right to death. The third chapter contextualises the theoretical component of this research with the clinical and legal practices of the UK and New Zealand; thus, providing relevant contemporary examples of individuals seeking the right-to-die, highlighting the similarities and

dissimilarities in practices for both countries. Chapter four introduces the methodological approaches to this research, the obstacles encountered and the outcomes produced; while considering the ethical implications of this research.

Following this, the discussion is written across three chapters, five, six and seven. Chapter five analyses the application of medical and legal power in relation to patient choice at end-of-life; and is achieved through discussing the role of religion in contemporary medical decision making and the power of medical discourse in directing the contemporary 'good death'. These modalities of power are highlighted through compelling narratives of personal and professional experiences together with the conclusions drawn from formal inquiries into practices. In chapter six I consider those individuals seeking their right to choice and death as being deviant in relation to accepted societal norms. Specifically I analyse the role of authoritative power, the power relations of control and disruptive practices in relation to medical and legal directives, expressed through narratives of fear and distrust in contemporary practices.

In chapter seven, the final discussion chapter, the experiences of individuals and professionals are further examined through the lens of symbolic violence in relation to expert knowledge and language. It also examines the misrepresentation of language choices and the value of anonymity in narrating experience as discussed and framed within the discourse of equity in power relations. Finally, this chapter discusses the future proofing of individual choice at end-of-life through an examination of discourses to ease the burden of intolerable suffering; together with considering the relocation of the contemporary death beyond that of the medical framework, to one which embraces individuality and personal choice. As a final point, the conclusion draws deductions and suppositions in light of the literature and data engaged with; highlighting the key findings from the research, research limitations and recommendations for future study.

Chapter One

"The fear of death follows from the fear of life."
(Mark Twain)

Death and dying: history

Introduction

The practices of death and dying have undergone cultural shifts over the centuries within the context of Western values and, as such, has seen the process of dying transform from an open and accepted part of living towards an elusive, secluded, unnatural and often controlled process. Dying has changed from being a natural and expected outcome of living towards representing failure despite the inevitability of the process. This fundamental shift in caring for the dying has produced a narrative of distaste when individuals wish to die as they have been able to live; that is through exerting the right to choice and, as such, the potential right to death if that is their preference. This is particularly notable as occurring in late modernity and is culturally dominant amongst people of European descent. Moreover, the penchant for individualism that has developed over the past 50 years within Western societies portrays an imagery that individuality and choice are tantamount to success, resulting in a problematic trajectory to death when such choice is not truly available.

I have, therefore, chosen to utilise a theoretical framework in order to contextualise this research which is written across three chapters, one, two and three through which I explore the contemporary engagement with the right to choice and the pursuance of the right-to-die, contextualised within the remit of medical and legal power. In this chapter I explore the subjectivity of death and dying, provide a brief history of dying from a social perspective, together with the influence of the *Ars Moriendi* in practice; and the positionality of fear and anxiety relating to this life event.

What is death and dying?

Death often remains unacknowledged, unmentionable and almost invisible in the context of daily life across Western cultures (Wilson, 2012).[8] The advances of individualism and secularism have led to a widespread deception that suffering, dying and death does not exist within the context of our daily living (Becker, 1973). This preferred obscuration of this natural end to living, however, provides a platform through which anxieties of death and dying can be produced and reproduced, thus death retreats to the unspoken enclaves of our society.

Death, as with the idea of life, becomes problematic when trying to reach a firm definition of what it is, particularly as the perception of death is an abstract, non-objectified notion (Mason, 2011), rather than being object specific. Death is empty as we currently understand it, having no functionality or purpose; other than to signal the cessation of biological function. Cultural understandings of death are built upon foundational belief systems which have existed since antiquity; with questions remaining regarding what death is and what it represents. However, we will never actually know death when it comes, as although we will all die, death will occur once we have passed into unconsciousness, leaving us unaware of its transpiration (Mason, 2011). To conceptualise death, therefore, appears impossible, as how can we quantify, explain and clarify something that is beyond our experience? Our individual deaths occur in the reality of those we leave behind, as for ourselves we no longer have knowledge of our non-existence. The moment of death, however, is dependent upon individual interpretations of when death occurs (Black, 2013) and, therefore, is subject to the subjectivity of individual agents.

Death, therefore, is the end to living, but questions remain unanswered as to when death occurs and to what part of the living being. Death is part of the life continuum, as we start by not existing, then exist and finally return to non-existence (Lane, 2013). It may be questioned, however, whether death occurs merely with the cessation of vital organs as the "body's organs and tissues do not die simultaneously" (Charlton, 1996, p. 956), or whether aspects of consciousness exist post mortem.

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[8] Daily life is referring to the day-to-day activities of individuals, families and groups and not to the media representations of dying for entertainment or journalistic purposes.

Human death has been defined fundamentally as the termination of life (DeGrazia, 2011), but biologically defined as the stopping of all biological functions of the body, or the "condition of being without life" (Nadal, 2011, p. 1). It is the end to organic existence, transforming the body into an inorganic status as "…the organic becomes the living…" and "…in the inorganic is the non-living…" it is the "inert, unfruitful – death" (Foucault, 1970, p. 232). A complete definition of death is difficult to quantify as the criteria for being pronounced dead has changed from simply the stopping of the beating heart in previous centuries, to what is now considered brain stem death, or the cessation of brain activity (Black, 2013; Marchant & Middleton, 2007).

This shift in definitions of death has been produced through the evolution of scientific discoveries, the development of medical practices and the simultaneous advancement in technology. A leading work on this was the President's Commission for the study of ethical problems in medicine and biomedical and behavioural research which produced the *Report on the Medical, Legal and Ethical issues in the determination of death (*1981), which sought to secure the definition of what death is as being "a matter of statutory law" (p. 1). More specifically, although there is notable criterion for diagnosing brain stem death (Black, 2013; Charlton, 1996), the literature remains limited but ever evolving in this field, leaving medical professionals together with lay persons in some doubt as to the point when one passes from existence to perceived non-existence. This is notable, for example, through the recounting of scenes in near death experiences when patients have been declared physically deceased but came back to life, thus questioning the potential existence of consciousness after the physical death has occurred.

A recent study has posed the possibility that the brain does continue to function after cardiac activity ceases (Parnia, Spearpoint, de Vos, Fenwick, Goldberg, Yang & Schoenfeld, 2014).[9] It appears that the conscious awareness of patients in the study, who were pronounced dead, continued for up to three minutes before being resuscitated, with them subsequently being able to recount accurately the events in

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[9] One specific individual in this study was able to accurately recall the medical events after he had suffered a cardiac arrest, describing the physician attending to him as being "chunky" and having a bald head, wearing blue scrubs and hearing medical staff say "shock the patient, shock the patient…" (Parnia et al, 2014, Table. 2); all of which was later substantiated through the medical records.

the resuscitation room (Parnia et al, 2014). This new study presents the juxtaposition of a body being perceived as dead from the perspective of the living, but may indeed be alive; and demonstrates that even through advancements in knowledge and our understanding of the biological form, the inability to truly define what death is, exposes the fragility of a concept that is open to subjective adjudication on what constitutes life, living and death (Charlton, 1996).

The permanence of death, in that there is an irreversible alteration to biological processes (Black, 2013), and that "life ends when the physiological systems of the body irreversibly cease to function as an integrated whole" (Luper, 2009, p. 1) validated the notion that life is over when brain function stops; that was until Parnia et al's (2014) research. An alternate perspective, however, is the rationale held by some scientists that mortality is genetically programmed into living beings, as a path of self-destruction once the usefulness of the body for evolutionary purposes has passed (Lane, 2013) and, thus, may provide some insight into the process and point of decay and dying.

The truth is that we currently do not fully understand what happens to the self at the point of death, as we are not able to return to living once truly dead. We are no longer able to police ourselves within the construct of society, or regulate our thoughts and conducts according to the constraints of the cultures in which we lived, irrespective of the fact that the self is always in a state of flux (Foucault, 1988). However, the remains of ourselves, in the form of the embodied self, are still subject to the power and structures of the regulatory bodies. As the self is no longer able to control the way we are perceived by others, and the physical self is now constrained by the functionality, ritual and routine of disposing of the deceased, the "temporary and illusionary existence of earthly life" (Minissale, 2012, p. 5) becomes evident to those still alive. The perceived separation of the physical self from consciousness can only be attempted to be understood through the constraints and structures of different discourses, whereby the embodied self that is perceived to function dualistically and interdependently in terms of mind/body, may in fact not be as dependent as previously thought. Even through the advances of science and medicine, and the undeniable fact that all living beings die, and that death can be pronounced, the ideas of post mortem consciousness (or not) remains purely

speculative, even in light of current research findings. Such ideas, therefore, produce and reproduce the burden of the unknown as being feared within contemporary Western cultures, but simultaneously provide a platform from which a belief in a spiritual afterlife can provide comfort for some.

It is the unknown, and the fear that this attracts, that renders this most natural life event opaque. The prospect that one will, at some point, no longer exist as we currently understand it, poses questions and discomforts that, for many, are simply too difficult to acknowledge until they are confronted by the prospect of dying or death itself. Death remains problematic even while attempting to produce a firm definition as subjectivity, cultural perceptions and the ever changing scientific knowledge base demonstrates how complex this can be; the concept of death under conditions of such uncertainty may be considered a modern day conundrum. Therefore, humans, as highly emotionally evolved beings often struggle to acknowledge, discuss and prepare for the ending of life, as the "state of death defies, radically and irrevocably, our intellectual faculties" (Bauman, 1992, p. 13), particularly when accuracy of what constitutes death is problematic.

The certainty of death, however, is less well acknowledged today in our day to day lives with family and friends than it was by our predecessors. Death was an intimate part of living in previous centuries, through the acceptance of death as an expected event supported through the cultural and religious rituals of the time. Death today, however, is seen through glamourised and/or sensationalised cinematic interpretations of how death occurs, thus, exposing a disparity between reality, fiction and contemporary individual expectations.

Social history of dying
Death rituals vary according to specific cultures but are pervasive throughout human history. The process of dying and the acts of death and grief were essential components of everyday cultural practices connecting the dying to the broader community within which they lived (Cipollo, 1993). Historically, the process of dying and the physical death were highly respected within Western cultures (Kellehear, 2008; Ariés, 1981), as dying was a common part of life through the presence of high infant mortality rates, famine, pandemics and the lack of medical

knowledge to treat such diseases (Scott, 2010). Dying was not solely a personal experience but a communal one (Heller, 2001). Communities cared for their dying participants, often acknowledged by simplistic yet meaningful ceremonies and symbolic gestures leading to an acceptance that death was imminent (Heller, 2001). This provided a comforting and familiar environment within which individuals felt secure when facing their last hours, thus ensuring that death was evident within communities, yet simultaneously reinforcing the fragility of life itself (Illich, 1974).

Historically, humans often sensed an impending doom that death was imminent (Seabrook, 2015) and would alert those closest to them of this; an instinct that remains present today but is often suppressed, as patients withdraw from their social contacts, to spare family members and loved ones from the trauma that life is at its closure (Leming & Dickinson, 2011). The dying person would take to their bed, refuse nutrition and ask forgiveness for sins and forgive those against him, then lay waiting for death to take him (Golden, 2010). This ritualistic behaviour not only highlights the normalcy of dying in these times, but an acceptance of this process as being the natural end to living, even when death was brutal; a matter less well tolerated today. Such lack of tolerance for the naturality of dying, together with the fear of the unknown produces a discourse of invisibility and isolation for the dying in the twenty-first century and, as such, replaces tradition with a new image of death (Ariés, 1981).

Dying is now less likely to occur in the family home, a home where one might have lived for many years, surrounded by memories, thus suggesting that it is probable that patients are transported in their last hours of life, separated from familiarity, to be cared for within the socially constructed, medically controlled sterility of a clinical setting.[10] This is despite hospitals being the least well equipped environment in which to care for the dying, as the dying patient is often seen as being of low priority in terms of healthcare needs within the acute setting (Ahmed & O'Mahoney, 2005). This relocation of the dying from home to hospital is evident given that by the end of the twentieth century the number of people dying at home had halved, with predictions indicating that in the UK less than one in ten will die at

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[10] A clinical setting includes acute hospital units, hospices and any other end of life care facility within society.

home by 2030 (Gomes, Calanzani & Higginson, 2012; Leadbetter & Garber, 2010); and only 31 per cent of cancer patients achieve this in New Zealand (Ministry of Health, 2001).[11] Moreover, the latest data available in New Zealand indicates that New Zealand is following the UK trend with 6,811 individuals dying at home in 2013, compared with 20,095 dying in a clinical or shared setting (Ministry of Health, 2015).[12] This data, however, contradicts the indicated preference of three out of every five people wishing to die in the comfort of their own home surrounded by family and friends (Leadbetter & Garber, 2010).

Care of the dying has become institutionalised through the socially constructed paradigm of individuals needing expert care in the final days of living, which results in the aspiration to die at home appearing to be less achievable today than previously (Leadbetter & Garber, 2010). There is recent data suggesting that hospital deaths are reducing in the UK, with a fall of eight per cent over the past ten years (Fox, 2013). However, this does not automatically mean that home deaths are on the rise merely that individuals are not dying in an acute hospital setting.[13] This reduction in hospital deaths is not present in the New Zealand statistics, with hospital death figures remaining relatively static over the past five years (Ministry of Health, 2015). The implications of this data suggest that if home deaths are continuing to fall, the dying must be being cared for outside of the acute hospital and, as such, within institutions with private hospitals, nursing homes or hospice environments being the likely locations.

Despite this data suggesting that home death statistics remain low and that home deaths will continue to reduce over the next 15 years there is one study, funded by King's College London, which suggests that the trend for institutional deaths is being reversed, with just over 20 per cent of deaths in the UK in 2000 occurring at home, compared with 18.3 per cent in 2004 (Gomes et al, 2012). This small reversal in figures over a six year period, however, is unlikely to be indicative of a true trend reversal, when the same study predicts that only one in ten of us will die at home by

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[11] It is notable that for Māori and Pacific peoples, the figure for individuals dying at home is 53 and 42 per cent respectively (Ministry of Health, 2001).
[12] A shared setting includes public hospitals, private hospital, nursing homes and rest homes.
[13] As home does not necessarily refer to an owned property. Home may now be a room in a rest home or private hospital or nursing home, but is classified as home.

2030. Yet, the authors of this study fully support this reversal, stating that "what seemed an enormous task has happened – the reversal of the longstanding British trend towards an institutionalised dying [sic]." (Gomes, 2012, para. 10). However, the reality appears that the trend for an institutional death will actually increase both in the UK and New Zealand (Gomes et al, 2012) and, as such, poses the possibility of the 'artful' death being re-presented today within a context of invisibility and fear.

Ars Moriendi: the 'art of dying'

Ars Moriendi, translates from Latin as the 'art of dying' and refers to an eponymous narrative of the same name developed at the beginning of the fifteenth century. The literature comprised of both text and images, thus making it available to the educated and illiterate, as well as the religious leaders of the time, in order to offer guidance to achieve a good death (Beaty, 1970).[14] It specifically refers to the religious concerns of the Christian populations of Europe between the fifteenth century and the end of the seventeenth century (Osborne, 2013; Atkinson, 1992), and is rich in content and illustration. Embedded in the popularised narratives of the *Ars Moriendi* is the notion that these works represent a pathway to dying well and not a discourse encountering fear and distress. It is assumed that the writings guide the dying person, not only to meet the needs of their religion, but to ease the burden of passing, ensuring an acceptable outcome for all concerned. More specifically, *Ars Moriendi* assured the dying that there was nothing to be afraid of, to have faith, spiritual pride and avoid despair, impatience and avarice, despite depictions of the devil or evil spirits in the images. It guided family and friends in appropriate prayers for the dying to provide comfort at this time, thus ensuring the dying had the best death possible (Blake, 1982).

Consequently, this normalisation of the dying process, and the rituals associated with it may be viewed as an art form, in so much as there was a pattern of good behaviour adhered to when the end was nigh, ensuring dignity of the dying individual within the context of the community setting. Rituals and behaviours helped to make sense of what was occurring. Life was fragile and often short with

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[14] Images of the *Ars Moriendi* can be found by following this link:
http://bav.bodleian.ox.ac.uk/news/ars-moriendi-the-art-of-dying

religion dominating societal behaviours including dying. The Church controlled life from birth to death, through the application of sacraments; baptism at birth and extreme unction when approaching death, thus ensuring that individuals died in accordance to rituals, traditions and religious requirements. It could be argued, however, that fear and anxiety were indeed part of the religious package and of the *Ars Moriendi* in the depiction of evil, thus control was contained and maintained through compliance with the power of the Church. Such processes ensured that support and comfort were available when facing the unknown entity of dying (Scott, 2010) and, as such, provided the framework to conduct this artful process.

Despite the deliverance of such material by the religious leaders of the time, there appears to be some hesitancy around the natural and inevitable nature of dying as a consequence of life, presented in the form of religious fear and uncertainty. The literature simultaneously attempts to ensure that individuals are prepared to meet the needs of the Christian religions at this time when dying, that they are prepared to cope with the process, but that death itself is indeed dreaded (Beaty, 1970). Nancy Lee Beaty, in her work *The Craft of Dying: A Study of the Literary Traditions of the Ars Moriendi in England* (1970), notes that religious leaders feared death as being "…difficult, dangerous", and "ryght ferefull and horrible"… ' (p. 7). This written fear of religious practitioners belies the more positivist propaganda advocated for the general population, thus suggesting the existence of conflicting discourses into the proclamation that dying is a natural process not to be feared. It is suggestive that despite the hierarchies enjoyed by the religious leaders of the time, they were mortal and fearful of the unknown experience that is death.

As death and dying have shifted away from practices founded in religion and now focus upon medical interventions at this life stage it is said that "nursing the dying is an art form" (Carter, 2014, p. 2) and "end-of-life care is an art" (Bryan, 2013, p. 1) and, thus, not a wholly scientific practice. With this shift, dying has moved from being visible and artful towards invisibility, existing at the edges of our consciousness (Ariés, 1981). The routine "mechanising and protocolising" (Bryan, 2013, p. 3) of many aspects of care renders dying less of an art form but rather a set of instructions and tick boxes for completion by healthcare staff (Sleeman, 2013),

with this contemporary cultural response to death producing not only death denying societies, but allowing the creation of narratives enhancing its mystery and terror (Ariés, 1981). Yet, as healthcare professionals are the "gatekeepers between life and death" (Timmermans, 1998, p. 454), and that times have changed in clinical practice, these individuals in positions of power still administer care according to the perceived social value of the patient (Sudnow, 1967).

As dying becomes bureaucratised and conducted within specialist institutions such as the acute hospital, hospice or nursing homes, the social role of formal caretaking evolves. Max Weber describes this as being the means through which bureaucratisation of society removes many social functions from family and fellowship networks and places them in autonomous institutions that are independent of emotional ties, thus, depersonalising them (Coser, 1977). Therefore, as the movement away from community and ritual towards the bureaucratic management and medical treatment of the dying occurs, aligning with the current values and structures that shape the society as a whole, it would appear a logical conclusion for the dying patient to comply with the broader patterns of social living. Contemporary Western cultures have, therefore, "deconstructed mortality" (Bauman, 1992, p. 131), leaving it void of significance, less artful than previously and, as such, death appears more distant and unrelated to the lives we now live.

Death anxieties
As our transition from life to death now becomes orchestrated from a medical perspective, not only do we become submissive to the new agents of social control, medicine, (Szasz, 1970), but the majority of dying individuals function compliantly with medical treatments for their illnesses. Such complicity arises through an implicit fear of not achieving the socially prescribed 'good death' of contemporary Western societies (Ellershaw, Dewer & Murphy, 2010). Such passive acceptance of religion being replaced by medicine as the overseer of dying, has not only produced the narrative of the 'invisible death' and removed the art from dying, but has simultaneously provided a means through which death and dying are manipulated by using the latent terror and mystique that surrounds this final act of living. The desire for a 'good death' becomes muted, however, if death is a sought experience to end intolerable suffering rather than the result of the longevity of living.

Mystery still remains around how we die; with many not aware of what happens to the physical self until the prospect of death arrives into their lives. The invisibility of the process produces a vacuum of fear, whereby leadership and expertise are sought and engaged with in order to control the demise of the body. Dying becomes a source of anxiety through the unknown and unknowable (Bauman, 1992). It presents a position of living that we choose, or prefer to ignore for as long as possible. It does not fit with the contemporary consumerism of the healthy body, which has become almost an obsession for some (Higo, 2012), as fitness and perceived health can be viewed as a means of negotiating the reality that the body will, at some point, no longer exist. The contemporary passion for body related consumerism, and the aging body in particular, is reflected upon by Bryan Turner (1982) in his discourse regarding the manipulation of the body through "diet, jogging and cosmetics" (Featherstone, 1982, p. 18) to fight the signs of aging. This produces the docile, disciplined body (1982) together with narratives of self-preservation in relation to the negative connotations of death. The fact that the human race is indeed mortal proffers a reality that is generally feared (Bauman, 1992) and "defies, radically and irrevocably, our intellectual faculties" (Bauman, 1992, p. 13). Death is mysterious, it is unfamiliar and un-tamed. To the rational being, therefore, death cannot be rationalised. It becomes a "fundamental cultural frustration" (Freud, 2002, p. 52) in that it is inevitable, but to acknowledge this is perceived as failure.

The ability of the human brain to perceive the end of the natural life as failure adds to the complexity of anxieties around dying. Failure is a negative outcome for any activity (Turner & Stets, 2005), particularly in view of the never ending quest for perfectionism, be it the perfect body, perfect fitness and for perfect appearance. Moreover, with medical advances and the quest to not only prolong life and reverse the aging process, but to achieve some form of immortality, it becomes obvious why contemporary Western societies prefer to deny the existence of death, yet simultaneously remain anxious about the unknown of how we die. Thus through our passivity towards death as being something futural it offers at least one insight into how this natural and inevitable life event has left a significant void in our cultural existence, previously filled by religion, and now securely seated within the realms of medical practice. Instead medicine becomes the protector or shield between the

reality of dying and the perception of it being an unreality. There are, however, some individuals who seek to invite death into their lives, as death appears preferable to life when experiencing intolerable suffering. Such inclusion of death and dying erodes the contemporary preference of passivity and invisibility of dying as they can be perceived as engaging with 'being toward death'.

'Being-toward-death'

The reinforcement of the transience of conscious life through ritualistic behaviours identifying as an art form, provides reflection of the present and is a reminder of the status of 'being-toward death' (Heidegger, 1962) throughout the lifespan. Rather than being afraid of the certainty of death, Martin Heidegger (1962) suggests that we should engage with the notion of 'being-toward-death', in that we are all in the process of dying from the moment of birth, thus acknowledging and understanding the resolute futural certainty that death will occur. 'Being-toward-death' allows for the development of the true authenticity of the self, through being aware of the ephemerality of life, ensuring that we allow ourselves the freedom of living in the present. Moreover, Heidegger suggests that we know time because we are going to die, as we know that the existence of humanity is temporal; and that through his concept of *Dasein* (being there) each person is located in the here and now, in the ever present, facing a future of possibilities. However, the notion of the authenticity of the self being defined by death is not a supposition held as true by Jean-Paul Sartre (1946). Although Sartre does agree that individual choice is relevant to the development of authenticity, he notes death as existing but does not believe that the prospect of death affects our authenticity to the same level as that of Heidegger. Rather than death playing such a significant role in the authenticity of the self, Sartre believes that our authenticity is reflected in living the life of choice and, as such, taking responsibility for such actions.

Sartre, however, also wrote that death, the unique individual personal experience of death was still 'free to be mine', as

> "Man [sic] can no longer encounter anything but the human; there is no longer any other side of life, and death is a human phenomenon, it is the final phenomenon of life and still is life. As such it influences the entire life;

it becomes like the words of Einstein, 'finite but unlimited'…But death thus recovered does not remain simply human; it becomes mine…Death is no longer the great unknowable which limits the human; it is the phenomenon of my personal life which makes of this life a unique life – that is, a life which does not begin again, a life in which one never recovers his stroke. Hence I become responsible for my death as for my life". (Sartre, 1977, p. 532).

Heidegger relates the idea of 'being-toward-death' with regard to the death of the self as being of primary importance, and that death can only ever be truly experienced in relation to the death of oneself. This viewpoint has, however, been contested as being both "false and morally pernicious" (Critchley, 2009, para. 8) as death comes into our lives, often uninvited, through the deaths of parents, children and those depicted in media representations of war and violent acts. Yet, the reality is that the death of the self cannot be truly experienced as it is the end of personal existence and, as such, presents the dichotomous situation that one has died, but through being dead one can no longer experience the process. Through this existential reality that death is the certainty of the future, in that it is an event that is yet to come to fruition, it provides the impetus to be in the present but simultaneously can sit in the minds of some who perceive it with fear and trepidation, but the truth must be remembered that we will all die.

Conclusion
Death is a necessary part of evolution but remains unwelcome and uninvited into our lives despite its natural foundation. Notwithstanding the narrative of passivity towards dying, if dying were to be acknowledged, even invited into the lives for those individuals experiencing intolerable suffering, dying would be less constrained by the contemporary cultural imposition of naivety over death. Therefore, consideration must be given to the dualistic subjectivity of fearing death thus producing a discourse of invisibility, but simultaneously for some individuals it remains an attractive proposition that is welcome to relieve suffering. Although for some, the medical care of the dying may produce an art form (Quinn, 2013; Collins, 2008), this remains subjective as for others it crosses and blurs the boundaries of practice, often disrespecting the natural circle of life (Childs, 2000). Moreover, the

medicalised 'good death' does not meet with the expectations of the contemporary self-centric individual who seeks the right to choice and self-determination with regard to the point of death.[15]

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[15] Self-determination refers to a theory based in psychology pertaining to autonomy and control (Deci & Ryan, 2012).

Chapter Two

"Western man has lost the right to preside at his act of dying"

(Illich, 1974, p. 204)

Patient choice: the influence of medicine and law

Introduction

As life events have become increasingly medicalised and contained within the construction of medical practice, it has produced a subtle but effective means of controlling populations. The contemporary unnatural death, guided by medical technology, has become polarised from the natural death (Seymour, 2007) and has produced practices in end-of-life care that restrict and constrain the individual at this life point (Chriss, 2013). Such a move has captured the notion that to suffer should be resisted (Kleinman, 1992), thus, creating a movement towards the rights of the self and individual choice over how life should end, encapsulated in the right-to-die debate. However, when exercising autonomous control over the self that does not reflect the expected and accepted clinical norms at this life point, medical practitioners engage in selective collaboration with lawyers to uphold the sanctity of life and human right-to-life principles over that of individual rights. Such collaborative experiences produce narratives of denial; denial of individual rights and that to suffer is problematic, thus, creating a discourse of resistance for some individuals when their choices are overruled.

This chapter in presented in two parts; with part one exploring the medicalisation of dying, the construction of palliation as a medical speciality in care and the need for diagnostic labelling of this life event. Moving forward I engage with the prolongation of life and death discourses through the attachment of medical technologies in caring and the subsequent development of medical models of care for those at end-of-life. I specifically discuss these care models in relation to assisted suicide and euthanasia and consider the actual differences in practice. Part two explores the role of law in supporting clinical practice in relation to the human rights framework, the right-to-life and right-to-death discourses. In examining these

issues, I consider the interrelated complexity of individual choice, the notion of resistance and the prospect of deviance for the self-determined individual.

Part one: Medicalisation and dying

Medicine is a scientific practice, the name of which is derived from the Latin *medicus* meaning a physician (Etymology Dictionary, 2015). Although medical practice derives from Ancient Greece, modern medicine or medical practice is founded upon the biomedical model of health, with its emergence closely associated with the accelerated growth of scientific discovery and fact over tradition (Giddens, 2009). It has superseded the explanations of religion with quantifiable data, thus providing a verifiable foundation upon which to practice; although it must be noted that this foundation is forever shifting as each scientific discovery may replace that preceding it. Since medicine emerged as an element of Western culture it has shifted from being a fraudulent profession perceived as 'quackery', to become a trusted source of perceived expertise.

Medicine, as a profession, has utilised the flexibility of its practice boundaries, together with its specialist knowledge, to replace religion as the administrator of the dying thus, becoming the new 'saviour' as people meet the demise of the physical self. This move by medicine, in guiding us through this natural life milestone, is intended to provide comfort for patients in their hour of need. The reality, however, is that medicine has identified yet another natural human life event as being medical in nature and not merely biological and, therefore, in need of medical attention.[16] Such identification and labelling of behaviours and practices has given rise to the concept of *medicalisation* (Conrad, 1992); a term used to describe the pathologisation of behaviours that are not directly associated with disease processes, but are usually natural human life experiences (White, 2002).

Medicalisation was originally proposed by Ivan Illich (1974) as a means through which personal challenges have been reclassified as being technical problems requiring medical intervention in order to rectify them (van Brummen & Griffiths, 2013). It simultaneously acknowledges that life expectancy is not solely related to

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[16] Other natural life events that have been medicalised include conception, childbirth and menstruation, for example.

the advancements in medicine but to the improvement in sanitation, housing, hygiene and other social indictors (Illich, 1974). In narrating *Medical Nemesis: the expropriation of health* (1974), Illich highlighted the impact of medicalisation upon the dying process in modern society and claimed that modern medicine had "brought the epoch of natural death to an end" (p. 210), together with the loss of capacity to accept death and suffering as meaningful aspects of life. As such, Illich described this inability of acceptance as a sense of being in a state of "total war" (p. 202) against death at all stages of the life cycle, culminating in a crippling of personal and family care, a devaluing of traditional rituals surrounding dying and death, thus, developing a form of social control in which the rejection of 'patienthood' by dying or bereaved people is labelled as a form of deviance.

Zygmunt Bauman (1992) argues that the medicalisation of death has resulted in death becoming a medical problem to be solved, or if it could not be solved, to be controlled by technology, with doctors becoming seen as the high priests of modernity. Illich upholds this view and states that "society has transferred to physicians the exclusive right to determine what constitutes sickness, who is or might become sick, and what shall be done to such people" (1976, p. 6). He further suggests that most deaths now occur in hospitals and, as such, are under the control of physicians who are conferred with the power to decide in what manner patients will die, what type of pain relief they will receive, what forms of technology may be used to help keep people alive for longer and declaring death has occurred, thus, supporting the views of both David Sudnow (1967) and Stefan Timmermans (1998). Vandana Shiva (1989), however, argues that "modern science is projected as a value-free system of knowledge which has displaced all other belief and knowledge systems by its universality and value neutrality" (p. 15). Medicalisation, therefore, represents a situation whereby naturally occurring human conditions have become subject to the medical lens and have subsequently been redefined as being medical conditions, under the umbrella of the expansion of the medical institution.

Through medicine now attending to normal life events in addition to ill health, it procures our compliance with their belief systems and, as such, it has been suggested that medicine has become a covert means of social control (Szasz, 2007; Conrad, 1992; Zola, 1972). This is notable through the labelling of individuals who

chose not to conform to standard medical practices as being outsiders (Bunn, 2008), whether that be outsiders in relation to mental health for example, or in this instance in the non-compliance towards the contemporary 'good death'. This discourse denotes a fundamental change in the structure of the medical knowledge base (Foucault, 1973) and, as such, encapsulates the social construction of this discipline.

Medicine as a social construct

Social constructionism refers to the socially created problems occurring within our environments covering a broad spectrum of daily interactions which have been specifically "created or 'constructed' by groups of people" (Giddens, 2009, p. 161), for example gender, race and social class. More specifically it is the assignment of meaning to events, material objects or occurrences within an individuals' environment, and the subsequent relationships developed between such interactions, that provides the impetus for the social construction of our reality, which is not necessarily the result of nature but resultant from human choices. The fact that socially constructed phenomena can result from the input of human decision making illustrates the idea that medical knowledge, in this instance, has been developed as a social construct through which clinicians enable some forms of social inequality to be reproduced (Conrad & Barker, 2010). It is, therefore, perceptible how medicine has constructed the contemporary 'good death' as needing medical care in order for it to come to fruition. Yet, the identification of dying needing such medical attention sits in opposition to the notion that to die is natural and invited into some arenas.

Although social constructionism in relation to medicine has foundations in phenomenology and cultural anthropology (Conrad & Barker, 2010; Albrecht, Fitzpatrick & Crimshaw, 2003), it does suggest that the belief in medical care and the understanding of the role of clinician is reflected through the lived realities of individuals and, as such, "involve[s] the reproduction of meaning and knowledge through social interaction and socialization" (Albrecht et al, 2003, p. 51). It is the reliance upon individual interpretation of the meanings of medicine and how it can assist in daily living that renders medicine to not be "value-neutral" but "implicitly or explicitly, shores up the interests of those groups in power" (Conrad & Barker, 2010, p. 73). It is this power that renders the individual to be at the mercy of the

caregiving clinician, as it is the only resource currently legally available through which relief can be gained. With medicine, therefore, creating an existence that dominates the longevity and well-being of the human body, it renders the individual powerless in the relentless progression of all-encompassing diagnoses which surrender to the gaze of the expert, and particularly within the confines of the institutional space. For the dying individual this poses the possibility of constraints when activating their wishes regarding their fate.

It is the clinic that provides an institutional or organisational base, and a constraining structure for the formulation of medical practice; a place where multiple practitioners join forces in applying their knowledge to the functions of the body (and mind), a place where likeminded professionals push forward their practices (Ciampa & Revels, 2013), providing a platform for the exponential growth of medical practice. It was the development of such institutions that simultaneously benefited patients through monitoring and curing the malfunctions of the body, but also benefited medical practitioners through the development of a closed monopoly on managing the body and, therefore, control over the lifespan of the individual. Such close range surveillance of the individual body presented an opportunity for medicine to micro-manage body conditions through regular observation, monitoring and recording of data in a clinical environment (Scambler, 2005; Terry, 1989).

Institutions such as the clinic are structures developed within societies to provide and maintain social order. They provide governance over expected behaviours and, as such, are intrinsic in the basic functionality of living within contemporary Western societies. Institutions are complex structures comprising of multi-faceted characteristics and pertain to religion, governments and the economy as well as healthcare (hospitals and clinics), but consistently serve to reinforce the inequalities at place within social structures, ensuring that the dominant groups uphold power (Saks, 2005). Such power elites exist today within the medical system, whereby highly qualified medical practitioners exert their influence through the construct of the medicalisation of natural life events, thus commanding the vast resources of clinical institutions. Moreover, the clinical institutions become a modality of power in the relationship between dominant social groups and the general population. Doctors occupy key positions within the institution, thus ensuring that their power

is rooted in authority (Elwell, 2013), simultaneously placing "…this authority in the hands of men of similar social background and outlook" (Elwell, 2013, p. 1).

Medical practitioners can be viewed as experts in their knowledge base and field of practice and, as such, renders it difficult for the general population to respond negatively to the coercive postulations of such practitioners (Abbott, 2014). Those with knowledge can quite easily outperform those without such knowledge which, in conjunction with the power of the institution supporting such expertise ensures they remain dominant, irrespective of personal patient wishes. This supports the discourse of coexistence of both knowledge and power presenting a dichotomous practice, where the goals of power and the goals of knowledge become inseparable (Foucault, 1979), as "…in knowing we control and in controlling we know…" (Gutting, 2011, p. 33). The knowledge/power dichotomy present within medical practice and the relationship with dying patients is mutually constitutive because there is "no power relation without the correlative constitution of a field of knowledge", that "power produces knowledge" and that "power and knowledge directly imply one another" (Foucault, 1979, p. 27). It is, therefore, the specialist knowledge imparted by medical practitioners to their patients that empowers medicine to influence the narrative discourse of their practice, gained through the production and reproduction of knowledge based expertise (Alcoff, 1999).

Moreover, it is the socially constructed nature of the clinical institution and the reliance upon practitioners to fix us when we are unwell that opens the pathway for medicine to dominate other fields of natural living. It underpins their ability to procure their position of expert over the human body and, as such, ensures their domination continues at our point of crisis or weakness. Doctors have become authorities in the subjugation of human life and death, the body and the self, through the clinical institution being perceived as a trusted modality of power. As such, as less individuals identify as having any religious affiliation in both the UK (British Humanist Association, 2012) and New Zealand (Statistics New Zealand, 2013), this has coincided with a shift from dying in the community towards the increasingly impersonal, sterile setting of the medical institution. This shift has not occurred merely of free will, but has transpired through the emerging and influential

powers procured by medical professionals, actualised through the *medical gaze*, together with the challenge of defeating mortality.

The *medical gaze* is a phrase coined by Michel Foucault (1973) to signify the dehumanising aspect of medicine whereby the human body is separated from the self-identity of the individual, in that the physicality of the body is monitored but not viewed as being part of the whole individual, but rather as independent flesh to be prodded and observed. Through using the *medical gaze* as informing the analytical frame of this research, this concept infers the notion of power within the diktat of medical practice, the presence of bio-power, and an authority possessed over the individual human body.

In terms of managing large groups of people, Foucault (1978) suggested that bio-power is an exercise of power/knowledge, whereby in this instance the medical profession has control over the body which then becomes the site of bio-power; and can be perceived as "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (Foucault, 1998, p. 140). This concept fits within Foucault's larger product of controlling bodies of population through different forms of surveillance and monitoring, which aligns with what occurs in the hospital setting. The idea, therefore, that the body is separable from the whole individual becomes problematic when the reality is that the human body and self-identity are complexly inter-related and, as such, require a more holistic approach to care (Shilling, 1991). Yet, the medicalised separation of the human body from the self remains a constant in many practices through the medicalisation of normative human behaviours.

Such separation of the body and self-identity remains problematic in the now medicalised control of death and dying outside of the private home, as clinical sterility out-manoeuvres the individuality of the patient who has been relocated from home to hospital, in that they then become 'a patient' in 'a bed' in 'a ward' full of such beings. Death and dying have become routinised within the care of medicine at a personal cost to the identity of the self and the express wishes of the individual. Therefore, the structural concept of death and dying, through the power held by the medicalisation of this natural event, removes any notion of agency from the patient when within the institution and, as such, disregards the significance of

the self and self-identity at this final point of living. Moreover, it removes the notion of self-determination that has been present throughout the lifespan; thus, rendering capable and independent individuals to the mercy of clinicians and to be burdened with the idea of dependence and loss of control, therefore, having the potential to reduce individual agency to a relic of the past.

Self-determination, as a theoretical concept, is pertinent to this research as it relates to the "human motivation and personality in social contexts that differentiates motivation in terms of being autonomous and controlled" (Deci & Ryan, 2012, p. 416). Specifically it can be utilised in studying healthcare behaviours and provides a means for understanding the relationship between controlling agents and the subordinates. Although there are a number of sub-categories of this theory, as a whole it is effective in understanding the "effects of social environments on people's attitudes, values, motivations and behaviours" (p. 416), and thus, becomes relevant to the doctor/patient relationship, together with the influence of the *medical gaze* for those individuals pursuing personal choices at end-of-life.

As the *medical gaze* now oversees the routinisation of dying today, the imprint it is creating is one of negativity, that death is a failure and that to be told you are dying is almost embarrassing to admit to others (Kalanithi, 2016; Lutz, 2015; Thomas, 1980). The *medical gaze* produces inequalities in what it observes, as those individuals conforming to medical models of care are labelled as 'good' patients and those not as being 'bad'. There is significant literature available on the good patient/bad patient discourse, for example the works of Alan Clarke (2010), Robert Dingwall and Topsy Murray (2008); but such inherent labelling of individuals for perceived conformity, or not, proves unhelpful in the context of promoting individual patient choice, regardless of the specific issue in question. Dingwall and Murray break this patient modelling down further by categorising what reflects the good or bad in patient behaviour, with much of this subject to the subjectivity of the clinician involved.

Good patients are broadly categorised as being compliant with medical care, but can also be considered as rule breakers, but responsible ones; whereas bad patients are rule breakers, irresponsible, usually responsible for their circumstances of ill health

and often perceived as deviant within the realms of acceptable social behaviours, for example drunks and those overdosing (Dingwall & Murray, 2008). Such categorisation arises from sweeping assumptions regarding the individuality of patients and, as such, this research, is not concerned with the subjectivity accorded to the good or bad status of the dying patient, but the interaction of medicine in regard to individual choice options at end-of-life. However, in order to achieve compliance of the good patients with the contemporary dying trajectory, medicine evidences their specialist knowledge through the construction of diagnostic testing and labelling for the dying.

Diagnosing dying

With dying producing a problematic emotive image for many individuals, medicine has responded to such anxieties by applying a label or diagnosis to the condition of dying, in order to legitimise death, for without the label it means nothing in medical terms (Deyaert, Chambaere, Cohen, Roelands & Deliens, 2014). The idea that a diagnosis is required to ascertain whether an individual is dying is a relatively new phenomenon despite diagnoses being pivotal to the functioning of Western medicine per se, and "in providing a sense of direction to both doctor and patient" thus "offering a modicum of certainly in an uncertain world" (Jutel, 2015, p. 4). This may be applicable to the diagnosis of disease and illness, but with regards to dying sits in opposition to those clinicians who feel it is impossible to know when someone will die (Marsden, 2015).[17] It has, however, become an emerging topic in end-of-life care issues, with numerous clinicians advocating the necessity of ensuring dying is diagnosed (Kennedy, Brooks-Young, Gray, Larkin, Connolly et al, 2013). But does dying require a diagnosis?

It may be considered that medical practitioners face difficulty in practice without such a label, as it is the foundation stone to providing relevant health related treatments (Davis, 2009). Without a diagnosis, irrespective of symptomatic presentations, a medical professional appears unable to proffer appropriate treatment pathways. This renders the patient as a disease rather than an individual in need of a personalised care plan (Davis, 2009), resulting in the disconnection of the

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[17] Dr Sue Marsden is a Palliative Medicine Specialist in New Zealand.

physical body from that of the self at end-of-life. Theoretically clinicians may be able to identify how imminently death will occur, however, through attaching a diagnosis to this life stage, which is interpreted in numerous and often oppositional contexts by clinicians, individuals, their social status and understanding of situations, dying "becomes far messier than anyone (lay or clinician) would hope" (Jutel, 2015, p. 4). Many doctors are unfamiliar with the signs of dying, often through the contemporary passivity of acknowledging and participating in caring for our dying (Leombruni, Miniotti, Bovero, Castelli & Torta, 2012). This situation has resulted in some clinicians equating the death of patients with failure in medical practices; thus preferring to rely on diagnostic guidance as without a diagnosis, medical practitioners and patients themselves appear unable to accept the actuality of the situation (Chen, 2009).

Despite the modern predilection for applying medicalised identifiers to previously perceived natural life events, it is argued that the formal 'diagnosis of dying' is often missed by medical practitioners (Gibbins, McCoubrie, Alexander, Kinzel & Forbes, 2009; Davis, 2009; Ellershaw, 2003), thus questioning both the training given to identify dying and the need for such labelling in the first instance. Arguments exist that a diagnosis is necessary so the dying can benefit from specific end-of-life care pathways, and that doctors are failing if they lack confidence to confer this diagnosis (Gibbins et al, 2009). The reality appears, however, that through the application of a medical, and possibly a scientific label to this natural life event, dying remains condemned to the scrutiny of the *medical gaze* which, in turn, produces the potential to expose dying individuals to the medical advances that prolong both living and dying.

The prolongation of death discourse: a social or medical construct?
New medical inventions regularly emerge onto the healthcare market producing hope in prolonging life, but they potentially prolong death also (Kadlec, 2013; Gawande, 2010). Such advancements in knowledge and technology have produced an emerging discourse whereby the potential to keep death at bay for some individuals is a positive move, transforming life expectancy from a matter of days to may be weeks or months (Jennett, 1995), but does not account for the quality of life achieved. In opposition to this, for those pursuing the right-to-die, this produces

the "modern tragedy" (Gawande, 2010, para. 100) in end-of-life care and, as such, can be equated with the phenomenological death, whereby seriously ill individuals are kept alive because it is possible to do so (Sweeting & Gilhooly, 1992). The phenomenological death has produced a narrative, where it becomes difficult to distinguish between "health, awareness, function and viable life on the one hand, and 'no longer a person', 'death in life' or 'death' on the other" (Kaufman, 2005, p. 62), thus, questioning because it is possible to extend life, is it morally correct to do so?

Medical practitioners are not legally obliged to maintain the living, they do not have to prolong life (Ward, 2013). They often do so because they dislike feeling as though they have failed a patient if they let them die, or can often be pressured by family members who cannot let go of a loved one, even if the patient no longer wishes to survive (Morris, 2012). Cases have emerged where patients who are heavily disease burdened, and at the end of their natural lifespan, have been placed on ventilators in intensive therapy units and have been given intravenous antibiotics and feeding tubes, particularly in the United States of America (USA) (Gawande, 2010). Such measures appear futile when considered in a narrative format, but when medical practitioners, patients and families face the reality of imminent death, human instinct grasps at whatever methods are available to delay the inevitable (Parker, 2015).

Unfortunately, prolonging life, often life that cannot be saved, produces a culture of hope, but hope is a clandestine premise formulated on the denial of reality (Ehrenreich, 2007), and in this instance that death is inevitable. Hope has become fashionable; it has become a cult of positivism (Ehrenreich, 2007) whereby all obstacles can be viewed as challenges that can doubtless be overcome. Hope has produced a utopian narrative through which present day abilities are viewed in relation to those of the future; and relates in this instance to medical practitioners making the world a more functional space so that natural events may be managed and even eradicated in the future (Davis, 2010). Medicine, therefore, through its advancement in empirical knowledge becomes the purveyor of positive illusions (Ehrenreich, 2007) in that death will still come, but if it can be delayed it provides a pathology of hope.

Living with hope as the only potential measure for alleviating suffering at end-of-life will produce disappointing results. Life cannot be saved through hope or positivity alone, or by current medical technology for that matter. Although machines and pharmacological agents can cure some diseases and alleviate suffering in others, the reality is that something will finally make the human body deteriorate to a state of dying. To die, however, from mortality alone is perceived as being no longer achievable (Bauman, 1992), or preferred. The culture of hope supports the denial of death discourse, together with medical practice where there is always something else that can be done for the dying body (Gawande, 2010). Such denial of death and reliance upon hope, however, results in opportunities being missed to encourage patients to confront their disease and make preparations for exiting this life. It appears, therefore, that technologies and chemical agents can provide comfort in this crisis situation, as they alleviate the discomforts we have to acknowledge when staring death in the face.

As death provokes anxieties of the unknown (Tang, Chiou, Lin, Wang & Liand, 2011; Vehling, Lehmann, Oechsle, Boyemeyer, Krüll, Koch & Mehnert, 2011), society has allowed medicine to seize this opportunity to tame the fear of death through providing solutions at end-of-life. This has resulted in the construction of a medical discourse through which our death anxieties have become muted. Moreover, the current day *formulae* (Higo, 2012) of dying whereby medicine delivers comforting pharmacological mixtures to the dying through machines to alleviate their discomfort, simultaneously sanitises dying thus ensuring onlookers are not repulsed by the natural state of the decaying body (Mathews, Burke & Kampriani, 2015).[18] Such machines are an effective means to quell the anxieties experienced when death is approaching, so much so, that choosing to be sedated has become the new norm. To be awake is less often chosen despite the possibility of participating in living for longer (Hartocollis, 2009); as not all living is synonymous with indignity and devoid of value (Kellehear, 2007). This switch to preferring sedation, however, has coincided with the rise of palliative medicine to care for the dying.

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[18] *Formulae* refers to a method or means of achieving a specific outcome that is often proved successful (Collins Dictionary, nd).

Palliative medicine

With the location of dying transitioning from community and religious care to that of medicine and the associated construction of anxieties towards this natural life event, the contemporary solution to address such fears has been the specific construction of 'palliative medicine'. Palliative medicine was developed during the 1960s (Clarke, 2007) and has provided the medical impetus to not only incorporate this natural life event into the spectrum of medical diseases to be treated, but allowed medical practitioners to develop treatments to alleviate intolerable suffering. Palliative medicine provides the framework through which practitioners care for dying patients. It is often provided through the hospice movement network but can also be delivered within other institutional settings, such as public hospitals, private nursing homes and private homes.

'Hospice' derives from the Latin word *hospes* meaning to "host a guest or stranger" (Amitabha Hospice, 2009, p. A brief history of hospice care). Although hospices as institutions are relatively new in terms of age, the word hospice was first applied to the dying in 1843 by Jeanne Garnier (Lewis, 2007). More recently, it was Dame Cicely Saunders, a registered nurse who retrained as a medical doctor, who opened St. Christopher's Hospice, London in 1967 following her experiences caring for a dying Polish refugee and the comfort he needed for his physical symptoms (Poor & Poirrier, 2001). St. Christopher's is now regarded as the first modern hospice providing palliative care for over 2,500 dying patients each year in the area (St. Christopher's Hospice, 2015). The objective of hospice was to focus on the patients' needs rather than the diseases suffered, thus introducing the idea of managing 'total pain' encompassing physical, psychological and emotional trauma (Clarke, 2000), through utilising a multi-disciplinary team approach to care.[19] [20] Palliative medicine, also known as palliative care, practices palliation whereby the symptoms and suffering for those with incurable diseases are relieved (World Health Organization (WHO), 2015). In a similar manner to the hospice movement, palliative medicine is

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[19] Multi-disciplinary team is composed of members from different health and social care professionals with specialised skills and expertise who collaborate to make treatment recommendations (NHS England, 2015).

[20] 'Total pain' refers to the encompassing of all aspects of pain: physical, psychological, social, spiritual and practical (Ong & Forbes, 2005).

"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, 2015. p. Cancer, definition of palliative care).

Palliative medicine, however, is denoted as a new specialist field of practice that is now being taught in medical schools, whereas this was not the case even ten years ago (Meier, 2010). In 2006, palliative medicine became a certifiable medical sub-speciality in the USA through which specialist fellowships can be undertaken by those interested in this field of practice (American Board of Internal Medicine, nd). Similar training is now offered in both the UK and New Zealand. It is notable that with similar goals to the hospice movement, many such specialist practitioners undertake hospice related work. Hospice, however, unlike palliative medicine does not merely focus upon symptom management and considers itself "not a building; [but] it is a philosophy of care" that "intends neither to hasten nor postpone death" (Hospice New Zealand, 2015, p. Vision & values). It is, therefore, through this broadened scope of practice that the values and virtues of hospice philosophy become challenged in relation to the selective application of medical models of care to prevent or alleviate intolerable suffering.

Intolerable suffering is a term frequently used in the assessment of those patients who are at the end of their lives, where management of physical and psychological symptoms become challenging to relieve. Intolerable suffering is conceptualised as being an important measure in the decision making process for individuals but is defined as a "subjective experience of suffering that is so serious and uncontrollable that it overwhelms one's bearing capacity" (Ruijs, van der Wal, Kerkhof & Onwuteaka-Philipsen, 2014, para. 12). The investigation and relief of unbearable suffering "is determined by a patients [sic] symptom or state that he or she does not wish to endure" (De Graeff & Dean, 2007, p. 67); thus, suggesting that intolerable suffering is a "relative experience" (Ruijs et al, 2014, para. 8). This, therefore,

reflects a situation where the subjectivity of the individual becomes a key component in extrapolating exactly what is being experienced.

Although palliative medicine literature acknowledges that the patient is the best situated person to decide whether care approaches offer adequate relief from their suffering, it is indeed the medical practitioners who take decisions regarding offering certain palliative models of care (Juth, Lindblad, Lynöe, Sjöstrand & Helgesson, 2010). This situation presents an uncertain picture of how individuals can invoke their right to participation and choice in care decisions, when there is clear potential that such decisions may be overruled through the application of expert knowledge to the given situation. Such decisions can be reflected in the use of specialist models of care at end-of-life and although there are numerous models available for palliative care, for the purpose of this research I have given consideration to *The Liverpool Care Pathway* (LCP) and 'palliative sedation therapy' (PST), sometimes known as 'continuous deep sedation' as specific practices through which medicine and law facilitate the 'pathway' to death.

Medical models of care: *The Liverpool Care Pathway*
The Liverpool Care Pathway (LCP) is a model of care "for the dying patient" and "is a programme of integrated care that is used at the bedside in the last hours and days of life" (Evans, 2012, p. 30). It is a means through which best hospice practice is transferred to the acute setting of public hospitals (Evans, 2012). The LCP was developed between the Royal Liverpool Hospital and the Marie Curie Hospice (UK) in the late 1990s (Ellershaw, 2011) and was used across medical specialities. The aim was to raise standards of end-of-life care in public hospital settings in line with hospice principles through providing a step-by-step framework of a "tried and tested integrated care pathway methodology" (Ellershaw, 2011, p. xx), that healthcare professionals could follow to ensure good care practices.

The intent was that the LCP would be a collaborative practice, in which the patient and their family would provide informed consent to use this plan of treatment. The LCP was designed to be a guideline document in the care of the dying particularly in the acute setting, but through a combination of time constraints, lack of training and lack of understanding of the needs of the dying (Neuberger, Guthrie,

Aaronovitch, Hameed, Bonser et al, 2013), it ultimately became another piece of administration to be completed in 'tick-box' style, thus offering a simple solution to busy staff working in acute care settings.[21] This tool made caring easy, but instead of care being personalised, individualised and holistic, it became routine, unimaginative and task orientated (Stephenson, 2014; Boseley, 2013). The LCP was not meant to replace clinical judgement, but to enhance and support practice through reflexivity (Ellershaw, 2011) to provide excellence in end-of-life care (Twigger & Yardley, 2014).

Palliative sedation therapy

Palliative sedation therapy (PST) is a clinical practice aimed specifically at relieving refractory symptoms in patients at end-of-life that cannot be managed in any other format (Maltoni, Scarpi, Rosati, Derni, Fabbri et al, 2012). PST is sometimes referred to as continuous deep sedation in the UK and Europe, however, is not so much a pathway to death but a model of care promoted specifically to remove intolerable suffering of the physical and psychological manifestations of pain (Caraceni, Zecca, Martini, Gorni, Campa et al, 2011). The definition of palliative sedation or palliative sedation therapy is again subjective and is dependent upon the perspective it is being drawn from (European Association for Palliative Care (EAPC), 2010). It is an ethically challenging model of care (EAPC, 2010) which is much debated through the perception that it shortens the life span (Barathi, 2012). PST can be considered as the

> "monitored use of medications intended to induce a state of decreased or absent consciousness in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health care providers" (Cherny & Radbruch, 2009, p. 581.),

or that it encompasses "intolerable distress due to physical symptoms, when there is a lack of other methods of palliation within an acceptable time frame and without unacceptable adverse effects" (Cherny & Radbruch, 2009, p. 584). It can also be described as the "reduction of consciousness, produced by pharmacological means,

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[21] Link to documentation and protocol for LCP:
https://www.whatdotheyknow.com/request/169193/response/419788/attach/4/CPME146%20V1.3%20Liverpool%20Care%20Pathway%20V12%20updated%20Jan%202012%201.pdf

to control symptoms that are refractory to ordinary palliative care approaches at the end of life" (Caraceni et al, 2011, p. 1300). Such definitions indicate how controversy over this practice arises, as it is designed to sedate patients at end-of-life when no other treatment plans have been effective.

PST is, therefore, medically constructed and accepted as "the use of [a] pharmacological agent[s] to reduce consciousness" and is "reserved for treatment of intolerable and refractory symptoms; and only considered in a patient who has been diagnosed with an advanced progressive disease" (Dean, Cellarius, Henry, Oneschuk & Librach, 2012, p. 1). This treatment is not used as frequently as the LCP, but remains a steadfast, if last resort in palliative care practices, and is used both in the UK and New Zealand, as well as numerous other Western countries.

Prohibited models of care: euthanasia[22]

Euthanasia derives from the Greek language meaning a 'good death', to die without suffering or "the painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma" (Oxford English Dictionary, 2015). Although the term euthanasia existed prior to the advent of modern medicine, it was first used in a medical context in the seventeenth century by Francis Bacon, when he considered it a "physician's responsibility to alleviate the 'physical sufferings' of the body" (Vickers, 2008, p. 630). More recently, during the late nineteenth century it gained it's more familiar and formal meaning of using "anaesthetics to guarantee a swift and painless death" (Lavi, 2007, p. 3) that is, an intentional death.

Euthanasia is not a single category but a collection of concepts that are classified according to who gives the consent for the procedure to occur. Currently there are four categories: voluntary, non-voluntary, involuntary and passive euthanasia. Although there are guidelines indicating what each category relates to regarding consent, such categorisations present blurred boundaries leaving each type of euthanasia open to interpretation. Voluntary euthanasia can be considered as a choice, it is a consensual and intentional act (Papavasiliou, Brearley, Seymour, Brown & Payne, 2013; Bernabe, van Thiel, Raaijmakers & van Delden, 2012;

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[22] Prohibited in the UK and New Zealand at present (2016).

Janssen, 2002) and is legal in a number of countries across the globe.[23] Non-voluntary euthanasia is a practice whereby the consent of the patient is unobtainable, for example in child euthanasia, or in those not deemed competent to make such decisions and that the person killed did not request to die (Bernabe et al, 2012; Broeckaert, 2008). Involuntary euthanasia is when a patient is euthanased against their will or has clearly expressed a wish to the contrary (Bernabe et al, 2012; McCormack, Clifford & Conroy, 2012) and passive euthanasia is the practice of withholding or omitting usual treatments and care necessary to sustain life, for example antibiotics or food and water, with the intent of the patient dying 'naturally' (Muckart, Gopalan, Hardcastel, Hodgson & McQuoid-Mason, 2014; Beckwith, 2013).

As with many concepts, there are many conflicting definitions of what euthanasia is, usually dependent upon the perspective from which the definition is being composed (EAPC, 2010). Euthanasia does not include the medical withdrawal of treatment regardless of competency to agree to this nor does it include involuntary or non-voluntary euthanasia (EAPC, 2010); but to clarify what euthanasia is, the EAPC regard euthanasia as being "the hallmark of which is that only physicians carry out euthanasia: that euthanasia is both voluntary and active by definition; and that it is performed by lethal injection" (EAPC, 2010, p. Ethics).

Despite Walter's (2002) conjecture that all hospice workers oppose euthanasia, a viewpoint I would argue that is sweeping in its assertion and possibly incorrect, euthanasia in reality is commonly practiced in most healthcare institutions where patients are towards end-of-life (Biswas, 2015). The routine usage of pharmacological agents to ease suffering, delivered constantly over 24 hour periods has been the stalwart of care throughout the duration of my nursing career to date; with awareness of the LCP and PST also being implemented. Families, and often patients themselves, are keen to be kept comfortable when dying; with comfort becoming a euphemism for end-of-life care. As such, it has become a common discourse that people should not suffer in their dying, with the potential that complaints may be laid where family believe their loved one has suffered undue or

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[23] Voluntary euthanasia is legalised in Belgium, Luxembourg, the Netherlands and Switzerland.

prolonged suffering. This need for comfort, however, is not akin to active euthanasia or assisted suicide, whereby a third party actively intervenes in care with the intention of ending a life sooner (McCormack et al, 2012).

Physician assisted suicide (in the UK and New Zealand)

Assisted suicide, or the assistance to end ones' life is not a new phenomenon. It has been talked and written about for centuries despite the advent of the *Hippocratic Oath* and the medical professions agreement to not assist individuals in pursuit of death (Pickert, 2009).[24] As with euthanasia there is no single definition of what assisted suicide actually is (McCormack et al, 2012), but is usually referred to as 'physician assisted suicide' as the physician prescribes the medication but the patient self-administers the lethal substance (Pereira, 2011). This difference when compared to euthanasia remains contested as the "definite intention to end life at the patient's explicit request" (McCormack et al, 2012, p. 24) remains constant. Yet, the difference can be viewed in that euthanasia is when a medical professional intentionally ends a patients' life through the administration of drugs, whereas physician assisted suicide is when a medical professional intentionally assists the patient through providing drugs with which to end their life, with the patient being competent to make this request (McCormack et al, 2012; Materstvedt, Clark, Ellershaw, Forde, Boeck et al, 2003).

Discussion: models of care

The models of care highlighted have become fields of academic interest with a proliferation of publications, particularly in medical journals, regarding the statistical usage of them, however, there is less scholarship investigating these therapies from a patient or family perspective. Despite the literature appealing to practitioners as PST being a last resort (Quill & Miller, 2014; Cherny, 2009; National Ethics Committee, 2006)**,** highlighting the need for consensual application of this care therapy, this does not always come to fruition in practice (Royal Dutch Medical Association, 2009)**.** The notion of intolerable or existential suffering and refractory symptoms remains subjective and dependent upon the perspective from

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[24] The *Hippocratic Oath* is a Greek medical text upon which a newly qualified physician swears to uphold professional ethical standards (North, 2012). The oath has often been revised to fit with contemporary cultures, with oaths suggested for science and ethics also (Rotblat, 1997).

which situations are assessed. A patient may not be distressed but family members or medical staff may be, or it may be that a patient's behaviours are not fitting with those expected of the dying and, therefore, need to be settled.

The use of these therapies is, therefore, believed to be an acceptable part of palliative care treatment from a medical perspective, even with concerns highlighted regarding the potential for misuse or abuse of sedation therapies (Dean, Cellarius, Henry et al, 2012). Yet, the choice for sedation is not always one that is made in an informed manner. The routine acceptance of these therapies as being of sound medical practice, despite the potential for misusing them, questions the difference between the LCP, PST, euthanasia and assisted suicide in relation to the human right-to-life and the ubiquitous belief of having the right-to-die. Legally everyone has the right-to-life as set out in the human rights framework, however, they do not have the legal or medical right-to-die. Moreover, there appears to be limited choice regarding the implementation of such pathways through the routinisation of end-of-life care for the compliant, but simultaneously the non-conformist patient is condemned to suffering; thus, highlighting the reality of attempting to exercise individual choice at end-of-life.

Patient choice
Choice in a simplistic definition refers to the "act of choosing between two or more possibilities" (Oxford English Dictionary, 2014), or "the power, right or liberty to choose" (The Free Dictionary, 2014). It refers to mental decisions or judgements resulting from the contemplation, comparison and deliberations of options available at any particular moment in time. However, these options may differ depending upon your needs, social positioning and ability to exert agency in making such decisions. Such one-dimensional and unsophisticated suppositions around choice demonstrate a naivety towards what can often be deeply complex situations from which decisions must be made.

Choice can also be understood through how "*liberal subjects* constitute themselves through choice-making, where freedom is the necessary first premise of an historical ontology of ourselves" (Peters, 2005, p. 392). In other words, choice is a means through which we both constitute and govern ourselves in the routine of

daily life and, therefore, this will influence our decision making regarding healthcare and ultimately the dying process. Yet, choice is not necessarily this simplistic as the choices we make through the consumption of goods and services are not made through free will alone, but become obligations through the notion that we are free in the first instance to make such choices (Peters, 2005), but must recognise that our choices may impinge on others or are constrained by what is available. Thus, our choices define the self we become and the life we lead and, as such, we become the sum of the choices made over a lifetime, ending with our choice of dying. The naivety surrounding the notion of choice, however, becomes apparent in the context of sociological literature which, through a deeper exploration of the subject matter, problematises choice through the potential constraints of social constructionism, social structures, hierarchies and structuration.

The duality of structure and agency, as an epistemological problem, have synthesised these two powers as an explanatory framework for the relationship between human action and the development of social structures; whereby the relationship between social structures and human agency are interactive and reciprocal in nature. Structure and agency are inextricably linked (Giddens, 1984), with structures being produced and reproduced through individual practices (Giddens & Pierson, 1998). The cyclical relationship of structure and agency is determined through the influential nature that structures play in the shaping of individual behaviours within specific cultural settings, but simultaneously those individuals can modify the structures to change the set of influences over human behaviours. Social structures provide the foundation for complex rules and regulations around acceptable behaviours; they are embedded in social practices and are reliant upon the complicity of agents to ensure the smooth operation of day to day activities (Little, 1990).

Social structures are relevant, yet different, across all societies, encompassing a diverse range of groups, which infiltrate societies across all stratifications, including race, gender and class. Structure is also an important component of choice as it can influence, limit and shape the path forward for those individuals faced with making choices (Brannen & Nilsen, 2005). It can be effective in dominating social landscapes, determining outcomes for agents irrespective of the relevance of stated

preferences; it shapes behaviours and actions and can be a persuasive and coercive partner, together with agency, in shaping outcomes to decisions. However, structure cannot survive without agency, and the capacity of individuals to function within a specific culture.

Agency can be a conscious or subconscious behaviour to act within the constraints of structures or against them (Archer & Maccarini, 2013). It is the force that permits the role of choice, albeit within a specific set of circumstances. Agency exists within social constraints, however, within those constraints freedom may be attainable, yet that freedom is somewhat questionable as will always remain constrained at some point. It is often referred to as the means through which individual players are empowered to make individual choices, thus offering the opportunity to act upon such choices, yet to always remain subjected to the structures within which it operates. In relation to the ability of agents to make free choices, this becomes problematic as there is always a set of circumstances, often unique to the given situation, within which choices must be made.

With the modality of structure being omnipresent across societies it is, therefore, evident that the medical profession provides the structural reinforcement with which dying patients and their families must confer if compliant end-of-life care choices are to be made. Patient decisions, however, will not be purely focused upon the physical dimension of their situation, but will simultaneously remain relevant to the lives already lived. It has been suggested that the next generation to die (that is the white European baby-boomers) will change what is currently occurring, namely the professionalisation of dying by medical practitioners, as they have experienced life through the lens of individualism and perceived freedom of choice (Ziettlow, 2012); but this could prove problematic as these individuals do not consider personal choice as being 'otherness'.[25] The potential shift in care choices and directives by the baby-boomers allows for the prospect of the renegotiation of power relations between clinicians and dying individuals; but has yet to come to fruition. This prospective revolution in dying appears to remain an insurmountable challenge when considered in relation to the power amassed by medicine and, as such, the individualism of the right-to-die voice becomes vacuous in the presence of

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[25] Baby-boomers refers to those individuals born between 1946 and 1964.

constraining structures of medical power, demonstrating the potential weakness in individual agency in such circumstances.

In 2000 the *BMJ* called to "…break the taboo and to take back control of an area [death] which has been medicalised professionalised, and sanitised to such an extent that it is now alien to most people's daily lives…" (Smith, 2000, p. 1); but currently little has changed in practice. The reality of personal freedom to choose is not as clear cut as we would like to think, as it is always constrained by the oppositional subjectivity of the involved participants. It could, therefore, be suggested that such constraining of individual choice by the collaborative powers of medicine and law result from the resource of symbolic capital, actuated in a form of symbolic violence against the general population.

Capital, as introduced by Pierre Bourdieu (1986), refers to the accumulation of objectified or embedded forms of resources that are not necessarily financial, but have the potential to reap rewards from cultivating them. Capital can be financial, cultural, social or symbolic in nature for example, with differing potential outcomes accorded to the variances of this concept. With regard to symbolic capital specifically, and in relation to medical practitioners, it refers to resources that are available to individuals formulated on a basis of honour, respect, prestige or recognition of achievement (Bourdieu, 1984). Symbolic capital can refer to those individuals who have fulfilled social obligations, for example, war veterans; however, can be similarly attributed to the status accorded to medical practitioners in their role of public healthcare clinicians specifically. Through the acquisition, therefore, of symbolic capital, medicine is able to exert symbolic violence over the subordinate individual and, as such, influence choice decisions.

Symbolic violence is a soft power utilised at an almost unconscious level, is predominantly exerted through symbolic channels of communication and emotion and is exercised subconsciously through the application of knowledge and practical recognition (Bourdieu, 2001). It is a gentle or soft violence, meaning that it is invisible, even to its victims. It is fundamentally the imposition of thought categories and perception upon dominated social agents perpetuating the action of the dominant category. It is embedded in the socially constructed classifications of the dominant category, which in this instance is medical practice. Symbolic

violence is a psychological effect, one that goes unnoticed in daily life whereby, through gender domination, or gender itself, it dominates the everyday social habits of an individual at a subconscious level (Caron, 2003).

Bourdieu goes further to suggest that there is a sense of complicity on the part of the dominated as symbolic violence can only be exerted on an individual whose *habitus* avails itself to it.[26] Therefore, the subtle use of symbolic violence exerted through the domination of power over that of the patient presents an image of the symbolic order as being both natural and right. Therefore, the application of symbolic violence in relation to dying within contemporary Western societies may reflect the subtle domination of medicine, and law, over the individual when their specific choices do not remain within the prescribed constraints of the contemporary death. As such, this opens the opportunity to examine the potential subordination of patients to the knowledge of clinicians and lawyers and to question the role of symbolic violence in the control of the end-of-life processes today.

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[26] *Habitus* is acknowledged as being a concept used to refer to the norms and practices of particular social classes or groups. It is, at least in a significant part, acquired through the embedded everyday actions and social practices of the individual (Bourdieu & Passeron, 1977).

Part two: Medical practice and law

Rules and regulations, or the laws of a particular society exist in order to ensure conformity to acceptable behaviours, serving punishment to those whose behaviours do not meet such standards. Law is a social construction providing a structured form of social control to communities (Hart, 2012), and is produced and reproduced through the positioning of structure and agency within the context of cultural preferences. The law represents a recurring patterned arrangement of rules that regulate behaviour to a standard deemed culturally satisfactory, but simultaneously remains dependent upon the actions of individual agents. It is the capacity, therefore, of individuals in expressing agency that determines whether rules remain intact or are contravened.

Historically laws have not always been codified through the judicial system as we know it today, but were informed by religious values and ecclesiastical power. The impact of such rules and regulations remains a constant part of living, in that they are perceived as guidelines drawn up as legal documents by which one can be constrained and restrained in daily activities (Sarat & Kearns, 2009; Lefebvre, 1987). Law is not a natural state, but one constructed to deal with the perceived misdemeanours of social participants; it surpasses cultural customs but simultaneously is dependent upon customs in order to construct the rules (Green, 2012). Law is, therefore, a dichotomous practice as it may not be until an activity is perceived as negative or unsavoury that it is categorised as such.

The academic study of law, from a sociological perspective, finds its roots located in an interdisciplinary space. The examination of law sits within the realms of sociology, but also criminology, political science and the legal profession itself. It can be considered a sub-discipline of sociology but also has the ability to stand as a research field in its own right and, as such, may be described as a theoretically grounded, systematic, empirical study of laws in relation to a specific set of social practices (Cotterrell, 2007).

Law, if viewed as a socially constructed phenomenon, results in the construction of another powerful institution, although one that was developed prior to the rise of professional medical practice, thus permitting those with the correct knowledge to

formulate methods of social control (Green, 2012). As the rules and regulations are formulated through the inherent practices within societies in order to guide acceptable behaviours, law simultaneously performs a coercive role. The law is presumed to be coercive to the point where little is actually narrated around this topic, it is simply a "given of social reality" (Edmundson, 1995, p. 1) but can be viewed as "a restriction imposed on another's will" (Yankah, 2007, p. 1). Coercion in law appears to be conceptually necessary and not solely a reflection of human weakness (Yankah, 2007); simultaneously the notion of coercion is not necessarily controversial, but can obscure the essential role that law does play (Yankah, 2007; Oberdiek, 1975).

Law guides, manipulates and works towards uniform conformity of the general population with prescribed rules, albeit through subversive, coercive tendencies; a view popularised through jurisprudence (Green, 2012).[27] Yet, this may not necessarily be correct, as the law can be viewed dualistically. Law can also be regarded as a set of rules prescribing sanctions should non-conformity occur; meaning that there is "an order to do something and a sanction for disobedience" (Green, 2012, p. xxxi). Rules can be viewed from either a conformity or non-conformity standpoint, thus reflecting the dualistic reading of the rules and the individual values potentially placed upon them. Law, however, is not merely a coercive process, but multifaceted, and must also be considered in light of moral behaviours, particularly when related to the field of medical practice.

There appears to be some discord in the value of moral judgements in law, as the natural law theory asserts that law and morality are deeply connected, in that laws that are not considered within the context of specific cultures have no position of authority.[28] However, positivism views law and morality as disconnected and separate, as law is perceived as being man-made and, therefore, a means of ensuring "the greatest happiness of the greatest number…" (Bentham, 1776, para. 2), thus formulating the foundation of morals and legislation.[29] Morality and law, when

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[27] Jurisprudence is theory and philosophy of law, it is formal and scientific in approach (The Law Dictionary, nd).

[28] Natural Law Theory is a "reflective critical account of the constitutive aspects of the well-being and fulfilment of human persons and the communities they form" (George, 2008, p. 172).

[29] Positivism refers to the study of society that relies upon scientific evidence and statistical data.

considered in the context of medical practice, however, opens a vast black hole of ethical necessity to safeguard patients from the practices of those with power and knowledge. Although the majority of medical practitioners function within accepted ethical guidelines and the *Hippocratic Oath*, and have the option to not participate in certain aspects of care, for example abortion, there will always be some who travel a more wayward path, thus, breaking the accepted rules and norms of societal function. This can be seen recently with consultant Myles Bradbury at Addenbrooke's Hospital, Cambridge, UK, for example, who breached his position of privilege by abusing those in his care (BBC, 2014); and previously by Harold Shipman, a general practitioner, who was found guilty of murdering 15 of his elderly patients, becoming the UK's most prolific serial killer (Batty, 2005).[30] Law, therefore, is not merely a set of rules, but rules that have been socially constructed to control the behaviours of the general population, as well as those in the position of privilege and power.

As medicine turned into a professional practice later than the advent of rules and regulations, it too is bound by certain laws. Medical rules and regulations are necessary to protect both patient and practitioner when decisions of care are being made and, as such, provide a solid foundation of enforceable social rules associated with professional conduct (Brock & Mastroianni, 2013). The fundamental component to medical law is the gaining of informed consent when a practitioner seeks to treat a patient; as informed consent ensures that individuals have the "right to make an informed choice and give informed consent" (Health and Disability Commissioner, 2009, para. Right 7).[31] This right, however, is waived if the informant is deemed incompetent to make an informed choice. The determination of competence and appropriate treatment lies in the hands of the medical professionals and, as such, reflects the dominance of a biomedical framework. Law, therefore, serves a doubtful purpose, in that it seeks to secure the power of patient choice and advocates for this right but simultaneously undermines such rights through the absolute power over life decisions given to medical practitioners in relation to individual competence.

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[30] Myles Bradbury was a consultant specialising in paediatric blood disorders and was found guilty of sexually abusing patients in his care.

[31] Informed consent refers to healthcare professionals ensuring patients understand treatments and procedures and agreeing to them prior to commencement (American Cancer Society, 2014).

Clinical ethics

The power possessed by medical practitioners in decision making settings is so vast that the law is simply inadequate in guiding choices; whether that be acceptance, rejection or withdrawal from treatment (Health and Disability Commissioner, 2009). The point at which prescribed and statute law ends provides the point at which ethical accountability begins (Brock & Mastroianni, 2013) and, as such, ensures that medical practitioners are bound by further obligations to ensure personal and patient safety. Ethics in the clinical setting can be defined as

> "…a discipline or methodology for considering the ethical implications of medical technologies, policies, and treatments, with special attention to determining what ought to be done (or not done) in the delivery of health care." (Brock & Mastroianni, 2013, p. 1).

Clinical ethics are the moral conscience of the steadfast laws that provide control in the practice of medicine (Gordon, Voilmann & Schildmann, 2013; Curlin, 2008), creating a shared objective in ensuring the best decisions are taken by practitioner and patient and simultaneously create an interdependence of the relationship between law and ethical practices (Bewley, 2009). The two disciplines overlap but retain independent boundaries in practice. Such boundaries are evident in that law is socially constructed and pertains to the maintenance of social order; however, ethical decision making is more fluid, in that decisions can be dependent upon individual subjectivity and social positioning (Harris, 2012). This juxtaposition in the control and safety of patient care suggests that not all care decisions will be made equitably as ethical standpoints will vary from practitioner to practitioner and can be bound in morality and judgement. Although professional boundaries should be applied when practicing medicine, it is less simple than merely applying those thoughts to the process.

Individual lives are conducted through socially constructed ideas of what is morally and ethically acceptable, either actively or passively, and with even the best training, such ideas are difficult to eradicate in the face of patients whose care decisions do not conform to the constructed notion of medical best practice. Such influences are notable in the debates around abortion and the ability of some

practitioners to opt out of involvement in such procedures through the use of 'conscientious objection' or 'conscience clauses' in employment contracts (Berlinger, 2008), although in recent times this has, on occasion, been rejected.[32]

When considering clinical ethics and moral judgements in relation to dying and death, the influences imposed upon medical practitioners become multi-factorial; with pressures from clinical judgements, knowledge base, social positioning, religious standpoints and personal interpretations of situations all having a role in the decision making process. Such personal impositions cannot always be overcome as our previous experiences also come into play, particularly when considering end-of-life care practices. If we have experienced a less than satisfying death of a relative, friend or patient, or an individual wishing to die, then the likelihood is for a degree of compassion in attaining this for others, reflected in a greater awareness of the need for acquiescing to personal preferences. Whereas, if death remains a ubiquitous concept, in that death becomes a routine event, then personal understanding by physicians may be more elusive. The interrelationship, therefore, of law, clinical ethics and personal morality remains absolute in the course of medical practice, particularly for the outcomes of patients in receipt of care. Such influences may prove positive or negative, dependent upon the circumstances in which patients are contextualised, but need to be more standardised in compassion and understanding if equity in care is ever to be a realistic goal.

The reality of achieving such uniformed practice is a difficult if not impossible challenge to surmount. To ensure that all practitioners conform to a set of rules is impractical let alone not ideal, as in reality the ability of practitioners to provide fluid, elastic care is necessitated through the difference in lifestyles, values and subjectivity of each individual patient. Despite doctors developing good 'clinical judgement' founded upon expertise and specialised knowledge, such privileged knowledge remains subject to the subject positioning of individual practitioners, attained through their education. Such judgements reflect the personal interpretation of knowledge and will always produce a bias towards personal values; however, when such values are questioned and do not align with patient's wishes, medicine

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[32] A recent case in the UK the Supreme Court rejected two midwives preference not to supervise other staff caring for patients undergoing abortions (BBC News, 2014b).

relies upon law to subjugate such wishes through a collusion of practices (Pereira, 2011). This is demonstrable in the current promotion of patient 'advanced care planning' (ACP) literature.[33]

The collaboration of medicine and law

The idea of ACP is a sound and positive move in accepting dying as being a normalised life event, yet, the legalised nature of the document, and that a 'do not resuscitate' order must also be signed by a medical doctor who can deem a patient competent to make such a decision, demonstrates the biomedical context within which it is located. It is significant to note, however, that a completed ACP is not legally binding from a medical perspective, as medicine can reject preferred care choices through the socially constructed belief that their knowledge is superior to that of the patient. In other words, patient choices can be over ruled by medical power and is clarified in the following statement from the New Zealand Medical Association (NZMA):

> "patients cannot demand or refuse anything in advance that they cannot demand or refuse when conscious and competent. Therefore, patients cannot refuse in advance compulsory treatment provided under the mental health legislation or demand euthanasia or assisted dying. Also, although advance requests or authorisation of specific treatment can be helpful, they lack legal weight if clinicians assess that treatment to be inappropriate" (NZMA, nd, p. Advance Directives).

This statement reflects the reality that personal preferences in care may not be met, leaving the patient in a position of vulnerability and dependent upon the subjectivity, positionality and knowledge of the clinician leading their care. Although the legal standing of ACP's in practice "are respected to the maximum extent possible within the law" (Cartwright, White, Willmott, Williams & Parker, 2016, p. 1), clinicians will remain mindful of the legal outcomes should they uphold

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[33] Advanced care planning is "the process of thinking about, talking about and planning for health care and end-of-life" (Advanced Care Planning NZ, 2013, p. Home).

such directives, demonstrating the collaboration of medicine and law being constraints on the reality of choice for the individual.

The structural dominance of the medical institution remains firmly in situ, presenting an illusion that patients do have choices at end of life, but the reality appears somewhat less certain. The right to choice is not automatic within the healthcare industry (Choice Framework, 2014; Rhodes, Battin & Silvers, 2012). Individuals do not have a right to request automatic resuscitation for example (Miekle, 2011; Clinical Ethics, 2001), nor do they have the right to invoke decisions documented through advanced care planning (NZMA, nd). Such rules and regulations around the care and policing of the self demonstrates the difficulties encountered when patients seek the right for self-determination. Yet, these constraints are further limited when considered within the framework of the human rights principles.

Human rights

Human rights are a set of internationally recognisable standards, adopted in 1948, and represent "the universal recognition that basic rights and fundamental freedoms are inherent to all human beings, inalienable and equally applicable to everyone, and that every one of us is born free and equal in dignity and rights" (United Nations (UN), 1948, p. *The Universal Declaration of Human Rights* (UHDR)).[34] This code is applicable to all human beings irrespective of race, nationality, gender, sex, ethnicity, colour, religion or language, and guides the law to ensure equity is achieved for all individuals without discrimination, with particular regard to freedom, protection and safety from harm (UN, 2014). Human rights present a universal concept through which non-discriminatory practices can be upheld, and those perceived as discriminatory be accountable. This notion of accountability, non-discrimination and equity is theoretically a positive move in a forward direction for the protection of vulnerable individuals, but in practice is more difficult to achieve.[35] The fact that all rights (listed as Articles) are "interrelated,

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[34] The United Nations is an organisation founded in 1945 with 193 member states that promotes action of issues that confront contemporary humanity.

[35] A vulnerable adult refers to a person aged 18 years or over "who is or may be in need of community care services by reason of mental or other disability, age or illness and who is or may be unable to take

interdependent and indivisible" (UN, 2014, para. 1), brings with it the reality and complexity of human life, in that achieving equity is not only difficult, but remains dependent upon individual subjectivity, values, ethics and moral attitudes.

The universality of human rights legislation, executed through law and the formation of treaties upheld internationally, provides a benchmark in the equal treatment of individuals, dependent upon their inherent needs, which may differ culturally and can be uniquely situation dependent. Human rights are unchallengeable, undisputable and absolute according to the UN (2014), but remain constrained by the context of law and criminality of each country. Yet, as all human rights are inseparable at some level, for example political rights, civil rights and the right-to-life, theoretically any improvement to one such right should simultaneously see improvements to those with which it is associated, and vice versa (UN, 2014).

Though broad ranging in the spectrum of rights encompassed, elements of the *Declaration of Human Rights* pertain to healthcare outcomes specifically, and the right to "…a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care…" (UN, 2014, Article 25). Of more interest, however, is the pertinence of Article 3, that "everyone has the right-to-life…" (UN, 2014, Article 3). This statement is unqualified in its application, but may be viewed as a more generalist approach to the value and sanctity of life, irrespective of what that may mean on an individual level.[36] Relevant to this research are the Articles relating to the attainment of freedom to have opinions and make choices "without interference" (UN, 1948, p. UHDR, full text, Articles 1 & 19), whereby social orders acknowledge such rights (Article, 28). As such, it is the amalgamation of these statutes, or the interdependence of them, that reflects the dichotomous situation facing medical practitioners, the law and patients when considering choices in end-of-life care; in that life is to be preserved but simultaneously patients have the freedom to opinions and choices also. Such a situation elevates the need for further investigation into

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care of him or herself, or unable to protect him or herself against significant harm or exploitation" (Department of Health, 1997, p. 8).
[36] The sanctity of life refers to the notion that human life is precious and holds a value that should not be violated (Gushee, 2006).

this juxtaposed positioning of three groups of individuals, to ensure that medical practitioners and lawyers function professionally on a fair, equitable and discrimination free basis with their patients, irrespective of a patient's preference for care (World Health Organization, 2015).

Human rights in a sociological context

The issue of human rights is relatively new within the field of sociological engagement. Human rights are no longer tied solely to issues of citizenship (Turner, 2009, 2006, 1993; Sjoberg, Gill & Williams, 2001), as this identifies individuals as being nation specific, but that human rights have become a focal point in the globalisation of institutions, through which individuals can claim institutional protection over personal situations (Deflem & Chicoine, 2011). How this functions in reality appears unclear, as it is the professionalised institutions that wield power, often exerted through specialist knowledge, over which individuals have little influence. Moreover, rather than offering just protection over personal situations, institutions function on a more corporate level offering less individualised options around care choices, particularly within acute hospital settings.

Although the current literature on sociological aspects of human rights tend to be focused upon legal institutionalisation and the sociology of law, it may prove enlightening to embrace the universality of human rights to engage with empirical issues and, as such, prove relevant within the context of dying in contemporary Western societies. More specifically, it is the knowledge that everyone has the right to make choices without judgement that proves pertinent to this research, although choice always remains constrained from true freedom, in that clinical settings prove contentious for patients engaging with their right to choose end-of-life care options.

The issue of human rights within a sociological framework, however, may prove problematic, as human rights sociologists tend to be supporters of such legislation, therefore, impinging a bias on the research conducted often through the demonisation of non-supporters (Deflem & Chicoine, 2011). Through taking a more constructionist standpoint, and considering a more cultural and social reality, the use of human rights in the sociological context may yet prove effective in understanding the fledgling field of the objectified human rights of those who are

dying within contemporary Western societies. More specifically, it may provide the absent framework through which individuals can be supported when making care choices that remain outside the norms of medical practices, thus, offering a means through which the renegotiation of the right-to-life and right-to-death discourses can be made.

The right-to-life vs the right-to-die discourse

The right-to-life and the right-to-die discourses have never been more prominent than the current media focus upon these issues and, as such, media representations of individual cases have brought the issue to the fore in many Western countries. Although individuals have the right-to-die in some Western countries through physician assisted suicide, for the majority it remains unattainable.[37] It is denied through a combination of factors including the application of expert medical knowledge to the situation, the belief that palliation is sufficient for all individuals irrespective of individual agency and subjectivity, together with the constraints of legislation. When considering, therefore, dying patients who wish to have the right to end their lives at a point of their choosing, or be allowed consensual assisted suicide to end their intolerable suffering, it is acknowledged that the medical and legal professions collaborate and unite in denying such assistance through such acts not being permissible under current legislation (Pereira, 2011). Yet, the non-consensual use of medical models of care for dying patients, for example the LCP or PST appears to confound the law in terms of legality but is overlooked in judicial practice (Pereira, 2011)..

Law and medicine have become representatives of governmental bodies or machines to ensure the compliance of the general population with legal and medical practices and are sometimes referred to as being 'machines of government' (MoG) and are attributable to the works of John Stuart Mill (Smith & Mill, 1998). Although MoG is a term often associated with systems of public administration, it provides a useful point at which to begin examining the inter-relational bond between the law and medical practices. MoG is suggestive of a loud environment, where the moving cogs progress slowly to achieve outcomes, and is entrenched in

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[37] The right-to-die is legal in The Netherlands, Belgium, Switzerland, Canada and some states in the USA, although strict guidelines are in place.

diktat, resulting in the engines of power being "maintained with varying degrees of competence" (MacKay, 2014, para. 7). Yet, the reality is that both law and medicine reside within the construct and constraint of such governing bodies, through which mutually convenient collaboration occurs to ensure the compliance of the general population with the wishes of these institutions. Such compliance is achieved through the commonality of specialist knowledge in both law and medicine and the development of the clinic as a specialist centre, through which power resides. Medicine, in conjunction with law and the government form "part of an extensive system of moral regulation of populations through the medical regimes" (Turner, 1995, p. 13) and, as such, produce a power relationship that no individual is likely to penetrate successfully, as the individual is unequal within this structure. It represents the asymmetry of power relations which is repressive in this instance, as the illusion of choice is constructed through the dynamics of power, but simultaneously withdrawn when individuals seeks partnership in choice.

Despite this analysis, the reality indicates that through the medicalisation of the dying process it is unlikely that clinicians will readily give up their control of this final phase of living, with the succumbing of the dying to the *medical gaze* (Foucault, 1973) remaining steadfast. For those, therefore, at the end of their lives, the right-to-life protracts the dying process; but the right-to-die remains elusive, as one does not legally yet have the right-to-die (Knill, Adam & Hurka, 2015; Allen, 2013), leaving the latter group exposed to the reality that choice is unachievable, and the probability of suffering and indignities will occur. This situation produces a narrative of inequality and presents a malleable application of law regarding medical outcomes, often dependent upon who perpetrates the action, with medicine more often supported in the act of care decisions than the individual patient (Cartwright et al, 2016).

Laws do exist around the criminality of dying and death when assisted by a third party. In England and New Zealand it is not illegal to commit suicide independently, and may be viewed as a 'breach of the peace' in Scotland if it is not conducted in private (Scottish Council on Human Bioethics, 2010). But the right-to-die has become a hot topic across the globe in recent years due to the advancing campaigns for legalised assisted suicide (Armstrong, 2015). More specifically, a

private members bill was launched in the *House of Lords* in the UK, for example, to legalise assisted suicide, thus giving terminally ill patients the option to die at a time of their choosing (BBC, 2014a), prior to the indignities and intolerable suffering experienced by many towards the closure of living.[38] This bill was unsuccessful. In New Zealand there have been two attempts to legalise euthanasia, both of which were also unsuccessful.[39]

One could suggest that human life is highly valued and is, therefore, worth saving at all costs; however, the reality is that for some individual patients they view their positionality very differently, often facing the uncertainty of losing dignity and capacity to function as life ebbs away. Yet, those deemed as sufficiently knowledgeable to draw up laws and ethical guidelines appear to feel compassion for animals, but less so for humans, in that animals are routinely euthanased if illness and suffering occurs (Hawking, 2013); but human medicine pertains to save lives irrespective of wishes, personal costs and outcomes. This situation renders animals in the precious position of having an advantage over human beings in that "euthanasia is not forbidden by law in their case; animals have the right to a merciful death" (Kundera, 1984, para. 1); although this statement may produce opposing viewpoints.

This argument is regularly used when advocates of the right-to-die campaign lobby governing bodies to change legislation; however, the difficulty is that our perception of life value differs from ourselves to those of pets or animals used for human consumption. Such differences do not really add any weighted value to the argument to be allowed control over our own demise, as the relevance of animals that are unable to give informed consent regarding choosing death does not equate to the societal value placed on human life, as the moral status between animals and humans is demonstrably different (McKeegan, 2013). Moreover, animals are euthanased on their owners command or following advice from a veterinarian, as it is often the comfort of the owner that becomes paramount through the difficulty in

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[38] The Private Members Bill – The assisted dying bill (HL2104-1015) is specifically aimed at those who have a prognosis of less than six months to live and have specific conditions such as terminal cancer or motor neurone disease for example.
[39] Michael Laws proposed the Death with Dignity Bill in 1995 and Peter Brown introduced a Death with Dignity Bill in 2003, both of which were unsuccessful.

witnessing their animal's suffering, or that they prefer to not have to manage the incontinence, vomiting or haemorrhaging that may occur.

Regardless of the value of this argument, is the reality that human beings have evolved to make life decisions, but have a lesser place in the decision making around how and when to die (Knill et al, 2015) than in respect to most other aspects of daily living. Moreover, choice-making is an obligation throughout life, but that obligation becomes obsolete at the point of death; as these choices can be disregarded through the professional power exercised by medicine and law, both separately and complicity at this life point.

The fact that intolerable suffering is deemed acceptable for some individuals by both medicine and law in the face of death demonstrates a dichotomy in discourse, as intolerable suffering is allowed to occur when assisted suicide or active euthanasia is legislated against, but relieved through the application of the LCP or PST in the clinical setting. Such a juxtaposed position contradicts the legislative agenda that denies a death of one's choosing when it suits, but simultaneously imposes the medically knowledgeable practitioner into a position of power and control over the death of patients through the application of medical models of care. Moreover, the ability to determine whether one should live or die will simultaneously be influenced by the same qualities that clinical ethics and morality are subjected to, thus, placing interchangeable values on the lives of those in the care of physicians.

Such practices appear to remove the element of patient choice in end-of-life care. The dying patient, if the human rights framework is truly invoked, allows for the right to not be subjected to "torture or to cruel, inhuman or degrading treatment…" (UN, 2014, Article 5) and the right to an adequate standard of "medical care" (UN, 2014, Article 25), but the presence of dichotomous practices in care suggests that reality is far from the original purpose of this framework.[40] Moreover, it may also be suggested that the human rights framework requires reconstituting to reflect the

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[40] It must be noted, however, that the original purpose of the framework was unlikely to have considered end-of-life decision making as needing guidelines, with the focus at that time being on access to healthcare issues and the right not to be tortured in civil and wartime settings outside of hospital care.

significant global changes occurring with regard to rights and choice. Current reality, however, presents a troubled narrative whereby having the choice or right-to-die may be fraught with danger; resulting in the self-determined individual being cast as 'other'. Such deviant behaviour, however, highlights the notion of resistance to contemporary medical models of care. It suggests that there is a tension between what is currently available and what is truly desired by some individuals, with resolution not yet apparent.

Reality suggests that having the right to end life legally through active euthanasia or assisted suicide may actually make those close to the end-of-life feel pressured into ending their lives prematurely to fit with societal expectations that caring for our dying is burdensome and pointless. The right-to-die could quickly descend into having to justify our "continued existence" through "explicitly and implicitly" (Penninga, 2014, para. 6) proving our value in continuing living. The right-to-die has the potential to turn into a duty for those of frail status, subsequently promoting death as being obligatory or mandatory. Medicine in collaboration with law, has maintained an unwavering stance that the right-to-die will produce a 'slippery slope' effect (Pestinger, Stiel, Elsner, Widershoven, Voltz et al, 2015), amounting to patients being obligated to terminate their lives prematurely; however, in opposition to this, medicine practices models of care that effectively constitute this very predicament.

The question arises, therefore, that when presented with the dichotomous situation that medicine and law combine their powerful forces to deny human beings the right-to-die through the use of active euthanasia or assisted suicide; and that law brings medicine to justice in the court of law for poor practice, errors and omissions; why then does the law negate its responsibility in light of doctors using medical pathways to practice what is perceived as euthanasia by stealth? This duplicitous situation serves to simultaneously remove choice from patients who wish to die and the choice of life from those deemed of less value from a medical perspective, thus suggesting that the two institutions collude when it is mutually agreeable (Pereira, 2011). It must be questioned how the right to choose life can be rejected by professional practitioners when it sits within the human rights framework of everyone having the right-to-life, but legally and medically not

allowed to have the right-to-die.[41] Yet, the appearance of 'cherry picking' the moments for collaboration fail to be ignored by the general population, as the right to choose and the right-to-die are currently at the cutting edge of end-of-life care issues if media representations are considered; with the argument split into two camps, those fighting for the right-to-die and those who fear the introduction of legalised euthanasia.

As the population becomes more engaged with individual health, their rights and preferred outcomes of choices, the fact that medicine remains in its gilded and privileged cage, making decisions based upon their expertise but not necessarily aligned with patient preferences, produces a negative response to perceptions of care. Stands are being made to promote the right to choice and the active engagement of patients with their care situations, particularly when dying, which are notable and worthy causes; however, a more in depth investigation of the presenting dichotomy of medical and legal practices appears pressing to determine the juxtaposed perceived availability of choice at end-of-life.

Conclusion

The denial of death and preservation of life on one hand by both medicine and law, and the simultaneous denial of life on the other appear somewhat problematic. Such juxtaposed interpretations on how the care of the dying should be managed, the role dying patients have in choosing their care and methods of exiting this life, the potential for intolerable suffering to occur and the constricting paradigm in which such patients exist requires not only investigation, but answers as to how professional structures preside over the end of life in ways that are, at times, constraining and controlling. The ability of humans to make appropriate self-care decisions is undermined through the application of medical expertise to what is a natural end to living; thus, leaving those facing the end-of-life process in a state of uncertainty as to how their end will be.

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[41] It must be noted that although *human rights* legislation may be pertinent to this research, it is not being included in detail in this work.

Chapter Three

"It is not death, it is dying that alarms me"
(Michel de Montaigne)

The United Kingdom and New Zealand

Introduction

For the purpose of this research I have focused upon the medical and legal practices of the UK and New Zealand as they have similar healthcare systems that are primarily publically funded, with healthcare available to all, unlike the USA for example. They are both Western countries with an interest in assisting their populations to live well, from before birth to the grave. They have active palliative care systems focusing on dying patients achieving 'good deaths' together with similar legal systems and viewpoints regarding such practices and, therefore, offer a comparative foundation from which to implement this study. Furthermore, I have clinical experience in both countries relevant to this research. In this chapter I contextualise the issues of individual choices when dying and the constraints that occur within both the UK and New Zealand, highlighting the legal cases pertinent to this research and the clinical practices in both countries.

Media, the dying and representations within traditional 'grey' media

Media representations of death and dying are a daily occurrence. Newspapers, online social media and television news programmes highlight a large number of deaths from various means in every report, from war torn regions of the globe, to murders and road traffic accidents. It is a part of life, yet is fragmented and not a reality with which we can readily equate, as it is mediated through a subjective platform that does not allow us to consider our own mortality. This view of mortality demonstrates Bauman's notion of a "deconstructed mortality" (1992, p. 131) in that the mediated death leaves it void of significance, thus distancing this death from that of our mortality. Such deaths differ from the previous community focused death to one of being unmentionable in the lived reality. The everyday, normal death has become pornographic in that it is offensive, and it is taboo (Gorer,

1965). Tony Walter (2002) questions whether death and dying can really be taboo given the extensive literatures available in the public domain. I would suggest, however, that there is a difference between discourse narrated in text or via the media and the reality of death for the living. The availability of discourse does not automatically equate with a narrative of visibility, rather an acknowledgement that death and dying exists but not necessarily in relation to the self but in relation to unknown others; and is simultaneously easily ignored if this is the chosen pathway.

Walter also highlights the virtues of hospice as a new means of handing back power to the individual in the self-centric lives now led and refers to the work of Elizabeth Kübler-Ross as being a "revivalist par excellence" (2002, p. 30). I, however, would disagree with Walter in this assertion as although Kübler-Ross's work was both empirical and ground breaking at the time, it remains prescriptive and contextualised within a medical model of care and has the potential to cause existential suffering to those who feel they are not meeting the articulate criteria for grieving. Despite the potential that death and dying are available in the public arena, they are, however, simultaneously sequestered to the isolation of the clinic and managed by medical practitioners, not sensationalised through media depictions of the unnatural death. This situation, however, is in the midst of change. The natural death or the desire for a natural death is spearheading the campaign for the right-to-die at a time of our choosing.

The human right-to-die is currently at the cutting edge of legal challenges being made across Western societies to secure the right to self-determination, as such individuals see the closing years of their lives dawn on the horizon. The fear of dying a less than perfect death or a death that is not of one's own choosing is fast becoming an important aspect of living for many (Ko, Kwak & Nelson-Becker, 2014; West & Glynos, 2014). Death, although feared by many, is coming out of the closet and no more so than in the UK and New Zealand. Death and the right to choose when and how to die populates common national media sources expressing the viewpoints of those for and against voluntary euthanasia and assisted suicide; with regular pieces portraying the positive and negative issues of such actions. The differing perspectives are truly oppositional in that most individuals are either in favour or against such legislative actions (Johnstone, 2012), with no optimum

outcome yet achieved in either country. Media representations, however, play a key role in mediating the views of populations, medicine and law, simultaneously highlighting the legal standpoints with regard to dying, thus, keeping up the momentum of these campaigns for all parties.

Draft death and dying bills have been presented before both the British and New Zealand parliaments over the past two decades, specifically in favour of voluntary euthanasia or assisted suicide for specific patient cohorts, yet these methods of dying remain illegal in both countries (Smartt, 2002: Bellamy, 1994). This is not a universal standpoint however, as a number of Western countries have adopted this as a legal means to end life if one should choose to do so, with constraints and safeguards in situ to ensure no mass killing occurs. The Netherlands is the most well-known country to adopt a euthanasia policy, together with Belgium, Switzerland, Germany, Japan, Albania, Colombia and most recently Canada (Payton, 2015); with assisted suicide legal in the American states of Oregon, Vermont, Washington, New Mexico and Montana, (The Guardian, 2014). Often such legislation is preceded by individual petitions for the right-to-die, some of which fail in the process.

Specific cases in the UK and New Zealand
There have been a number of such key cases in both the UK and New Zealand over the past 20 years, most of which have been unsuccessful in achieving the right-to-die. In the UK, the first notable case was that of Tony Bland, a 23 year old male who was in a 'persistent vegetative state' (PVS) and being kept alive through artificial feeding.[42] [43] Bland was not dying but not consciously living either. He was unable to request the right-to-die, but was kept alive through medical interventions in feeding. He was treated for infections, although if he had not been treated he would have died from natural causes. Medical practitioners caring for Bland took the matter to court in a bid to legally euthanase Bland, which was approved. Bland died from starvation and dehydration and not PVS or the Hillsborough disaster according to some literature, whereas others state that it was his inability to self-

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[42] Tony Bland was a male who was injured in the 1989 Hillsborough Disaster and never regained consciousness.
[43] Persistent vegetative state is when patients have severe brain damage but appear to be in a state of partial arousal (Cranford, 2004).

feed that caused his death (McCullagh, 2004). This specific case highlights the duplicity in decision making, in that Bland died although he did not ask to do so with the decision made between the collaboration of medicine and law; and reflects dimensions of the contemporary tragedy of some individuals being located between life and death, but unable to articulate their preferences.

Dianne Pretty, Tony Nicklinson, Paul Lamb and a man known as Martin are other landmark cases in the UK, all of which were denied the right-to-die.[44] These individuals had expressed their inability to live with what they perceived was intolerable suffering, yet the highest courts of the country denied them the right to end their misery at a time they wished to do so. The key point to these cases is, however, that they were unable to end their lives themselves by suicide due to personal incapacity, and although their family members understood their wish to die none would assist them, either because of the legality of doing so or that they felt unable to assist them. They were, therefore, reliant on a third party to assist them to die, for example a doctor, professional carer or lawyer (Boseley, 2011), and this is the point at which each case failed. A further notable case is that of Debbie Purdy, who wanted to ensure her partner would not be prosecuted with aiding and abetting if he accompanied her to the Dignitas Clinic in Switzerland.[45] [46] In a truly landmark case, Purdy won her case, but eventually was too unwell to travel.

In New Zealand the story is slightly different. There have been cases whereby family members have been tried for murder when relatives have died and a very recent case of requesting assisted suicide. Lesley Martin was given a seven and a half month prison sentence for assisting her mother to die (Gardiner, 2004) and Sean Davison also attempted to assist his mother to die through offering her morphine (Shepheard, 2009). More recently Lecretia Seales legally challenged her right-to-die, requesting that her general practitioner could assist her without fear of prosecution.[47] Her legal bid failed, but she died naturally prior to the decision being made public (Savage, 2015). Such cases have received intense media attention

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[44] Dianne Pretty had motor neurone disease, Tony Nicklinson had locked in syndrome, Paul Lamb had suffered a major accident and was completely paralysed and Martin had a brainstem stroke.
[45] Debbie Purdy had multiple sclerosis.
[46] Dignitas is a clinic in Switzerland to which individuals can travel in order to die when they choose.
[47] Lecretia Seales was a lawyer based in Wellington, New Zealand and had a brain tumour (oligoastrocytoma).

irrespective of the standpoint taken, but have yet to really influence change. Medicine appears to have a more favourable chance to influence the direction of legal challenges, in that it proffers knowledge to ensure that such legal bids remain just that, bids that fail.

UK, New Zealand and *The Liverpool Care Pathway*

Media representations are always subjective with both medicine and the dying being of general interest, resulting from the increased consumption of healthcare services. Media interests, however, appear heightened when a medical story is not necessarily about the latest scientific triumph, or another failed bid to secure the right-to-die, but when medicine appears to cross its professional practice boundaries, through using legitimised medical models of care. As discussed the LCP was produced as a supportive tool in caring for the dying, yet this medical model of care has now become tarnished as a 'pathway to death' in the UK (Smith, 2011).

Despite the idealism of the original document, this model of care has subsequently become lost in the chaos of real world healthcare, thrusting it into the media spotlight through compelling narratives of poor care of the dying, particularly within the public hospital setting. It depicts patient harm being caused through the (mis)application of this care pathway and increased numbers of patients being placed on it in UK hospitals, often without consent (Smith, 2011). The pathway is perceived as delivering poor quality care for the dying while the UK government pay out financial incentives to National Health Service (NHS) hospital trusts who implemented it (Bingham, 2012). The pathway has been dubbed the "road to death" (BBC, 2013, para. 3), thus becoming a euphemism for euthanasia (Bingham, 2012). There have been numerous depictions of harrowing care over many years in relation to the LCP, resulting in its dissolution in the UK as the preferred tool for end-of-life care, while it continues to be practiced in New Zealand.

New Zealand has been actively training healthcare staff to utilise the LCP since 2004 (Palliative Care Council of New Zealand, 2014) and it has been rolled out and used across approximately 350 public and private healthcare settings (Dudding, 2013). It is used in some hospices throughout New Zealand, including Mercy

Hospice in Auckland and Auckland District Health Board (Mercy Hospice, 2015) and remains visible on the Ministry of Health web pages. In New Zealand it remains the gold standard model to provide excellence in care for the dying (MacKenzie, 2011), with the Ministry of Health supporting the continued use of the pathway as an integrated approach to care for the dying (Vandervorst, 2013). It appears, therefore, that despite the failings of this approach to end-of-life care in the UK, where it was originally developed, there is little literature or media attention given to similar outcomes in New Zealand. This may be because the pathway is implemented differently in New Zealand, in that in New Zealand "the focus is on using the pathway tool as a component of an integrated approach to quality palliative end-of-life care, supported by specialists and other health professionals. It is not intended to replace clinical judgement and practice" (Vandervorst, 2013, para. 6). Reality, however, suggests that this may not actually be the case, as reports are surfacing of slow euthanasia (Dudding, 2013) occurring in some instances and of some district health boards discontinuing the implementation of the LCP in favour of re-branded individualised care plans (Waitemata District Health Board, Auckland, 2014, personal training).

When considering the realities of care in both the UK and New Zealand it appears, therefore, that healthcare practices are similar, with New Zealand often following in the footsteps of its colonial past (Cohen, nd). It appears that despite the chilling literature emanating from UK sources, some of which is known to be sensationalist but others more factual, that this is generally ignored in favour of continuing with the planned roll out of care in New Zealand. In light of the illegality of euthanasia and assisted suicide and the non-consensual use of the pathway in both countries, this paradoxical situation provides a fascinating backdrop for this research.

Conclusion
As all forms of euthanasia, together with assisted suicide are illegal in the UK and New Zealand, we must consider the similarities between PST and the LCP as being acceptable forms of care, and the potential sedation of an individual, at their request, to terminate their intolerable suffering and subsequently their life. Moreover, we must consider if there is any difference in care, or is it merely the point of intent that is the differentiating factor. Given the nature of these medical

treatments and the antithesis of legal statute, it illustrates quite clearly the difficulties that may arise when medicine instigates treatment plans that appear to have a purpose similar to illegal acts. The medical construction of therapies to alleviate suffering, that also appear to end life in a legally acceptable manner, blur the boundaries between such therapies and illegal acts of mercy killing.

This juxtaposed narrative has not arisen through chance, but through the controlled and intentional appropriation of life events by the field of medicine as a means of social control. Arriving at the situation we currently experience within Western societies has been achieved through a wide variety of practices, not least because dying has now become a medical event which is to be averted if at all possible, rather than accepting the naturality that life is always finite. This brings us to question the existence of genuine individual patient choice in decision making processes at end-of-life, as at present it appears that irrespective of advanced care directives and the ability of competence, all preferences can be overruled through medicine collaborating with law, irrespective of whether the choice be life or death.

Chapter Four

"...all research is a practical activity requiring the exercise of judgement in context; it is not a matter of simply following methodological rules"

(Hammersley & Atkinson, 1994, p. 23)

Methodology

Introduction

I have worked in a diverse range of clinical settings, from the emergency departments of busy city centre hospitals in the UK, appearance medicine clinics, aged care and now specialise in palliative care. The right of patients to make informed, considered and relevant life choices has been one of the foundation stones of my clinical practice. The right to make individualised choices in end-of-life care is critical to patients succeeding in achieving the death they seek and should be respected. Not all choices will be the same as no two deaths are ever identical, but often patients are ultimately seeking control of their death. This has never been as obvious as it is currently within contemporary Western societies, and the UK and New Zealand specifically, with media stories and social media platforms highlighting and discussing death and dying. Such narratives highlight not only the loss of the artful death, but that the right to make choices at end-of-life should be a naturally occurring phenomenon, not a newly constructed idea arising from medical discourse. Moreover, such narratives focus upon a patients right-to-die at home, the right to deny medical treatment and the right to choose to end one's life (with assistance if necessary) when the burden of intolerable suffering becomes too great to manage.

In this chapter I outline the steps I have negotiated in order to undertake this research, detailing the relevance of my methodological choices and mode of implementation in relation to the other methodologies considered but not deployed. I discuss the methodology used in this research, namely narrative analysis, the use of thematic analysis as a means of extracting relevant data from the research output, together with notes and discussion on validity and reliability in relation to this

qualitative methodology. I also identify the dominant themes emerging from the analyses which I perceive to be most pertinent to my research questions, thus formulating the framework for the onward discussion of my analytical findings.

Research questions

The questions I have developed for this research draw upon the mutually agreeable collaboration between medicine and law as machines of government in relation to patients who would choose to die if they could, and those who die through the non-consensual use of medical models of care. The questions focus upon how Western societies have constructed the contemporary death in relation to the previous artful death. They consider the culturally imposed unfamiliarity of this life phase, through the invoking of social, physical and psychological anxieties of the known and unknown in relation to death and how medicine has utilised such naivety to manage the fear of impending suffering. The questions engage with the effectiveness of patient choice through the human rights framework, in that choice is a marketable feature of contemporary healthcare, yet choice appears to be a clinical construct for patients at this life stage, resulting in some individuals being outcast from the accepted norms of the contemporary death. The following questions, therefore, provide a starting point from which the narrative analysis into this field of research is performed.

Q1.   Is patient choice an achievable reality within the constructs and constraints of contemporary Western societies' acceptable processes when dying, or is it an illusion? What barriers or obstacles are encountered when dying patients exert their self-determination to achieve a death of their choice?

Q2.   What are the consequences, if any, for those seeking the right to autonomy over the self at life's end? And can this be overcome through re-conceptualising the *Ars Moriendi* as a means of facilitating a futural 'good death' for the twenty-first century individual?

Specifically, therefore, this research considers UK and New Zealand patient experiences in end-of-life care decision making through the lenses of individual choice and having the right-to-die, the human rights framework and the *Ars Moriendi*, but contextualised within a medico-legal discourse.

Research design

The literature in this specific field of research is currently somewhat limited to answer these specific questions. Despite there being a wealth of academic literature on death and dying, suicide, and on medical law in sociological terms; the study of the collaboration between medicine and law in controlling the way we currently die is less well documented. The current sociological research that focuses upon death and dying covers a broad spectrum of issues including the social construction of death, societal attitudes towards death, the medicalisation of death and dying, suicide and genocide, all of which "do not occur in a social vacuum" but are "largely influenced by the social context in which they occur" (Thompson, Allan, Carverhill, Cox, Davies et al, 2016, p. 1).

There has been some recent research exploring patients' rights to make informed choices and patient empowerment in the UK (Dixon, Appleby, Robertson, Burge, Devlin et al, 2010), but not specifically in relation to the dying patient. With regard to assisted suicide and medical models of care at end-of-life, there is a plethora of medical papers substantiating these issues in practice, however, little of this literature is written from a sociological perspective. Yet, it must be noted that much of the literature produced regarding the LCP in the UK and New Zealand is not necessarily produced through academic or sociological effort but through the medium of 'grey literature', and that of professional interest in conjunction with funded review panels responding to specific issues that have been raised regarding practices in care.[48] [49]This is illustrated through the *More Care, Less Pathway* (2013) review undertaken in the UK at the instruction of the Minister of State for Care Support, Norman Lamb MP and the *New Zealand Palliative Care Strategy* (Ministry of Health, 2001) under the direction of the Ministry of Health. More specifically, it appears that such research is only prompted by negative media representations of medical practices and, consequently, relies upon palliative care charities or government funded responses to acquiesce patients and families (BBC, 2013a).

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[48] 'Grey literature' refers to research that has been produced outside the publishing fields of commercial organisations of academic institutions (Barrat & Kirwan, 2009).
[49] It must be noted that many such review panels will often have academic expertise as part of the group make-up.

There is a proliferation of media stories giving a voice to the general public in relation to poor healthcare issues, with research evidence indicating that this method of communication is effective in engaging medicine with changing practice (Bingham, 2012). While there is considerable engagement of the media with patients who have died in less than desirable circumstances, who sit outside the socially accepted biomedical paradigm for dying, or would like to have the right to choose to die it appears to have not prompted extensive independent and sociologically scholarly research to further investigate these experiences. In this research, therefore, I examine the barriers encountered when individuals seek control of the dying trajectory and how this unfolds for the patient compliant with the contemporary interpretation of the medicalised 'good death' and for those seeking the right-to-die; the equity of doctor/patient relationships and the role of law in supporting medical practices. I also consider these issues in relation to moving forward to improve outcomes for the self-determined individual

My original research design intended to engage directly with dying patients and their families through invitation to participate in interviews. This would have provided a clear picture of care experiences at end-of-life within New Zealand and allowed patients to anonymously voice how they were experiencing this. However, through my knowledge of the palliative care setting in New Zealand, the constraints of achieving anonymity in a close knit community together with a patient's potential reluctance to have their thoughts committed to paper for fear of being labelled as negative, or the fear that doctors would seek revenge at subsequent medical appointments (Clwyd & Hart, 2013), this methodology proved to be difficult to implement successfully. Furthermore, the known difficulty in recruiting from this patient cohort meant this initial research design was discarded (Steinhauser, Clipp, Hays, Olsen, Arnold et al, 2006).

I then considered using participant observation as I have direct access to patients, their families and medical practitioners in my workplace. As I spend time on a daily basis with dying patients and their families, participant observation as a form of ethnography would have provided a deeper understanding of the practical experiences these individuals encounter in this phase of life (Clifford, French & Valentine, 2010). Furthermore, in my role as a specialist palliative care nurse a

trusted bond is developed between patients and myself and, therefore, felt that this methodology would produce stimulating and thought-provoking data. Despite this methodology being one that is often easily accessible, in that we can study through 'people watching' on a daily basis in order to gain "a greater understanding of phenomena" (DeWalt & DeWalt, 2011), to work with them on such a sensitive matter within the constraints of an institution proved more prohibitive. Having both informally and formally approached my employer with regard to conducting this research, including presenting a research proposal and ethics consent application, consent was declined, with no specific reason given; although I am sure ethical issues, risk management, patient confidentiality and liability would be behind this decision.

In light of the already dismissed methodologies I further considered implementing an auto-ethnographic element to my research, through the experience I have gained over the past 25 years in the healthcare industry. As auto-ethnography is a form of self-narrative, which is currently gaining momentum in a sociological context (Wall, 2008), it would offer an engaging, vibrant and relevant contextualisation of my research. Through using "self-observation and reflexive observation" (Maréchal, 2009, p. 43) I believe it adds a depth to the research narrative. However, through my knowledge of the issues of dying patients both in the UK and New Zealand, together with my concerns around identification of patients from scenarios recounted I have determined not to implement this, as this research attempts to be as objective as is possible in its aims and be easily replicated. I feel, therefore, that auto-ethnography cannot truly uphold these virtues.

In order to address the complex subject matter of this research, together with the contemporary nature of this field of study, the data for this research is obtained through the use of narrative analysis, drawing upon secondary data sources from a variety of online environments. Using narrative analysis I implement data collection to ensure the acquisition of the most pertinent data to inform an understanding of the issues present in this specialist field of practice.[50] Using a narrative analysis as a

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[50] Qualitative research aims to gather an in-depth understanding of a particular phenomenon or human behaviour (Ritchie, Lewis, Nicholls & Ormston, 2013; Bowling, 2002).

qualitative methodology I ensured that relevant key data was acquired to inform my academic inquiry through conducting 62 searches, using a total of 32 databases in each search of the academic literature. Alongside the database search I implemented a secondary search using Google UK and Google New Zealand search engines to accumulate the online social media data required to give a voice to the research.

Qualitative research

Qualitative research is a broad label pertaining to a number of research methodologies, particularly in the social sciences, that are founded upon theories, but do not rely upon the gathering of purely statistical data from which to draw conclusions (Silverman, 2013). The wide range of qualitative methodological approaches available to the researcher demonstrates a diversity necessary to underpin the varied research attempted within the different research disciplines (Ritchie, Lewis, Nicholls & Ormston, 2013). Yet, "qualitative research is difficult to define clearly. It has no theory or paradigm that is distinctively its own… nor does qualitative research have a distinct set of methods or practices that are entirely its own" (Denzin & Lincoln, 2011, p. 6). Generally, qualitative research can be identified as covering approaches that are naturalistic and interpretative in nature (Ritchie et al, 2013; Bowling, 2002), and are concerned with exploring phenomena or human behaviour from an internal perspective (Flick, 2009).

The purpose of qualitative research is to study people in their own environments, whether that is at home, work or other activities. It presents an opportunity for a researcher to immerse themselves in the field of study, observing how the participants attach meaning to the events witnessed. It is a literary narrative as opposed to being numerical in nature, thus allowing for the production of detailed observations. It is, therefore

> "…a set of interpretive, material practices that make the world visible.
> These practices transform the world. They turn the world into a series of
> representations, including field notes, interviews, conversations,
> photographs, recordings and memos to self … qualitative researchers study
> things in their natural settings, attempting to make sense of or interpret

phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2011, P. 3).

The ability to bring visibility to often less well known phenomena allows the articulation of subject matter that can be obscure, sensitive or complex in nature. Qualitative research and the lack of utter specifity of what it represents, provides a flexible framework most relevant to subject matter that has little pre-existing knowledge or identifiable research already in place. This is, therefore, the reason I have decided to base my work within the qualitative framework of narrative analysis.

Sample

In order to obtain the most relevant data for my narrative analysis I utilised the theoretical sampling technique. I have purposefully chosen this approach as it is particularly suited to emerging fields of academic research (Corbin & Strauss, 2015; Holloway & Wheeler, 2010; Draucker, Martsofl, Ross & Rusk, 2007) and is informed by evolving theory and emerging trends (Holloway & Wheeler, 2010; Strauss, 1987; Glaser & Strauss, 1967). Theoretical sampling presents the opportunity to select "incidents, slices of life, time periods, or people on the basis of their potential manifestation or representation of important theoretical constructs" (Patton, 2002, p. 238), thus structuring the data collection process. Sometimes referred to as 'purposive sampling' or 'judgement sampling' (Abrams, 2010), it offers the researcher the opportunity to make judgements on the best perspective to approach the research and assimilate the key words, phrases or research strategies accordingly. That is, that "'real-world' examples (i.e. operational examples) of the constructs in which one is interested" (Patton, 2002, p. 238) can be identified and utilised to provide clarity to the research being conducted. The opposite effect of this, however, is that theoretical sampling has intentionality about it; the researcher already has a goal in mind when initiating the research or the researcher has already done sufficient work to have formulated thoughts around potential hypotheses (Bagnasco & Sasso, 2014). Yet, theoretical sampling is also flexible in nature as this purposeful sampling strategy has the benefit of being able to be manipulated and changed as the study progresses (Abrams, 2010; Holloway & Wheeler, 2010).

The ability to select suitable material for data collection, informed through the reflexivity of my lived and worked experiences in relation to this research, provides a relevant and detailed sample from which interpretative theories are drawn. Theoretical sampling, in that it can be useful when studying the 'hard to reach' populations or cohorts (Abrams, 2010) or fledgling fields of study, provides a foundational framework from which to analyse current practices in both medicine and law in relation to dying within contemporary Western cultures generally, and the UK and New Zealand specifically. This intentional research strategy ensures I collected the most appropriate and concise sample through which I can generate an informed and informative analysis of the data (Glaser & Strauss, 1967), together with a lively debate of the prominent issues.

Structuring my research to achieve selective saturation of the data, and being mindful that this research is exploratory in nature, I identified 32 databases as having the potential to be of both interest and relevance to this research (Appendix 1). This is an intentional methodological strategy as through implementing theoretical sampling it allowed me to utilise my reflexivity of practice in identifying literature that would have the potential to generate conceptual theories from a sociological perspective. This strategy allowed me, therefore, to quickly identify literature of potential interest, thus, discarding those that did not meet my outlined criteria. The databases identified as having the potential relevance to my research were used as platforms from which I could reflexively analyse the narrative content in a bidirectional manner. Bidirectional reflexivity, in sociology, proves a useful tool whereby self-reference and examination of the narrative data can affect the eventual outcomes of the research, through the continuing strategy of reviewing and, therefore, realigning the research actions.[51] Through using bidirectional reflexivity, I was able to analyse, modify and refine the key research phrases as a constant and dynamic process, making amendments as indicated. This resulted in only the literature that had the most potential relevance being identified.

In order to conduct this research I created a list that finally totalled 62 carefully considered key words and phrases which, due to my prior and current knowledge of

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[51] Bidirectional reflexivity refers to the bidirectional relationship between the narratives examined in this research and that of the researcher (Kupferberg & Green, 2005).

the research field, encompassed the multi-faceted nature of medical practice as a profession, specialist palliative care, law, human rights issues and patient experiences (Appendix 2).[52] This is a complex research framework and required not only attention to detail and the ability to procure the relevant literature, but to be able to read the literature from a number of dynamic and inter-related perspectives, through implementing bidirectional reflexivity. The dualistic nature of some of the phrases ensures that multiple perspectives have been covered in conducting the database searches. Furthermore, to ensure that the returned results were not only of relevance, as models of care such as the LCP have not been in existence for an extensive time period for example, I limited the time frame for the research to the last five and a half years, that is from January 2010 to June 2015 inclusive.

A total of 3,419 literary documents were returned for this time period, but this was refined and modified through bidirectional reflexivity to 437 that I felt were sufficiently relevant to warrant further investigation. With such a large initial return on the search, I expected some duplication in documents; however, only five papers were duplicated in total and, as such, eliminated from the final figures. The 437 documents consist of a variety of literatures including acts of parliament, court papers, transcriptions of legal cases, newspaper articles as well as scholarly journal papers and, as such, now constitute the foundation of my narrative analysis into medicine, law and dying in the UK and New Zealand. They provide not only a fascinating wealth of relevant information, but a diversity of narratives which will provide a depth to this research. In constructing this research, however, I have not focused on the issues of gender, race or ethnicity specifically, as these are not truly identifiable when engaging with online forums and blogs due to the nature of anonymous posting of communications and the privacy this maintains. Furthermore, to identify any of these issues would have required direct interaction with the individual commenting, thus confounding the ethical guidelines of internet research.

In structuring the second phase of my research I decided upon using Google as the search engine of choice with it being a dynamic platform from which I could reflexively analyse social media contributions in order to answer the questions

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[52] This list was modified and amended throughout the research process to achieve this end result.

posed previously. Online social media encompasses a "broad set of Internet-based communications, tools, and aids" (Korda & Itani, 2013, p. 15) providing channels facilitating communication both personal and public. Narratives can be either anonymous or named, representing an infinite number of subjects and interests, thus offering a voice to those who may otherwise feel voiceless (Ingram, 2010; Brogan, 2007). The use of such social mediums is relevant in today's technologically driven Western societies, particularly as the Internet is now presented as being a "…key site for the articulation of social issues" (Mautner, 2005, p.1). The Internet is a medium providing a contemporary means of communication and a platform for observing human behaviours and relationships (Kietzmann, Silvestre, McCarthy & Hermkens, 2011) through the plethora of blogs, forums and micro-blogs published. It is also a source whereby contributors from multi-dimensional intersections can convey their personal narratives regarding particular interests or concerns. It is particularly useful when considering government activities, public affairs or interests of a public nature in relation to personal experiences and perspectives.

Social media provides a means of connectivity in a world where such integration and kinship was previously unknown (van Dijck, 2013). It provides visibility to the voice if it wishes to be heard and, as such, becomes relevant in adding an experiential element to this research. The lifestyle preferences of those dying are relevant in that the unknown becomes knowable, but in knowing we simultaneously begin to question practices of both care and law. The failures or achievements of previous years or decades become highly visible, often inundating online social media platforms with debated narratives which can be equally empowering or exploitative (van Dijck, 2013). Such online presences provide a contemporary mode to explore this research field, as the use of the Internet as a resource tool is becoming increasingly more commonplace, irrespective of age or gender. The Internet is also the only platform for social media interactions today and, as such, provides a current and, therefore, highly appropriate means with which to analyse current experiences of end-of-life care issues. Moreover, it provides an often anonymous platform through which those who fear the repercussions of professional experts or institutional bodies can verbalise their anxieties, fears and experiences without the concerns and reservations experienced in face-to-face contact, even if the interviewer is unknown to the participant.

In a similar manner to deploying the previously conducted database searches, I again utilised bidirectional reflexivity to search Google for relevant open forums and blogs. I used Google as it is both reliable and effective for producing relevant search results on a global basis, offers specialist advanced search options (Consumersearch, 2009) and is the most utilised of all search engines, with 98 per cent of users trying Google first (Schwartz, 2014). I did consider adding a further search engine to the research structure and, in particular, Yahoo as it is perceived to be the second most popular search engine when compared with Google and equal with Bing (Schwartz, 2014); but as it is less sophisticated than Google in its search capabilities and refinement options (Consumersearch, 2009), this option was not implemented. In order to gain sufficient data and achieve saturation, I used both Google UK and Google New Zealand, conducted as two separate searches, thus gaining perspectives from both countries. I used the key words and phrases already utilised for the database searches (Appendix 2) to ensure continuity and clarity in the research methodology, however, added both 'blog' and 'forum' to each search to access the required information.

Blogs and forums

Blogs and forums are products of the technological age of communication and did not exist prior to the instigation of the Internet. Both formats, although different, are exponentially used across the globe as means through which communication and articulation of ideas and knowledge are accessed by an enormous audience. A blog is a shortened version of the word weblog (Blood, 2000) and consists "of entries (also called posts) appearing in reverse chronological order" and are "similar in format to a daily journal" (Gunelius, 2015, p. Definition). Blogs are often used as a "frequently updated online personal journal or diary" and "is a place to express yourself to the world" (Byrd, 2015, para. 4), thus allowing the inner voice of the individual the opportunity to express themselves when other means are unavailable. The proliferation of blogging transpired with the advent of online publishing tools during the late 1990s and has grown significantly since, with over 152,000,000 blogs online in 2013 (Gaille, 2013). Some blogs are purely expressive with topics ranging from make-up tips to political activism, with some inviting social interaction through the option to comment on posts with personal opinions.

Online forums, however, differ from blogs in that their intention is to produce online discussion on a variety of subjects, not merely express personal opinions. Forums are also known as 'discussion boards', 'message boards' or 'bulletin boards' (Tech Terms, 2011) and have 'threads' (or conversation threading) started by individuals relating to a topic of their choice. Forums are a popular means of communication and a means of passing on experiences and knowledge, again covering a broad range of specific topics including healthcare, sport and beauty. Blogs and forums are often accessed simply through search engines, however, there are some that are closed and, therefore, not accessible unless one signs up to become a member. For the purpose of this research I have only included blogs and forums that were openly accessible without a gatekeeper or membership requirements; although it must be noted that forums are usually moderated, with such moderators able to delete some posts if deemed unsuitable.

The timeframe searched was January 2010 to June 2015 and was conducted between January 2015 and June 2015, therefore any additions to, or withdrawals from either the Internet or these websites prior to or after these dates are not included in this research. This resulted in a combined total of 17,161 blogs and forums returned from the Google UK and Google New Zealand searches. Consideration was then given to the content of each search result to ensure they were either a blog or forum, that the forum search results had an interactive content, and that each result had at least one of the searchable phrases (Appendix 2) in the website synopsis. Furthermore, due to the high volume of website returns, all websites with the following subject matter were excluded as not being relevant to this study:

➢ Scholarly literature (as was retrieved through the database searches)
➢ Abortion
➢ Television shows
➢ Palliative care for children
➢ University course contents listings
➢ NHS Trust & district health board clinical information
➢ America, Australia and Europe

as I have tailored this research to be pertinent to adults who are deemed competent to make their own decisions within the UK (as a whole) and New Zealand only. Once again, through the implementation of thematic sampling and the application of bidirectional reflexivity, the large sample was analysed on an ongoing basis, with search criteria amended accordingly.

When the sample was further broken down, Google UK returned 5758 blogs, 1155 of which were duplicate results, with 533 retained for further analysis and 6919 forums, 826 of which were duplicate results, with 86 open forums retained for further analysis. Google New Zealand returned 2506 blogs, 885 of which were duplicate results, with 289 retained for further analysis and 1978 forums, 579 of which were duplicate results, with 111 open forums, from a variety of sources, retained for further analysis (Appendix 3). All blogs and forums included in the final results are publically accessible, without a gatekeeper or need to register in order to access the dialogue.[53]

Triangulation

Triangulation is the employment of "several research tools within the same research design" (Sarantakos, 2012, p. 159). It is a powerful methodological technique when implementing more than one research strategy to examine the same phenomenon. Triangulation can also infer a level of confidence in the results produced through the removal of some of the potential weaknesses in some methodological approaches; although this is not a view upheld by all researchers (Sarantakos, 2012). Triangulation is not merely a singular perspective, but has a number of types within its classification, for example method triangulation, investigator triangulation and time triangulation. For the purposes of my research I have implemented sampling triangulation as this allows for the deployment of two or more samples within the same research project (Sarantakos, 2012).

This sample, therefore, has been designed to reflect more than one source of data in order to produce a balanced interpretation of what is happening in practice between medicine and law in relation to the contemporary death in Western cultures. This

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[53] Although it must be noted that some reports would require registration and/or payment in some instances and are not freely available.

data source triangulation method has allowed me to analyse the narratives collected over a five and a half year period from January 2010 to June 2015 from multiple perspectives including the professional and lay lenses (Denzin, 2012, 1978; Patton, 1999). Through using sampling triangulation I have been able to crosscheck the collected data in order to produce accurate results and, therefore, demonstrate "a more detailed and balanced picture of the situation" (Altrichter, Feldman, Posch & Somekh, 2008, p. 147) through the use of narrative analysis.

Ethics

Ethics are the moral principles that govern the behaviour of individuals and, as such, apply not only when conducting research with physically present human participants, but remain relevant when using the Internet for similar purposes. As such, Internet research can be viewed as a sub-category of general ethical principles, with Internet research ethics (IRE) being defined as

> "the analysis of ethical issues and application of research ethics principles as they pertain to research conducted on and in the Internet. Internet-based research, broadly defined, is research which utilizes the Internet to collect information through an online tool, such as an online survey; studies about how people use the Internet, e.g., through collecting data and/or examining activities in or on any online environments; and/or, uses of online datasets, databases, or repositories" (Buchanan & Zimmer, 2016, para. 1).

This is a very general statement regarding Internet research, but for the purpose of this study it is essential that the material published on the online forums and blogs was always intended to be accessible and for consumption in the public domain (Association of Internet Researchers, 2012). This is relevant as online social media platforms of communication are temporal spaces, and can create ambiguity with regard to the ethical challenges posed with this form of research (Economic and Social Research Council, 2012). In terms of ethical guidelines for information that has not been subjected to gatekeeping practices and is freely available in the public domain it correlates as not being equitable with human participants in the sense that this data is not retrieved from identifiable private information, nor is it obtained through interaction with identifiable individuals (Buchanan & Zimmer, 2016).

Therefore, for the purpose of this Internet based research, Human Ethics Participants Ethics Committee (UAHPEC) guidance was sought in 2014, with the panel subsequently determining that formal ethics approval to proceed with this study was not required.

Narrative analysis

In implementing a narrative analysis approach to this research, I acknowledge that, like many other methodologies, it remains contested, with there being "no automatic starting or finishing points" (Squire, Andrews & Tamboukou, 2013, p. 1) for example. Indeed, the entire methodology appears to be one positioned as being of value, however, with the actual definition of narrative being disputed together with it not having clearly structured processes regarding the means through which data is collected or for performing data analysis (Squire et at, 2013), it has the potential to prove problematic in implementation. Yet, narrative analysis is raising its profile to become a useful tool as we attempt to engage with and explore our changing methods of communication and, as such, is appropriate to this research.

Narrative analysis (or inquiry) emerged as a discipline within the context of qualitative research during the early twentieth century (Riessman, 1993), as a means to unpick life experiences. "Narrative inquiry is an umbrella term that captures personal and human dimensions of experience over time, and takes account of the relationship between individual experience and cultural context" (Etherington, 2013, p. 3). Narratives provide one method of making sense of the world in which we live and the life stories we accumulate (Riessman, 1993); they are a form of storytelling (Bamberg, 2012) that do not necessarily "assume objectivity" (Riessman, 2000, p. 2) but are the foundation of qualitative research work. Narrative analyses are the product of what has been termed the "narrative turn" (Harvard, 2008, p. 1; Riessman, 2000, p. 1) whereby traditional social science research was transformed into a field of practice through which humanised accounts of social practices were embraced and published. This provided a reality to the research conducted, thus providing a methodology through which human knowledge could be organised. This human knowledge is considered valuable and, as such, when organized and understood using a narrative analysis it provides a powerful tool through which knowledge and experience is shared (Bruner, 1990).

Narrative analysis, like many other flexible and interpretive methodologies, appears to not have a single accurate definition of what it actually is (Riessman, 2008), with a number being in circulation at any given time. To better understand what narrative analysis entails we need to start with defining what narrative itself means. Usually narrative refers to stories that have been given a chronicalised or descriptive format, in that they are formulated to retell experiences that have occurred within social practices in order to understand and make sense of lived experiences. A fundamental element, therefore, of what narrative analysis comprises is simplistically stated as being "a method of qualitative research in which the researcher listens to the stories of the research subjects, attempting to understand the relationships between the experiences of the individuals and their social framework" (The Free Dictionary, 2013); or alternatively narrative analysis is when

> "narratives or stories occur when one or more speakers engage in sharing and recounting an experience or event. Typically, the telling of a story occupies multiple turns in the course of a conversation and stories or narratives may share common structural features" (Cohen & Crabtree, 2006, p. definition).

Narrative, therefore, in simplistic language relates to the telling of stories and analysis refers to the subsequent examination of the narrative.

Such simplistic descriptions or definitions of narrative analysis, however, remain subjective to the meaning imposed upon them either by the narrator or those interpreting the information, searching for key ideas or themes. Stories will always be subjective as they are reconstructions of other people's experiences (Etherington, 2013) and, as such, will be recounted to suit the audience to hand. Additionally, with narrative analysis often referring to the verbalised recounting of experiences, the experience of listening to the raconteur again infers influence in the way it is both told and listened to through both systematic and instinctive processes. Storytelling is both a collaborative experience and a relational activity (Riessman, 2000) through which experiences are shared, thus, illuminating the intersection of biography, history and society (Riessman, 2000) but always recounted from a subjective perspective as there is always a point to what is being imparted. Stories

can also be "viewed as a window into a knowable reality" (Etherington, 2013, p. 7) but are simultaneously open to interpretation as the focus may be on the content narrated, or the meaning implied or, on occasions, both.

It is, therefore, possible to consider a definition that suggests that "narrative analysis attempts to systematically relate the narrative means deployed for the function of laying out and making sense of particular kinds of, if not totally unique, experiences" (Bamberg, 2012, p. 4). Yet, as narratives "give narrative form to experience" (Bamberg, p. 35) they are also "practiced in everyday interactions … where these narrative practices are the grounds in which identities and sense of self can constantly be innovated and redefined" (Bamberg, p. 36). Despite there being a number of thoughts on the construct and content of narrative analysis, it may be most prudent to not take them as inflexible classifications or explanations of the methodology, but to consider the "ties that bind" (Riessman, 2008, p. 5) the various definitions in order to maximise the best of each. That is, to consider the "…sequences of action, choice of language and narrative style, and varying degrees of analytic interest in audience/reader response…" (Duque, 2010, p. 2).

Such definitions relate quite specifically to the passing on of oral information and knowledge through which conclusions can be drawn; and although most often associated with the process of interviewing participants and transcribing the narratives (Duque, 2010), not all narrative need be in the oral format. It is one of the benefits of narrative analysis that it is an adaptable tool that can be dynamically manipulated in order to meet the ever changing needs of social structures. It has been used over many years by scholars to respond to the challenge of changing methods of imparting information and knowledge (Duque, 2010: Riessman, 2008) and, as such, was a logical choice when using alternative means of gathering data when the direct interviewing of dying patients is both difficult to achieve and has considerable ethical implications.

There are different forms of narrative analysis – some focus on 'content' of stories; others on 'meaning' (maybe both). Depends on philosophical position. Stories can be viewed as a window onto a knowable reality and analysed using concepts

derived from theory e.g. thematic analysis, or concepts derived from the data e.g. grounded theory – analysis of narratives

Through implementing and utilising narrative analysis for this research it has, therefore, allowed me to interpret the stories held within the texts examined to provide a rich and informative discourse through which the social practices and potential dichotomy of dying within contemporary Western cultures may be understood. Yet, in order to achieve this outcome, narrative analysis alone is insufficient to achieve this goal. I have, therefore, taken a collaborative methodology and subsequently implemented a thematically analytical approach to the data sourced to assist in the identification of themes from the narratives examined and to assist in deriving concepts from the data (Etherington, 2013); which is supported by a multi-stranded theoretical approach to data analysis.

A multi-stranded theoretical framework allows the production of multiple narratives running alongside each other and is relevant to this research in considering death and dying, the involvement of medical practice and religion together with human rights law through the sociological lens. I have implemented this approach as I suggest that a singular theoretical approach cannot account for every situation, thus incorporate the works of Michel Foucault, Pierre Bourdieu and Peter Conrad in particular. Foucault and his work on power has been influential in understanding the dissemination of power which is beyond both structure and agency, through power being located 'everywhere' and not merely available to those with accepted, embedded means of power and thus coercion. Foucault focuses upon the medicalisation of the body and the disembodiment of the self from the physical being in his work *Birth of the Clinic* (1973) and, as such, provides a strong framework for data analysis and interpretation, however, alone is insufficient in understanding the current situation in end-of-life care in the UK and New Zealand.

Foucault's theories are, therefore, supported by Conrad's discourse on medicalisation of natural life events and although neither theorist specifically considers death and dying, their works remain essential in underpinning the following discussions on the sequestration of dying by clinicians. Yet, this analytical framework remains incomplete without the addition and influence of

Bourdieu and his analysis of power focusing specifically on the development and social change processes occurring and, as such, not only highlights the relevance of subtle, covert symbolic power, but does so through considering the constant interplay between structure and agency. As such, these theorists will provide an opportunity to produce an enlightening discussion of the data produced.

Thematic analysis and coding

Thematic analysis is one of four specific methods of narrative analysis, the others being structural analysis, dialogic/performance analysis and visual analysis (Duque, 2010; Riessman, 2008). Thematic analysis is a qualitative methodology used for the identification, analysis and reporting of themes within data (Rohleder & Lyons, 2015; Braun & Clarke, 2006; Boyatzis, 1998). This analytical tool offers an accessible and flexible approach to the analysis of qualitative data, allowing both the manifest and latent content of the data to be organised and interpreted systematically (Boyatzis, 1998). Manifest content is the actual, visually present content of the websites, with latent content being the underlying, not necessarily written subtexts that require interpretation to provide meaning to them. This is particularly suitable as often the subtexts can provide not only a depth to the analysis but often interesting and notable concerns that are not being raised as a primary issue.

There are, however, a number of concerns suggesting a vulnerability in using thematic analysis as a research methodology, with questions raised about its validity, and criticism for themes simply emerging from the data without thought or articulation (Braun & Clarke, 2006); with such negative inferences potentially rendering the methodology as questionable. Moreover, failure to account for how themes have emerged can be

> "…misinterpreted to mean that themes 'reside' in the data, and if we just look hard enough they will 'emerge' like Venus on the half shell. If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them." (Ely, Vinz, Downing & Anzul, 1997, p205-6).

However, despite the contentious issues around thematic analysis as a research methodology, I decided to implement it as I viewed this tool as being a means through which I could actively interpret the data from all sources attained from my own individualistic and subjective standpoint. It is particularly pertinent to the conceptual nature of this research and allowed me to create links between the textual narratives depicted in the professional papers, the media representations and the social interactions, together with my personal and professional prior knowledge of this field of practice.

The analysis of the data, through the narrative lens, produced a large number of emerging themes (Appendix 4); although my professional knowledge also played a role in interpreting the data. With such a large number of themes being produced, through my specialised knowledge I was able to group the trends and patterns together in order to reduce the thematic elements to a more manageable number. As such, the following four thematic collections demanded further analysis:

1. Patient choice and equality as being elusive in end-of-life decision making.

2. The power of authority in constructing the self-determined individual as deviant.

3. The medical vernacular as being symbolically violent in the doctor/patient relationship.

4. The futural role of the *Ars Moriendi* in creating an acceptable narrative for inclusive decision making for the contemporary individual.

These themes will provide a framework for an in depth discussion of the pertinent issues in this field, together with the opportunity to draw unique and perceptive conclusions regarding current practices.

Validity and reliability
Validity and reliability are determinants that provide a means of verifying the quality of the research to hand. Validity is a means through which good qualitative research can be rigorously tested and replicated and, as such, ensures that it is "fit

for purpose" (Cassill & Symon, 2011, p. 638). Reliability is the "degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions" (Silverman, 2013, p. 302).

Validity comprises of "reliability, validity, objectivity, and rigour" (Cassill & Symon, 2011, p. 640) and allows a multi-directional flow within conversations to identify chains of consistency. Validity within the construct of qualitative methodologies appears to have its foundation within the quantitative field of practice, in that rigour and replication are paramount to the outcomes being taken as valid. Qualitative research generates the possibility of producing "different kinds of measures of the quality, rigour and wider potential of research" (Bryman, 2012, p. 389), thus sticking closely to "conventions and principles" of "quantitative research" (Bryman, 2012, p. 389). Yet, one reality is that good qualitative research must stimulate ideas and as such, replication and rigour are not its primary purpose. However, another reality is that such receptiveness to interpretative research is that the documentation of findings much be clearly articulated if trust is to be developed (Cassill & Symon, 2011).

Validity can be further deconstructed into both internal and external validity (Bowling, 2002). Internal validity demonstrates a consistency between the outcomes of the research and the theoretical framework developed and, as such, strengthens the qualitative research through the "prolonged participation in the social life of a group over a long period of time" (Bryman, 2012, p. 390). This I demonstrate in my research through using the constructs of the *Ars Moriendi*, medicalisation and knowledge/power structures in relation to the experiences of dying patients within contemporary Western cultures. External validity refers to the ability to apply outcomes to the more generalised population. This, however, is often problematic within the context of qualitative research, as such research often utilises small sample groups or case studies (Bryman, 2012). External validity is, therefore, more difficult to achieve but attention has been given to this, with the outcomes of this research potentially applicable to a greater number of Western countries than those included in this study.

Reliability is a further necessary component of competent research and is apparent through the concise documentation of the procedures utilised when formulating and undertaking particular research, together with demonstrating a consistency in using specific categories (Silverman, 2013). It is one element of methodological construction that provides a measure of stability and reproducibility to the research (Bowling, 2002), in that the results can be reproduced through repetition of the research methodology (Pope & Mays, 2006) and, as such, avoids the research becoming merely an impressionistic piece of work (Silverman, 2013). In a similar manner to validity, reliability can also be referred to as being both external and internal. Internal reliability refers to there being more than one observer or researcher, through which clarification can be sought regarding incidences witnessed (Bryman, 2012), thus adding rigor to the study. External reliability refers to the effectiveness of being able to accurately reproduce the research. This, however, becomes problematic in qualitative research as due to the nature of such research, a situation at a specific time can never be truly replicated (Bryman, 2012).

The validity and reliability of my research is of great importance. Therefore, in order to provide a degree of rigor to my research I have produced a study that is both transparent and logical, with the connections between physical data and my interpretation of it being understood in a clear and concise manner. I offer my work with a transparency to the construction of the research field, my personal experiences in this matter, the construction and execution of the research process (narrative analysis), with my outcomes being clearly visible. My attention to transparency and clarity allows for credible and accurate replication of my research format, however, owing to my personal and professional knowledge of dying in Western societies in relation to that of future researchers, interpretation of the data will always be dependent upon the social positioning and knowledge of the researcher involved, together with their specific aims. My positionality in relation to this study is, therefore, discernible through using a high level of reflexivity.

Personal reflexivity in relation to academic study produces very individual results that will always sit in relation to the subjectivity of the researcher. Thus, my positionality and use of reflexivity allows me to reflect on the data on multiple levels and perspectives (Alvesson & Sköldberg, 2009). Although it is noted that

there are different forms of reflexive practices, more generally it allows the relationship between "processes of knowledge production and various contexts of such processes" (Alvesson & Sköldberg, 2009) and, as such, ensures my constant assessment of the data in relation to the knowledge held and the means through which I interpret this.

In this instance my research is both inspired and influenced by my academic, personal and professional interest in dying within contemporary Western cultures and the experiences of those in the UK and New Zealand, the construction of the new *Ars Moriendi* and the constraints within which we live and die. Yet, with all of these interests clearly identified, the data produced in this study remains both apparent and understandable to those with no prior knowledge of healthcare practices, medical law and the process through which death occurs; therefore, allowing the possibility of accurate replication of the structure of the study in the future.

Conclusion
The consideration of numerous methodologies and subsequent dismissal of many to reach the desired outcomes requires dedication to ensure the correct one is chosen. The frustrations met in being denied access to patients for face-to-face encounters has given me the opportunity to explore alternative qualitative research methodologies within the sociological framework. The production of this research has, therefore, embraced modern communication platforms to evaluate the experiences of both practitioners and patients when dying in contemporary Western cultures. A point of note, however, is that while examining the content of such a contemporary means of communication and expression, a number of the blogs in particular were less interesting and useful than originally anticipated and that conversations, at times, were quite limited. Given that social media could be seen as a place where there are few or at least less social barriers to speaking about difficult and sometimes controversial subjects, this was a surprising outcome.

The methodological pathway using narrative analysis is presented in a clear, concise and transparent manner, although complete replication of the results will always be exposed to the subjectivity of the researcher. The sample is dualistic in

purpose to ensure a broad range of viewpoints are captured to inform the discussion. Using thematic analysis has proved helpful to develop and identify the four broad ranging themes in a dynamic manner in conjunction with my professional experience in palliation, as this specific research field appears underrepresented in the current sociological literature.

Chapter Five

"Death is the wish of some, the relief of many, and the end of all"

(Seneca, 4BC-65)

Patient choice at end-of-life: reality of illusion?

Introduction

Societies, through the application of power, devise methods of controlling and managing life events of the general population to maintain order (Giddens, 2009). Historically, within Western societies the dying process was constructed as the religious culmination of living, and was integrated naturally into the communal activities of daily living. With the erosion of religious practices, dying has become feared and unknown, thus provoking anxieties which demand taming. This has resulted in the rise of medicine as the overseer of the dying, thus, containing this natural life event within the constraints of medical practice; while simultaneously discouraging the notion of individual choice regarding the dying trajectory. Patient choice has become a focal point in many healthcare settings, but remains problematic when narrated in relation to the powerful discourses of medicine and law.

This chapter pertains to the notion that patient choice regarding end-of-life care is an unreality and is divided into three parts. Part one explores the sanctity of life discourse in relation to the right-to-die, the role of medical power and doing no harm together with the prolongation of death discourse. Part two discusses the construction of palliative medicine, the exposé of patient experiences when subjected to medical models of care at end-of-life, together with relational dollar value of life versus death contextualised in relation to the UK and New Zealand. Part three draws upon the aforementioned experiences to consider the confluence between medicine and law in end-of-life decision making and the distribution of power over the individual.

Part one: Human rights and the sanctity of life

The construction of specialist medical care for the dying may be viewed as a progressive step in reassuring dying patients in need of care that medicine will be supportive to their needs. There exists a tension, however, as palliative medicine is grounded in the right-to-life and, as such, may be at odds with patients who would prefer to choose death. The right-to-life is a fundamental component of the human rights framework and has dominated discourses around the value of human life, with the fact that "everyone has the right-to-life, liberty and security of person" (UN, 1948, p. Article 2); but not necessarily that of individual choice. The idea of choice, however, is

> "based upon the principles of free will, human dignity and the exercising of choice, [and] this argument considers the individual to have sovereignty over the thing and circumstances of his or her death [and] see the active euthanasia debate in terms of a power differential between patient and provider" (Smokowski & Wodarski, 1996, p. 61).

The idea of free will and dignity, as values of personal choice, are clearly articulated in this statement, and would be perceived to align with the values of the human rights legislation. The human rights legislation did not emerge from a medical paradigm, but from the perspective of politics at the end of World War II, however, it has become pervasive within the construct of medicine. It speaks clearly of individual rights, demonstrating particular strength in relation to the autonomy of the self; this sits, however, in opposition to the early rhetoric of this framework which had a strong collective orientation.[54]. Irrespective of this shift in application, Article 2 has become both a focal point and a constraining crux in relation to life and death choices, in that the right-to-life becomes the most significant factor in the collaboration between medicine and law when considering individual choices in relation to dying; actualised through the duty to preserve life over encouraging death, even when death is inevitable.

The right-to-life discourse pervades most aspects of medical care, and without this human right all others become irrelevant (Human Rights Commission, 2010). The

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[54] World War II spanned 1939-1945.

right-to-life refers to the individual's right to be protected from "the state and public authorities" (Director of Public Prosecutions (DPP), 2001, p. 3). This does not give individuals the right-to-die, but preserves the right to self-determination in light of impending death and the relevance of treatments offered (DPP, 2001). This produces a paradigm of complexity for those wishing to have control over their demise; as without legal sanctioning, and the absence of the right-to-die it contributes to the unequal power dynamic in the doctor/patient relationship. It suggests that although the individual has the right to self-determination (UN, 1948, p. Article 1) and the right to participate in care decisions, when considered in relation to the knowledgeable and powerful institution of medicine, it becomes apparent that to implement such freedoms are problematic. The idea that we have the right-to-life but not the right to choose death produces a complex challenge for the contemporary individual; with dying becoming an intricate issue, no longer merely founded in being a natural status.

The sanctity of life has origins in religious doctrine, and is one element upon which both law and medicine are created (Bayertz, 2012). It becomes a dominant factor in end-of-life decision making when all other avenues have failed to secure the status of the right-to-life (Gillon, 2014); and supports the argument that "there is a conviction that human life is sacred" (Steyn, 2014, p. 16) through the application of "life is not 'ours' even if the life in question is 'mine'" (Kerrigan, 2013, para. 8). The notion that life is not ours relates to the position of religious views over the ownership of the body, in that we live our lives through the body, but the body we have has been given to us, and has not been chosen by us. That is, that our bodies are given by a higher being and we live in it subjectively in relation to that being. Yet, higher beings are founded in non-scientific means and, as such, exist in the faith upheld by those who believe in such systems, but not by others who question them. Thus, for medicine and law to be founded in the non-scientific, non-evidential embracement of a higher being, suggests a frailty that lies at their foundations. It suggests that although much of medical practice is now founded in empirical scientific evidence, their reasoning in relation to the non-physical dimensions of care rely on a somewhat controversial source; albeit one of power and control in itself (Davie, 2013).

When weaknesses in such institutional paradigms become apparent, it provides a window of opportunity to explore and exploit such frailty for those who wish to secure the right to self-determination. It suggests that medical power, achieved through medicine's reliance upon science as being a source of "knowable truth" (Whitney & Smith, 2010, p. 70), becomes less solid when questioned by those in search of alternative care pathways. It must be noted, however, that while the power of explicitly religious explanations has been significantly eroded it continues to inform the values and norms of much of Western society's practices, thus, it may be viewed that medicine can be seen in some instances as upholding these norms and values that are influenced by religious doctrine. It is such reliance on outside resources that paves the way for the intertwining of religious beliefs with scientific knowledge, with both playing a significant role in the outcomes for those individuals seeking choice at end-of-life.

Medical power: *Iatrogenesis*, the sanctity of life and self-determination

The sanctity of life is a subjective and personal positioning, dependent upon a variety of factors and, as such, should not be bound incongruously by inflexible medical or ethical practices. The right-to-life argument sits in opposition to those wishing to sequester the right-to-die; but the right-to-life at any cost has become a point of contention in the sanctity of life debate and should not occur "at any price" according to Archbishop Desmond Tutu (2014, para. 1). This view is heralded by some academics in that "the sanctity of life law has gone too far" (Gillon, 2014, Lecture), and that patients prior wishes should really hold value when facing incapacitation and prolongation of life. To deny the dying the right-to-die, therefore, produces a contentious and problematic discourse for both clinician and patient, and no more so than when medical law dictates that medical practitioners should 'do no harm' and should consider the 'best interests' of the patients; yet the best interests of the patients are not necessarily the same as those of the practitioner.

These two phrases sit in opposition to each other, in that for clinicians to assist or support the extinguishing of life opposes the *Hippocratic Oath*, but in undertaking to 'do no harm', they may actually cause further distress by not acquiescing to patient wishes. The value of the individual, however, is negligible in legal terms, as even if "… an incapacitated patient would not want life prolonging treatment" they

"should, according to one judge, be given very little weight when set against the legal principle of sanctity of life" (Gillon, 2014, para. 5). This statement highlights the imbalance of power between the patient and clinician, held in the clinicians favour, as to verbalise the preference for self-determination appears insufficient in the view of the law and, as such, the individual fades to invisibility within the institution.

Such idealism surrounding the sanctity of life does not equate to the lived reality for some dying patients. Their intolerable suffering remains subjective and should not be merely subjected to principles of law and religion as opposed to care. Suffering is different for each individual, and those wishing to control their demise express concerns over what will occur once incapacitation befalls them. The act of suicide, in terms of self-determination, remains outside of their capacity or even their belief system, as physician assisted suicide remains contextualised within the medical framework of treatment, which provides comfort to those for whom suicide is populated with fear, aversion and possibly shame. Such positioning of assisted suicide, however, shows the power of medicine to be seen as critical in death as well as of life choices. It is the inability, or choice, of the individual to perform suicide that has led to the rise of physician assisted suicide and right-to-die campaigns in both the UK and New Zealand. As the right-to-die, or physician assisted suicide, remain illegal in both countries, it condemns the incapacitated individuals to continue living with intolerable suffering; with Diane Pretty being an example of an individual whose suffering was unrelieved by contemporary medicine.

Being articulate of mind, if unable to control her diseased body, Pretty wanted the right-to-die with assistance "when I could do nothing for myself any more" (Pretty, 2002) and not before. Pretty fought for the right to self-determination in death and encountered both medical and legal barriers to achieving this and ultimately failed, as have others since. Such a decision sits uncomfortably with elements of the human rights act, and it is a fine line of interpretation through which such judicial decisions, based upon medical knowledge, appear to be made. For Pretty to not be allowed to die subjected her to her worst fears of suffering and, through denying her right to self-determination, inflicted such suffering, ultimately to be managed in a

medicalised manner. This demonstrates that the sanctity and right-to-life has overridden Pretty's right to be free to make choices, reflecting the dominance of both the medical and legal professions over the perception of individual choice; as choice cannot be truly free when one has to rely on others for it to occur.

Medical power, therefore, produces a juxtaposed paradigm whereby dying patients "should not be forced against their will to endure a life they no longer wish to endure" (Steyn, 2014, p. 17), but do so through medicine and laws' reliance upon religious beliefs and values in upholding the sanctity of life at all costs. It must be noted, however, that although this is a presumptuous statement in that the sanctity of life narrative relates solely to religion, there is always the possibility that it can be reflected as a community value and not always that of religion. Moreover, there are clinicians who may be non-religious but who will continue to uphold the value of sanctity in a similar manner to viewing the taking of life as sitting outside of the medical domain; however, as I have and will continue to demonstrate, there remains a linkage of religious belief to both medicine and law. The only current means through which self-determination to die can be achieved for the incapacitated is, therefore, through starvation and the refusal of nutrition and treatment and, as such, is legally upheld through the human rights framework, Article 1.

The value of previous personal autonomy of thought appears negligible in reality (Gillon, 2014) and, as such, medicine and law limit the living when dying through the collaborative prohibition of physician assisted suicide. Arguing for the right-to-die becomes problematic for the dying patient and is manipulated through the language used to negate this request. The right-to-life does not reflect a choice to die, although dying is acknowledged as being the final act of living and is reflected in Article 8 of the human rights framework in that "…while individuals are living their lives…there is nothing to suggest that the article has reference to the choice to live no longer" (Pedain, 2002, p. 512). Article 8 states that

> "[1] everyone has the right to respect for his private and family life, his home and his correspondence" and "[2] there shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the

interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others" (UN, 1948, p. Article. 8),

and, it is this framework that proves flexible in interpretation in law when applied to those wishing to secure the right-to-die. For some petitioners Article 8 has deemed to be engaged, for example Purdy, but for others it has not, for example Pretty, Nicklinson and Lamb (The Supreme Court, 2014; The Lawyer, 2012; Chahal, 2009; Pedain, 2002). Such inconsistencies demonstrate flexibility in the application of the human rights framework and, as such, the difficulties encountered by individuals when pursuing their perceived individuals rights and freedoms. Article 8 is such a lengthy and all-encompassing statement, that its application covers a vast array of situations and, therefore, when applied to having no "choice to live no longer" (Pedain, 2002, p. 512), demonstrates such flexibility. It also supports the notion of life preservation irrespective of personal cost, thus prolonging both living and dying.

Medical knowledge: prolonging life and death
The prolongation of living, and dying, is often achieved through 'physician assisted suffering' and the application of palliative medicine practices to the individual which, in turn, provides "justification for the management of death and dying" (Whitney & Smith, 2010, p. 70).[55] Prolonging life, however, may not be the preferred option of the dying and appears to contradict the perceived liberties of democratic societies, in that both medicine and law constrain the freedom of the individual to die (Pedain, 2003). The medical and legal prolongation of life has become subjected to the narratives of public opinion which, in the contemporary moment are articulated through the use of online social media which supports the stance that we "should not be using intrusive modern medical procedures to prolong the suffering of people, who, if saved, will have no quality of life … we seem to

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[55] Physician assisted suffering is the application of treatment to patients that increases their suffering rather than reducing (Marsden, 2015, personal communication).

have lost sight of the fact that there really is a time to die" (Daily Mail, 2012, Comments, para. 8).[56]

Despite the intentions of palliative medicine, it has not necessarily guaranteed a better pathway to death (Gawande, 2010), but has the potential to prolong both living and dying. This has produced a situation whereby "modern medical science has become a double edged sword" (Stirling, 2014, para. 7) in that the creation of knowledge has resulted in the production of treatments and technologies which dualistically can cure the suffering of the unwell and has the potential for individuals to "suffer a lingering, excruciating and inhumane end" (Stirling, 2014, para. 5). Through the application of physician assisted suffering and the focus upon saving lives, the naturality of dying confounds and opposes their clinical training (Cheesman, 2014).

Immortality is not yet achievable, but this appears to have been forgotten in the palliative medical discourse suggesting that to accept dying and, therefore, death, equates to accepting defeat in the race for immortality (MacNair, 2013). This presents the accepting individual as 'other' in relation to the contemporary recognised norms; which sits in opposition to the work of Elizabeth Kübler-Ross (1969) and her five stages of grief, whereby acceptance was perceived as the point of actualisation for the patient. Patients of palliation are dying, their death is inevitable, yet when palliative measures are the preferred option for the patient, medical ethics can prove counterproductive. An example of this relates to a man who died during surgery and the medical team wanted to resuscitate him; the man was Dutch, and had been diagnosed with an intestinal cancer and had cardiac issues. As his wife recalls, during surgery "they said, 'our first concern is keeping him alive'…but that's not what he wanted" (Willemson, 2015, para. 9). On this occasion, and despite the initial intention to keep him alive, the medical team took notice of his wife, but only after she produced his ACP advising of the same (Ross, 2015).

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[56] The *Daily Mail* is a British newspaper but simultaneously has an online presence within interactive forums, thus, aligning what may be perceived as 'old media' as being a contemporary means of communication.

This incident demonstrates the prominence of contemporary Western society values being focused upon supporting an individual's right-to-life through the sanctity of life narrative and is pertinent to the conditions in the UK and New Zealand. Such positionality attempts to dissuade those who seek the right-to-die from doing so, as death sits opposed to liberal freedoms and human rights (Lupton, 1997) and in one sense opposes our sense of immortality. Simultaneously it evokes a response in some for the right to individualism and autonomy of the self and, as such, presents an image of potential chaos in end-of-life decision making.

Despite patient choice being presented as a problematic narrative, the notion of patient choice continues to be advanced in some respects by the medical profession in that the *BMJ* in 2014 supported *Lord Falconer's Assisted Dying Bill,* thus "insisting that choice [is] now the most important principle in medical ethics" (Bingham, 2014, para. 1). This simple but authoritative statement of support for patient choice is presented in the context of choice now being "more important than preserving life" and that "respect for autonomy – rather than the ideas of the Hippocratic Oath [sic] – is now the "cardinal principle" in medical ethics amid a patient revolution" (Bingham, 2014, para. 2).[57] This positive response by the *BMJ* was, however, overturned by the *British Medical Association* (BMA), who own the *BMJ*, declaring that such statements did "not represent its [sic] views or those of the wider medical profession" (Bingham, 2014, para. 9) and that "The BMA should adopt a position, not of opposition or indeed support, but of studied neutrality towards a change of law to permit assisted dying for terminally ill, mentally competent adults" (Professor Tallis in Pickover, 2012, para. 10).

The former statement could be viewed that the *BMJ* saw an opportunity of engaging in the wider debate with those who are pursuing choice over the self, even if to educate them ultimately in the preferred route of the medicalised death; together with acknowledging the problematic discourse of prolonging life and death. The latter statement portrays the closing of ranks within the medical profession to protect their status and position of power and control over the general population;

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[57] Patient revolution refers to the promotion of "joint participation in the design and implementation of new policies, systems, and services, as well as in clinical decision making" (Richards, Montori, Godlee, Lapsley & Paul, 2013, para. 6).

thus, demonstrating the power of knowledge and the alignment of governing power in social institutions. It must be noted, however that the *BMJ* does not speak to a general audience, but one of academic physicians and, as such, may have been attempting to create the space for physicians to debate the issues at hand.

Palliative medicine is, therefore, introduced as the hero in arresting death and saving the dying through applying specialist knowledge to the naturality of the human body as a means of power and, as such, ensures this specialist field of practice is accepted through the "social contexts in which such accounts are constructed" (Pfohl, 2008, p. 1). Palliative medicine, however, can only be perceived as heroic in light of the general population upholding its construct and engaging with its practice, thus, suggesting that the control of dying through medicalisation is wholly supported. Yet, this is not necessarily an accurate reflection of what is occurring as those petitioning for the right to choice and the right-to-die oppose the 'saviour' narrative of palliative medicine in favour of personal rights and freedoms over the self.

Part two: Medicalising contemporary dying

The process of dying has become such a taboo of contemporary Western societies that it no longer naturally enters the life discourse and has become feared as a form of human failure (Gawande, 2014). Such fearful anxiety over death suggests that we have forgotten "the majesty of death" (Fitzpatrick, 2013, p. 576), in that lives that have been lived well should be rejoiced and celebrated as this natural status is inevitable. However, with the development of medicine as a powerful institution of knowledge, existing within a wider structure of knowledge, it has produced a discourse through which dying is contextualised as a burden to be cured; yet discourses change constantly through the continual production of new empirical facts (Cole & Bird, 2014). When considering the movement towards a specialist framework for dying, discourse has provided the structure for palliative medicine to be developed, with previous experiences of dying being superseded by contemporary knowledge, thus producing a new means to manage this natural life event (Foucault, 1973). The contemporary orchestration of the Western death is, therefore, achieved through ascribing current empirical scientific and clinical knowledge to the process of dying (Cherny, Fallon, Kaasa, Portenoy & Currow, 2015; National Institute of Nursing Research, 2010) in order to provide a platform from which the contemporary interpretation of a 'good death' can be achieved.

Constructing the biomedical death

The need for a diagnosis suggests that dying is not viewed holistically, but that death is a disease in need of categorisation and treatment (Kennedy, Brooks-Young, Gray, Larking, Connolly et al, 2013; Smith, 1996). The *medical gaze* becomes the lens through which the dying are condemned to be "…just another body to be fixed, another patient to be regulated" (Whitney & Smith, 2010, p. 69). This produces a discourse that lacks individualism and, as such, clinicians must view the "patient as a person and not merely a condition or disease sat in a hospital bed" (Granger, 2013, para. 4), or "as a set of symptoms rather than a person" (MacMillan, 2014, p. 28) when providing end-of-life consultations or care.

This is significant as the dying patient remains a human being who has a life of experience, individual characteristics and should not become a commodity within the routinisation of conveyor belt care. However, such routinisation may be a

coping mechanism for palliative practitioners due to the constant nature of the role, in that to procure a diagnostic label and attach it to the dying patient provides a comfort that they formally recognise the natural end to living is nigh (Ellershaw, 2003). It may also remove personal involvement and construct the professional boundary that is required in order to function within such emotive healthcare practices. The palliative lens, however, reinforces the *medical gaze* and the need for diagnostic input through the dying process being deconstructed into phases, for example dying can now be categorised as pre-terminal (pre-active) and terminal (active phase of dying) (Romem, Tom, Beaucheme, Babington, Scharf et al, 2015); and is considered necessary in order for appropriate care to be accorded (Sullivan, Lakoma, Matsuyama, Rosenblatt, Arnold et al, 2007).[58] Palliative care has made a case for the dying to be treated differently from curative patients and this should be applauded, but should differential treatment for a natural life event necessarily require the attachment of such extensive labelling? It is argued, however, that a palliative diagnosis requires the attachment of specialist knowledge and experience to the dying patient (Wee, 2012) and is considered an important factor in care. A recent UK study, *National care of the dying audit for hospitals, England,* suggests that 87 per cent of healthcare professionals were able to diagnose dying in their patients (Royal College of Physicians (RCP), 2014), thus supporting the notion that diagnosis is necessary.

Palliative medicine, however, is a construction that lacks a specific "disease, bodily organ or life stage to call its own" (Clark, 2002, p. 908), therefore, simultaneously lacks scientific evidence of determining the imminence of death. Often patients are "judged to be 'dying'" (Hickman, 2012, para. 1), with some professionals finding dying to be "difficult to predict" (Bubna-Kasteliz, p. responses, in Treloar, 2008). Responses are particularly vague when clinicians are asked by patients or families if death is imminent as they "assume you can predict death" (Marsden, 2015, personal communication), thus demonstrating how palliative medicine is perceived as being "an inexact science" (Spooner, 2010, p. 18); with such responses sitting in opposition to the ability and need to diagnose dying. Baroness Neuberger in the *More care, less pathway: a review of the Liverpool Care Pathway* report in 2013,

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[58] Pre-terminal or pre-active phase refers to the two week period before death occurs (Paice, 2015). Terminal or active phase refers to the three days prior to death occurring (Paice, 2015).

highlighted this diagnostic disability as requiring further research to determine whether "it is possible to predict death with any degree of accuracy" (Donnelly, 2013, para. 9) as the present situation appears less than satisfactory. Moreover, Neuberger suggests that at present the practice of diagnosing dying remains, at best, an inexact medical practice and, at worst, irrelevant to the dying trajectory, thus questioning the need for it at all.

Medical practitioners appear unable to function to their full potential without exposing the physical body and the visible symptoms to the *medical gaze* and, thus produce a diagnosis, which can leave the dying patient feeling vulnerable and powerless in expressing their preferences of care. This subjugation is demonstrated in the *National care of the dying audit for hospitals, England,* which indicated that only 46 per cent of patients were consulted about preferences of care when dying in the UK (RCP, 2014a); leaving over 50 per cent without a voice. No equivalent data is available currently in New Zealand, however, the UK data demonstrates a trend against patients having a freedom of choice in care, if less than half of those dying are not included in a collaborative manner with medical practitioners in the decision making process.

The fact that clinicians fail to engage with less than half of their dying patients reflects a less than favourable position for those in their care. The reasons for clinicians not engaging with some patients is not apparent, however, it must be considered that the West's contemporary cultural discomfort with dying may play a significant role in addressing this issue (Gawande, 2014). Some clinicians may be uncomfortable with discussing dying, as are some patients, but this allows the dominant values of fear and anxiety to pervade practice and, as such, dying in the UK and New Zealand becomes "something to be resisted, postponed, or avoided", thus the "charge of creeping medicalisation has also been levelled at palliative care" and has "brought the epoch of natural death to an end" (Illich, 1974, p. 210). Thus, if clinicians are unable to discuss the inevitability of death with the terminally ill, it produces a paradox in that they wish to care for the dying through palliative medicine but simultaneously decline to be involved with such conversations.

Palliative medicine, however, remains a bureaucratic institution through which the contemporary death is now managed both efficiently and effectively within the context of clinical practice and, as such, ensures the that the

> "medical profession shapes, guides, and controls death across the boundary of the doctor-patient relationship" and "is inclusive of institutional spaces in which discourses of medicine permeate in conjunction with specific rules and regulations (Whitney & Smith, 2010, p. 73).

This statement can be viewed through differing lenses in that it provides intelligible support for the dying, but, simultaneously the construct of palliation manipulates the natural life end by subjecting it to medicalised labelling, thus ascribing a normalcy of medicine to this life trajectory. This is evident when an individual known only as Tony talks openly about the immediacy of dying, autonomy and supplication to medical practice. Tony is an older academic who has been given a palliative diagnosis of cancer and for whom the opportunity to openly narrate his feelings are covered in a visual presentation entitled *Postures of the Heart*.[59] Despite his highly functioning knowledge base and his ability to reason and analyse his situation, he describes the failings of the body and his futural care in that it will be "my body [that] will dictate the course of events [when dying]" (Tony, 2014, 18:19 min) but then corrects this to say it will be "science that will dictate the course of things" (Tony, 2014, 18:44 min).

These sentences are powerful, in that they are part of a coherent conversation whereby a knowledgeable person talks about the experiences expected of the self, but immediately subjugates his body over to the medical practitioners not only to provide care, but to give direction and instruction as to the process that will occur. This provides an interesting insight into the workings of individual thought processes but also the overriding notion that clinicians will lead and take over his care. It suggests that to subjugate to medical power is the normal and almost expected outcome when given such a prognosis. This individual's experience also suggests that despite his engagement with knowledge per se, it is medicine that

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[59] *Postures of the Heart* is a video recording of a man known as Tony, who talks through his experiences of having a palliative illness and is used in hospice training programmes.

remains dominant in the field of specialist knowledge surrounding natural life events. The culmination of the use of such specialist knowledge results in dying individuals becoming passive actors before and within the institution of medicine, as demonstrated by Tony's thoughts. Patients succumb, both overtly and subtly, to the routinisation of dying, thus handing the power of the self over to the clinician. Not all patients, however, subscribe to this pathway with some wishing to be "active agents rather than passive recipients of doctors' orders" (Conrad 1985, p. 31).

Medicalisation: controlling the dying through technologies of knowledge
The boundaries of contemporary medical practice continue to extend to encompass a massification of treatments, often now administered through technological advances in both machinery and pharmacology; and, as such, have become a resource of power for medical practitioners. Intensive therapy units, specialist cardiac care units and emergency departments in Western countries are all fitted out with the latest gadgetry to save lives, but simultaneously such machinery and medicine fails to meet the needs of the dying (Gawande, 2010). The dying need comfort and compassion, and to "suffer with another" (Tony, 2014, 16.20 min); they need to trust those who specialise in supporting them as they approach life's end, but not necessarily through an engagement with machinery and technology to delay the inevitable. Tony's desire to "suffer with another" (16.20 min) highlights the human needs of the dying process and the need for not only physical comfort, but also psychological and spiritual comfort when facing the unknown.

Palliative medicine comprises of a complexity of care models and pathways to cover every eventuality when dying, for example the LCP or PST and, as such, may replace the idea of the *Ars Moriendi.* They may provide comfort for the compliant, appeasing individual when facing the anxiety of end-of-life but for the less compliant, self-determined individual seeking the right-to-die, they provide a structure of constraint against which they must rally if their beliefs and choices are to be met (Wasserman, 2008). Patient experiences of these palliative care models are well documented both formally and anecdotally, particularly through contemporary methods of communication such as online social media, which provides a resource for the populous voice to be heard (Kietzmann, Hermkens,

McCarthy & Silvestre, 2011). Experiences are varied and sit in opposition to each other. Some experiences demonstrate that the models of care can provide the support that is required when facing dying, whereas for others they suggest that such care acts as a shield for what is effectively euthanasia by stealth (Hamel, 2014). Realistically, the reality will sit between these opposing views in a middle ground of negotiation. Medical practitioners seek the reassurance of guidelines for best practice, as do some patients, but for others they seek the right to choice and self-determination in their final hours and, as such, find the use of prescriptive care models detrimental and constraining in relation to their cause.

Palliative medicine: intent of care

In an ideal world, a natural and pain free death, accompanied by ritual preferences when suffering with palliative conditions would occur for all, without having to defend their right to either life or death; but the contemporary reality and social constructs within which we exist are unlikely to deliver this idyllic paradigm. In relation to the models of care currently available to medical practitioners, there appears little to set them apart from each other and their difference may be founded upon the intent with which they are implemented. The LCP for example, is aimed at providing comfort care at the end of life, whereas PST is aimed at sedating the individual until they die, as they are experiencing intolerable suffering beyond the current management capabilities of modern medicine (Robinson, 2013).

It is at this point that consideration must be given to the argument regarding the relationship between the dying patient and intolerable suffering. How do those who have legally sought to have the right-to-die at a time of their choice, because of their fear of intolerable suffering differ from those placed on PST by medical practitioners because of their unmanageable intolerable suffering? This produces a dichotomous paradigm through which some patients are managed through the medically accepted norms of practice, while others are reduced to having to comply with palliative measures as their right to die is legally removed. It suggests that there is duplicity at play, in that those who conform to, or acquiesce with medical practice when dying can be offered an easier pathway to death, but for those who do not, such avenues remain steadfastly closed to them. This reality subjects the active self-determined individual to the powers of medicine and constraint of law but

simultaneously demonstrates the fragility of the palliative construct of care, in that the distinction between PST and passive euthanasia becomes attached to the purpose and principles through which the treatment is mandated, rather than there being a tangible difference between the actual physical treatments given. It is no wonder, therefore, that the medical profession has been cast with allegations of passive or stealth euthanasia over the past decade both in the UK and New Zealand.

The practice of passive euthanasia is not necessarily new, more that the overdosing of the dying with morphine that has been practiced for centuries informally (Lavi, 2007) has been formalised through the construction of palliative medicine.[60] This passive activity in keeping the dying comfortable has now populated contemporary Western conversations through the advent of global online social media commentary. It is, therefore, the rise of the independent voice that has brought the issues to the fore, thus, raising questions around the practices of PST, for example, that would previously have only been limited to scholarly publication. This new found voice for the general population may have contributed to the idea that contemporary Western societies are producing cultures of death, in that the ability to openly question medical practice is a relatively new phenomenon and, maybe, a situation with which medical practitioners are not yet comfortable.

The fact that medicine and law appear to becoming more openly accountable for their decisions and practices does, however, favour the self-determined individual in securing their preferred choices at end-of-life. For some of the general population, however, the knowledge of such medical practices are not surprising as "they've been killing 100s of thousands of patients with morphine overdoses…for years, so why is anyone surprised by this?" (Mazzermitchell, in Stanford, 2012, para. Comments). However, others have begun to question how medical practitioners can stand by their practice when it appears to amount to some form of euthanasia; something not offered to those who actually want to die.

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[60] Freidrich Wilhelm Serturner was a pharmacist assistant and between 1805 and 1916 created what is now known as morphine for clinical use and became preferred over opium for effectiveness (Mandal, 2013).

PST is bound up in medical and legal ethics, together with issues around consent and intent and, as such, produces a framework of practice that proves difficult to justify for many patients. If healthcare professionals themselves have to ask such questions as "when terminally ill patients are given continuous deep sedation [PST] without hydration, should we call it a form of palliative care, or is it in fact slow euthanasia?" (Shepherd, 2012, p. 24), it suggests that the general population have a point in querying these practices. Moreover, if healthcare professionals do actually liken it to euthanasia, then where are the government initiatives and protocols to protect the vulnerable at this life point? It has to be acknowledged that these practices are complicated and the boundaries between treatment and euthanasia are both blurred and narrow in interpretation, but simultaneously if we have to ask if the treatment is indeed euthanasia, then the dying are indeed vulnerable to such practices. Responses to the question of treatment or euthanasia were founded in the need for patient consent and medical ethics in that "its [sic] ethical if the patient requested it – otherwise, it gets very tricky legally" (Stone in Shepherd, 2012, para. Reader's Comments); and

> "legally, the situation becomes nightmarish, if the instructions do not come directly from the patient! ...but if the motivation of the part of the clinicians is effective pain control when they agree to the sedation, that appears to be legal" (Anon in Shepherd, 2012, para. Reader's Comments).

Such comments from healthcare professionals using a blog in the *Nursing Times* to debate the issue, suggest that if there is expert uncertainty around practices then better guidelines are required or that such practices should be disbanded.[61] It is not so much that these are poor practices in principle; it is the inequalities in the application of such practices that raises concerns, in that some are allowed to use PST, but for those who seek to fulfil their preference to die, such treatments are withheld. Furthermore, when distinguishing between PST and euthanasia, the dominant theme arising is that of intent of use in that "the intent of palliative sedation is not to cause death, but to relieve suffering" (Morrow, 2014, para. 9) and that "when a patient's life expectancy is already short, it has been argued that CDS

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[61] The *Nursing Times* is a UK professional nursing journal.

[PST] without hydration has little or no effect on life shortening" (Beland, 2012, p. 25).

It is, therefore, little wonder that some lay persons struggle to follow and understand the purpose of sedative therapies within palliative medicine, when the professionals themselves question the effects in reality. This suggests that although specialist knowledge produces the power to instigate such practices, the reality lies in that currently the knowledge is not sufficiently available to gain true clarification of the distinctions in practice, or if the knowledge is present it is not disseminated in a clear and concise manner for all to understand. A further possibility is that PST is a form of euthanasia but through having a medical label attached to it legitimises the practice.

The potential of such a hypothesised situation has major ramifications. If palliative practices are being implemented and death hastened or prolonged but the practices are not fully understood, or distinguishable from euthanasia, medicine has secured its position of power through a falsification of knowledge base. This potential lack of true knowledge of practices being implemented can be seen when the clarity of what PST actually is and entails remains evasive in that definitions are always stated in relation and opposition to that of euthanasia. For example "palliative sedation is not a euphemism that is morally equivalent to euthanasia" but is a "legitimate pain-controlling medical treatment" (Smith, 2013, p. 63) and is no different to the array of other medical treatments offered in that

> "if the patient dies [from PST], it is usually from the underlying condition or as an unwanted side effect, which can happen with any medical treatment. In other words, PS[T] is no more euthanasia if a patient dies from complications than if a patient dies during heart surgery" (Smith, 2013, p. 63).

When justification for constructing and implementing such therapies relies upon its relational value to that of the illegal practice of euthanasia, it proffers the suspicion that the distinction between the two treatments treads a very fine line. It appears that medical practitioners, both through and despite their specialist knowledge, have to

justify the value of sedating the dying until death occurs and how this differs, if it does, from passive euthanasia. This paradoxical situation produces a discourse of distrust in clinical practices and, therefore, renders the dying vulnerable at a time of need.

The social media voice: challenging medical practice

Many medical practitioners become defensive when their knowledge and practices are scrutinised as publically as they have been, particularly in the UK over recent years in relation to the care of the dying and the potential use of passive or stealth euthanasia.[62] Until now clinicians have been shielded from open questioning from the general public regarding their knowledge and practices and, as such, the voice of online social media is a new experience for the majority. This has produced an uncomfortable and unknown situation for many practitioners and has been witness to knee jerk, defensive reactions to allegations rather than encouraging a more transparent practice. The most common response of practitioners suggests that the media and patients alike are "doctor bashing and feel that we as doctors must have some sinister, ulterior motives underlying our work in end of life care" (Granger, 2012, para. 3).

The once held specialist knowledge of the medical practitioner is now easily accessible, with little or no cost involved, thus, providing an opportunity to gain knowledge and challenge clinical practices. Such available knowledge enhances the reflexive self-governance of the individual (Fox, Ward & O'Rourke, 2005) and, as such, erodes the illusion of the clinicians knowledge being superior (Houts, 2012). Yet, expert knowledge will undoubtedly be greater in most instances as clinicians are able to contextualise the information within the jurisdiction of their practice and, as such, interpret this information in a more refined and accurate manner. Nevertheless, the cossetted and protected gilded cages in which clinicians have resided are shedding their protection, exposing the practitioner to the scrutiny of a global audience.

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[62] Stealth euthanasia refers to the practice of intending to end the lives of patients, but through the legal administration of medical models of care (Hamel, 2014).

In an idyllic world the notion of a balanced doctor-patient relationship, founded upon trust would produce a utopian discourse through which self-determination of those dying patients who seek it would not be viewed as opposition or 'otherness', but would be upheld as an action of their human rights. Moreover, if such a utopian relationship did exist, then there would be no need to question the knowledge, power and authority of institutions. The reality, however, appears that despite the best intentions of palliative medicine it has become a messy field of practice fraught with legislative dangers through non-communication with patients and family members, together with the ego of the expert clinician. It has placed the clinician in a position whereby they must now justify their actions, in a similar manner to most other professions, but the discomfort with this is palpable. Justification of their choices of care options is not familiar territory for some clinicians, but this is not an excuse for not engaging with this role. However, the medical professionals disquiet with this contemporary phenomenon is formulated through the formal written word and not generally through responding to publications in the mass media. An example of such a response to the damning reports about the LCP, for example, was to have 1,300 medical signatories on a letter supporting this medical model of care (Adams, 2012). This action, however, appears more of a protestation than a fully-fledged fight against the issues raised, with a more subtle strategy simultaneously emerging from the medical perspective, suggesting that those lay persons concerned about medical treatments being forms of euthanasia being labelled as hysterical (Granger, 2012).

Hysteria, a term burdened with historical relevance to medical practices of old, is used here to suggest that the response to PST or the LCP is inflated and that the practices are both legitimate and useful. It also provides an emotive outlet to be used against those questioning medical practices, as emotional connotations of the lay person provokes a suggestion of instability of the mind in rational thought (Piechowski-Jozwiak & Bogousslavasky, 2014). It plays upon historical doctrine of the hysterical which was gender specific in its reference to disturbances of the uterus in the ancient world and could only be experienced by women; or that if men were deemed hysterical they were de-masculinised. In this instance it plays upon the emotional distress accorded to the unknown and unknowable about dying, thus, producing an image of the unstable individual in questioning medical practices. The

use of emotive language produces a discourse of disharmony and, as such, threatens to weaken the relationship between doctors and patients. Clinicians are using the notion of hysteria, however, in an attempt to de-escalate the rising wave of concern regarding the uses of PST and the LCP in practice, as they appear to be finding it difficult to digest why it is that questions around such practices are only being raised now as "we have been using the pathway for years so why now?" (Granger, 2012, para. 1).

This question is difficult to answer specifically, but suggestions may be posed around the immediate availability of knowledge through online social media and the rise of the individual voice. It may also be considered that through the ability to have an anonymous voice through online social media, that those working in clinical practice together with the individual, feel they are able to engage in encouraging open discourse in practice and, as such, is notable in the following statement as "I will tell you were [sic] the hysteria [sic] came from it came from whistleblowers [sic] working in the same field of work" (Concerned in Granger, 2012, para. Comments).

This demonstrates the use of anonymity in online social media, as to reveal one's identity can reap major ramifications in practice. Experience suggests that such whistle blowing is a necessary part of clinical practice to highlight poor care, thus enabling improvements to be implemented. An alternative viewpoint is that medical practitioners continue to engage with the practices of the LCP and PST, as to withdraw now would suggest that the issues highlighted have a foundation for complaint. This is highlighted in Granger's blog, with one respondent suggesting that "if she did not she [Granger] would feel guilty from putting patients on it as professor glasser [sic] stated its corrupt medicine especially paying doctors large amount of money to put patients on it" (Concerned in Granger, 2012, para. Comments).

Social media: a voice to highlight medical experiences
A more contributable factor is probably equitable with the *Telegraph* newspaper in the UK publishing an "open letter signed by palliative physicians and other pain-control experts" (Smith, 2013, p. 65) in 2009, highlighting what they perceived as

major faults in care when using the LCP at end-of-life. More specifically, Professor Patrick Pullicino, a consultant neurologist at East Kent Hospitals University NHS Foundation Trust, expressed concerns over "… the extent of suffering that have come to light through people who have been on the pathways" and this "warrants nothing less than a formal government inquiry" (Pullicino, 2012, para. 29) when referring to the LCP. It is these statements that sparked the 'hysteria' over the use of pathways in end-of-life care and ignited the debate around self-determination and the right-to-die. It is this letter, therefore, that heralded the demise of the LCP in practice in the UK as it highlighted the routine implementation of this model of care which "threatened the lives of patients who did not need sedation based on their medical conditions" (Smith, 2013, p. 65), and has subsequently had major ramifications for clinicians per se, and palliative medicine in particular.

This statement is upheld by Dr Stephen O'Brien, a senior lecturer at Newcastle University who highlights that

> "the hospice movement in Britain continues to teach that rehydration via a drip is rarely necessary – despite evidence from America to the contrary" and, as such causes "dehydration [which] can cause the build-up of toxic metabolites from morphine and other drugs, resulting in confusion, drowsiness and jerking or twitching. This is then often managed by sedation rather than rehydration. When I last audited my use of intravenous rehydration in a hospice setting, 50 per cent of the patients went home – which invites the question of what happens to patients in those hospices which still refuse to offer rehydration. The answer perhaps lies in the disturbing number of deaths in Britain following continuous deep sedation [PST]" (O'Brien, 2009, para. comment).

These statements highlight the problematic nature of using a formula in order to manage nature. The use of a formula equates to the advances in scientific knowledge available to medical practitioners and, as such, attempts to engage empirical knowledge with the naturality of dying. This, when conducted within the "modern penitentiary" (Turner, 1995, p. 12) of the hospital produces a "system of control" (Turner, p. 12) thus applying systems of moral regulation to the process of

dying, to ensure conformity and docility with such structures. When the general population, however, choose not to engage with the formulas of control, medicine again raises its defensive shield when their practices are externally critiqued, with such external evaluations perceived as being unwelcome and simultaneously taken as a fabrication of reality and condemned as the general population being hysterical. This is identifiable through the personal blogs of some clinicians in relation to the LCP (and similar models of care) in practice, in that when there are any negative responses to the themes within the text, the commenter is immediately reprimanded for being "despicable and evil" (Norton in Granger, 2012, para. Comments) in questioning the clinician or highlighting issues from personal experiences; thus suggesting that to disagree with medical opinion is both incorrect and unwelcome.

In Grangers' blog, it is notable that the blogger appears to no longer correspond with the commenters when they sit in opposition to her argument, in that their personal experiences of the LCP, from a lay perspective, are more negative than the medical framework supported by the blogger. Blogging is meant to be a means of free speech and for the voice to be heard, but remains limited in its ability to countenance every opinion that differs from the author. Although blogging often draws upon the experiences and opinions of the writer, it does open a window of engagement and, as such, should be prepared for voices that may not align with the story narrated. In Granger's blog, opposing views are routinely ignored so while views may be expressed it may not contribute much to the broader debates. There will, however, always be respondents who oppose the views held in a particular blog and there is always the risk of discordant voices online (Anderson, Brossard, Scheufele, Xenos & Ladwig, 2014); and bloggers should be both aware of and prepared for this eventuality. In fact blogging and social media communication appears to produce "inherently unethical" dialogue through the security of anonymity (Reader, 2012, p. 496).

The LCP: statistical data
Accurate and formal statistical data detailing how many patients have died when placed on the LCP is unattainable, with no records held with health ministries in the UK and New Zealand (Ministry of Health, 2015, personal communication). Anecdotally, in the UK, it is suggested that between 100,000 and 130,000 patients

have been placed on the LCP each year (Martin, 2013; Malone, 2012). When broken down further by English Trusts it ranges between 200 and 1980 patients each year approximately, per Trust (Sturdy, 2013).[63] Further data suggests that 33 per cent of deaths are conducted through the LCP and that 77,000 patients die on this pathway each year according to a recalculated statistic from the National Audit Office in England and Wales (Adam in Age UK, 2012, para. Comments). This data cannot be used to make substantive claims regarding both the usage and the efficacy of palliative care models, but demonstrates that its place was at the forefront of much palliative medicine since its creation. Despite this evidence, and that inside whistle blowers have raised the lid on such practices through Pullicino's open letter in 2009, many medical professionals stand by their practices, citing that they would want their deaths managed using the LCP, as it provides best standards of care (Chris, 2012; Granger, 2012). Yet, 'tick-box' pathways should not be a replacement for sound individualised and compassionate care at end-of-life, although some justification is given in that such pathways are necessitated in the hectic contemporary healthcare institution (MacNair, 2013).

It may be felt necessary by clinicians to have this supportive framework as an aid to care in relation to those dying within the acute clinical setting and, as such, may reflect the fact that the contemporary death is predominantly located within the "modern penitentiary" (Turner, 1995, p. 12) of the hospital. Yet, this situation sits in opposition to the known fact that the majority of individuals would prefer to die at home (Arnold, Finucane & Oxenham, 2015). To attempt to justify the construction of prescribed care for the dying, dependent upon intent of use, because of the busyness of the institution suggests a self-absorption of medicine to control the contemporary death and merely ignore the wishes of the majority. Yet, the idea of invisibility at end-of-life, despite the media attention given to the LCP for example, has produced a negative discourse exposing the medical profession to allegations of inappropriate practices, and must be considered in relation to financial gain for using specialist models of care.

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[63] 'Trust' refers to a National Health Service organisation serving a geographical are in the UK or provides a specialist function and are public sector corporations.

Contemporary dying: a financial crisis

Medical practitioners are expected to be able to consider the best interests of the patient, and to 'do no harm', but given the financial incentives created by the British Government for NHS Trusts who implemented the LCP, and other forms of sedative practices at end-of-life, it suggests that clarity of judgments may have been tempered by other institutional drivers. It is morally and ethically abhorrent to equate the care of the dying patient with funding needs for NHS Trusts, but the reality is that it did occur in the UK (Neuberger et al, 2013; Bingham, 2012). To advocate for the best interests of the dying patient, such decisions must be made without rewards being made available to acquiesce to institutional requests, as the decisions must always be made on clinical judgement. It appears to be normal practice for NHS Trusts to receive "financial incentives for the implementation of best practice" (Neuberger et al, 2013, p. 34), but this instance raised concerns when "money can be attached to the percentage of dying patients implemented on the LCP [and] gives rise to a suspicion among some that people are being hastened towards death to help the financial situation of the Trust in question" (Neuberger et al, 2013, p. 34).

The fact that Trusts were paid a financial sum for each patient who died on the LCP removes the automatically default element of trust expected by medical practitioners of their patients (Granger, 2012), as trust is a key element in the patient-doctor relationship. That institutions have received payments for implementing care pathways, however, crosses the boundaries of the doctor/patient relationship, thus, exposing the notion that medical practitioners were making financial based choices when implementing such care pathways, rather than knowledge based decisions. It suggests that the best interests of the patient may have been overruled by a need to perform well against targeted statistics, with professional knowledge not always equating to the expectations of institutional management strategies. The use of incentives in managing the dying, therefore, proves "extremely problematic" and "must call into question at least some of the prognoses and decisions made" (Neuberger et al, 2013, p. 34). This high level questioning of clinical practices through the *Neuberger Report* lends credibility to the anecdotal allegations emerging through online social media outlets and, as such,

has given rise to medicine having to take note of the recommendations for futural care of the dying.

This statement by Neuberger suggests that some clinical decisions in relation to patient outcomes may not have been correct and, as such, has potentially hastened the deaths of some patients. It also questions the reliability and authenticity of the *medical gaze* through the primacy of medical authority, in that the analysis of the given situations has been determined through the power/knowledge relationship of the clinician within the context of knowledge and expertise (Foucault, 1973). This has resulted in dire consequences for some patients involved and, as such, questions the knowledge and skill of the professional autonomy of such practitioners and their relationship to the "system of medical domination" (Turner, 1995, p. 156).

The *Neuberger Report* is a formal questioning of medical practice associated with end-of-life care, conducted through the judiciary of the UK and, as such, introduces the narrative that medicine may no longer be able to sit unjudged in a protective gilded cage; but becomes accountable for those end-of-life care practices that have produced blurred boundaries in relation to their similarity to some forms of euthanasia. If the literature around PST and the LCP is to be believed, these approaches to care for the dying are meant to be collaborative arrangements, in that patients and families give informed consent and not for clinicians and Trusts to be rewarded financially for "dispatching frail and elderly[s] patient more quickly" (Boseley, 2013a, para. 4). The strength of the statement, written by a journalist, imposes the emotional reality on what has alleged to have occurred in some clinical environments and, as such, brings to the fore the differential value of the individual through the perceived worth or worthlessness of human life derived from it being aged or frail. It portrays the subjectivity of the clinician in relation to that of the patient, with the power relationship between the two tipped in favour of those with knowledge and thus power; but in this instance power is given through the mediation of funding, with the professionalism of the clinician being questioned in relation to their partnership with their patient's best interests.

The notion that skilled palliative medicine clinicians may be swayed in their professional judgement suggests that the correlation between incentives and

outcomes may prove influential, in some instances, to the pathway advised or taken by the clinician in question (Doughty, 2012). It suggests that for some clinicians, the means of obtaining additional funding for their workplace supersedes the actual clinical needs of the patient in their care; a patient that trusts the given knowledge as being truthful and, thus, consents to placement on such clinical pathways, demonstrating a flexibility of the empirical knowledge upon which medicine is founded. Moreover, it suggests that institutional drivers may be more important to some practitioners than decision making according to need, thus reflecting the needs of the medical corporate complex being favoured over patients.

The reality exists, however, that in some instances the LCP has been increasingly implemented across Trusts at a comparatively unusual rate compared with previous years (The Lawyer, 2013); for example, "Central Manchester University Hospitals – which received £81,000 in 2010 for meeting targets relating [to] the LCP – said the proportion of patients whose deaths were expected and had been placed on the pathway more than doubled to 87.7 per cent in the past year" (Brexit in Pullicino, 2015, para. Comments). Furthermore, it is suggested that when analysing the activities of 72 UK NHS Trusts "at least £12.4 million has been paid out in the past two to three years to trusts which hit targets associated with the use of the care pathway" (Bingham, 2012, para. 14).

This data presents both evidence and clarification that such 'cash per dying patient' did exist in the UK in relation to the LCP. It is a worrying phenomenon that individual lives had a price tag allocated to them and is coming to the fore in New Zealand also. It is suggested that the care of the dying in New Zealand imposes a financial tag of $180 (New Zealand dollars) per person per night for those in residential care over and above the original funding in place, and that such needs are not being met at present (Mason, 2016). At present, this funding is not related specifically to the implementation of the LCP, but is proposed for use to meet specific needs in end-of-life medical care. As such, with this knowledge now available in the public sphere of online social media it can be seen how the lay person correlates such findings with the negative care experiences of relatives who were dying at this time within acute clinical settings in the UK, and will now promote concern for those in New Zealand. More importantly, however, is that this

exposé of unethical practices may prove detrimental in the expected trust in the doctor/patient relationship, as the monetary value of life should not be the identifier for treatment.

The ethics of funding: beneficence and non-maleficence

Contemporary Western medical practitioners tend to make ethical decisions founded upon the four principle approach, that is: beneficence, non-maleficence, justice and autonomy (Cronshaw, 2014) which, at first glance, appears to offer a suitable construct through which patient related decisions can be made, and medical trust gained. In relation to using PST or the LCP one must question the beneficence of such pathways when compared to the potential maleficence that may occur. When considering the LCP, for example, what beneficence was this to the dying patient who may have been placed on it without consent? As it has been suggested that 45 per cent of patients were already unconscious when the LCP was commenced (Linder Myers, 2013) with consent being unattainable. Were patients placed on the LCP because it was in their best interests, thus the decision being taken as a form of beneficence for the patient, or was it for the beneficence of the institutions and clinicians within them? It could also be suggested that it was for the benefit of family members, as culturally we have become deskilled in caring for the dying. This is just one instance in which the power relationship between the medical practitioner and the patient can be interpreted as being in favour of the clinician rather than the patient, thus presenting one obstacle that precludes the patient from autonomy in decision making. That said, one would always hope that the correct decision for each individual patient would be identified.

When considering ethical decision making in relation to financial incentives to use specific end-of-life pathways, and relate such practice to the right-to-life and right-to-die arguments, the waters become quite muddied. Although the right-to-life is upheld through the human rights framework (Article 2) it could be argued that palliative medicine has contravened this right through implementing care pathways in a non-consensual manner for financial gain. The deprivation of life, even if that means by a matter of hours for some of the individuals concerned, remains problematic, questionably unethical and sits opposed to the foundation of contemporary welfare and human rights. Moreover, it appears difficult to

comprehend that such examples of professional end-of-life care have occurred when the supposition and expectation of the knowledgeable clinician would intend no harm, yet, it appears that harm can take on many guises. Harm can occur through the application of power, demonstrated in these instances through the *medical gaze* and is an interpretative formulation whereby the rights and autonomy of the dying have been overridden or ignored and justified to the institution through ethical debate. Yet, for the patient no longer living and the family left behind, it suggests that the role of personal autonomy and the ascribed right-to-life is but a token gesture on the part of the paternalistic medical profession.

Contemporary dying: towards the future in the UK and New Zealand

The LCP when instigated in the UK was portrayed as an opportunity to use the framework as guidelines for practice which were to be tailored to the needs of the individual, but this ideal was superseded by the 'tick-box' tool it eventually became (MacKintosh, 2014). Whether the newly indoctrinated *Priorities of Care* in the UK will change previous practices is as yet an unknown.[64] In New Zealand, however, despite the recent demise of the LCP in the UK, it has been rolled out across more than 350 institutions (Dudding, 2013) including hospices, private and public hospitals. It remains the gold standard of care and best practice in New Zealand (Best Practice New Zealand, 2011) and is used in 86 per cent of New Zealand hospices, 45 per cent of hospitals and 60 per cent of aged care facilities (Goodhew, 2013). Literature on the benefits of the LCP in New Zealand outweigh the cases against it, with the reasoning behind this being that "because the death of a loved one is so traumatic, the event itself automatically colours people's perception of the process and generates complaints that are often unjustified…this produces a false picture of the state of terminal care in the country" (McVeagh, 2009, para. 1).

This statement appears both patronising towards those families left behind after a loved one has died and simultaneously reverts back to the notion of hysteria in relation to lay individuals. It suggests that individuals are not able to provide clarity of thought because bereavement provides a shallow foundation on which to make such assertions and, as such, smooths over any untoward issues that may have

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[64] Priorities of Care are outlined in *One chance to get it right framework* that has been developed in the UK to provide care at end-of-life following the retraction of the LCP (NHS England, 2014).

arisen (Human Rights Watch, 2014). It demonstrates an institutional mistrust of journalistic representations of experiences that potentially threaten the liberty and rights of the individual over that of the institution (Foucault, 1979). It also alludes to the lay individual being incapable of sound judgment with respect to clinical care.

More perturbing, however, is that complaints and allegations have obviously been made, but do not appear to be taken seriously in New Zealand. This is evident when "a spokesman for the health and disability commissioner said it receives complaints relating to end-of-life care, but without reviewing individual files it was unable to say how many, if any, of the complaints directly concerned LCP" (Dudding, 2013, para. 10) and that "[Dr Simon] Allan says he isn't aware of any complaints about LCP in New Zealand. If anything, you hear complaints about the opposite, where families are unhappy about the pain their parent suffered as they died" (Dudding, 2013, para. 42). This presents a paradoxical situation given that 85 per cent or more institutions in New Zealand are now utilising the LCP in practice. This statistic, however, does not take into account cases of PST and, as such, would suggest through the laws of probability that some of those complaints received will indeed be related to LCP practices, if not the other models of care utilised. The notion, however, that no complaints have ever been received in New Zealand, as stated by Allan, regarding the LCP paints a utopian discourse of the New Zealand healthcare system, a discourse that is never achievable in reality.

Complaints will always occur in healthcare due to the subjective perception of the encounter (Wessel, Helgesson, Olsson, Juth, Alexanderson et al, 2012), but to deny the existence of any complaints in light of the extensive use and abuse of the LCP that has been proven, to some degree in the UK, is problematic. In a democratic society, this lack of transparency alerts one to consider that problems are occurring but to acknowledge them equates to a failure of healthcare provision. It suggests that the power residing with the medical professional in New Zealand dominates the outcomes of care, in that the individual voice exercised through online social media is not valued or listened to; but is subjected to the power of the institutions of both medicine and government. This is reflected in a recent statement by Ministry of

Health for Cancer Services spokesperson, Ricarda Vandervorst, who continued to support the use of the LCP in New Zealand despite its failings in the UK (2015).

This situation accords an insidious and unhelpful discourse of power to a situation that has international repercussions for the dying patient. To suggest that the application of care pathways in New Zealand is different to that overseas highlights a selective power in choosing what to accept as occurring and omitting the remainder. Yet, acknowledgement allows for the correction of errors and improvements to occur. Such practices do not serve to protect the dying, but to protect the medical elite, their knowledge and their status, irrespective of whether their practices are hurting the patients they purport to care for or not. Moreover, this sublimation of perspective, in that family members are incorrect with their complaints, and that such complaints are dismissed through invoking thoughts of hysteria, removes the practice of autonomy and choice, let alone self-determination when dying in New Zealand; but proffers the notion that clinicians are indeed knowledgeable, powerful and remain untouchable in their gilded cage.

Part three: The confluence of medicine and law

Medicine and law stand separately as institutions of knowledge and, therefore, power; with their collaboration and reliance upon each other generally invisible in day-to-day healthcare practices. However, this situation is reversed when clinical decision making becomes ethically challenging, and is clearly demonstrable in right-to-life and right-to-die (with assistance) debates that are occurring within the UK and New Zealand.

Collaboration: life vs death

The collaboration between medicine and law can be traced back to the origins of informed consent in healthcare practices (Mallardi, 2005) and has developed in both complexity and interdependence in practice over time. Informed consent forms the basis of all inter-relational interactions in health care (Barry & Edgman-Levitan, 2012) and is founded in law, but is not always achievable for practitioners as previously noted. The legality of medical practices, due to the evolving nature of empirical knowledge, engages the collaboration of medicine and law through more formal means when dilemmas are both ethical and moral in construct. This is no more evident than in the cases presented petitioning for the right to determination over the self when dying and those whereby medicine petitions for the right to withdraw or withhold treatment against the wishes of the individual.

Historically, one of the most notable cases of medicine seeking the right to withdraw treatment, and therefore induce death, was the legal ruling with regards to Tony Bland in the UK in 1992, which set a precedent in practice for individuals in certain situations. Bland had not been able to make a conscious decision regarding his care and life outcomes due to his incapacitated state, however, medical practitioners initiated court proceedings, with the family's subsequent consent to withdraw artificial feeding as they perceived it to be in his best interests. What his best interests really were, were not attainable in retrospect. In a more recent case in France in 2015, a 38 year old former nurse became a tetraplegic following a road traffic accident, was incapacitated and unable to understand or communicate. Through a ruling in France, following lengthy legal proceedings and delivered through the *European Court of Human Rights*, it was decreed that "authorised

doctors" could "put an end to the intravenous food and water keeping Vincent Lambert alive" (Kessler, 2015, para. 3).

In this instance, medicine has taken notice of previous personal autonomy in that Lambert would "never have wanted to be kept in this state" (BBC, 2015, para. 9) according to his family. This decision sits opposed to that of Bland in that Lambert had actively stated his wishes in advance, but Bland had not. This statement reflects the need for acceptance of personal autonomy of the incapacitated and his wishes to be upheld in the face of poor life quality and intolerable suffering. Such sentiments are well supported in the media, with some expressing the wish to "find peace for my tortured and shattered body" (Welby, 2007, para. 5) or that "I, for one, do not want to continue living when I have lost control of my bodily functions". With others stating that "in my opinion, it all boils down to the respect we have for a person's quality of life and their own opinion on the subject" (Alex, para. Comments in Kessler, 2015) or if "I had to be reliant on life support after 7 years being in a coma just to stay in this variant of "alive" I would want to be turned off too" (Winteriscoming, para. Comments in Kessler, 2015). Further comments supporting this right-to-die suggest that it is "cruel to let him live like that" (Daddymac, para. Comments in Kessler, 2015) but that they are often "forced by the state to remain alive when they don't want to be" (Lancelot, 2009, para. 3).

The support to let Lambert die appears one to be lauded in that his perceived suffering has ended, but this situation is less transparent than the immediacy of this ending of life. It suggests Lambert's, and his family's autonomy and right to self-determination have been upheld, but it produces a dichotomy in that it is only through a medical practitioners' decision to discuss the possibility of ending the life that it has occurred. It is this point, in that it is only at the instigation of medical involvement in reviewing his life value that his quality of life became questionable and, as such, demonstrates the power held by such practitioners. They had supported his life for seven years, but now questioned it. One could ask what provoked such questioning. Whether clinicians listened to family wishes or whether other external factors and institutional drivers became significant, we do not know at the present time. It demonstrates, however, the significance of influential directives, in that should such directives have been derived solely from the family

perspective it would be unlikely that Lambert would have been allowed to die, but because medicine played a significant role in the assessment of life value the decision was upheld. Lambert's situation demonstrates that the locus of power in the doctor/patient relationship is one fraught with danger, often for the patient, as once treatment has been commenced and the individual is no longer able to communicate, the right to terminate such treatment does not lie with the individual.

This situation renders the incapacitated individual to the mercy of the subjectivity of the professionals caring for them and the directives of institutional drivers. It highlights how anxiety and fear of losing control over the self arise, becoming visible to the individual patient; thus, demonstrating how the rise in pursuing the right-to-die has gained ground. The fear of becoming "a bedridden, pain-racked and drugged shell of my former self, totally dependent on others…" (Dastgheib, 2015, para. 12) overrides all notions of life value and, as such, having the right-to-die would appease this narrative, thus, removing any doubt about the potential inadequacy of palliative care measures. Yet, palliative medicine and the sanctity of life discourse can often attempt to overrule such desires and are evident in the case of 'Miss B' in the UK in 2002. A former social care professional, Miss B was 43 years old and had suffered a catastrophic rupture to a blood vessel in her neck rendering her a tetraplegic and unable to breathe unaided.

In a landmark case in the UK, Miss B who had been kept alive for 11 months on a ventilator made an application to have her enforced treatment stopped and, thus, die (Dyer, 2002). Being considered of sound mind, Miss B made a legal bid to be removed from the ventilator, but medical practitioners refused her request; they found it difficult to comprehend that such a young woman would give up on life. Clinicians pursued this patient through the courts while she remained hospitalised to convince her to engage with medical solutions for her condition despite her protestations of suffering and poor life quality. Moreover, they refused her request because she had not yet "tried special rehabilitation to improve her condition" (Hamilton, 2002, p. 565). This statement, in light of the woman's situation demonstrates the clinician's inability to see that death for this woman was preferable to the life she was living.

The sanctity of life and right-to-life frameworks, however, dominate this situation and, as such, appear to overrule the choice of the individual or what the individual perceives as being in her best interests when discussed on an equitable basis. It suggests an ego within the power statute of both medicine and law, that to fail or be perceived as failing is not tolerated. But, in considering failure, it could be postulated that continuing with ventilation for this patient is detrimental to her wellbeing. This incident, however, ended in a separation of medicine from law, in a case of opposed collaboration, as Dame Elizabeth Butler-Sloss, President of the High Court in the UK at that time, upheld that Miss B's human rights and freedoms had been breached. However, she was clear in her direction that in clinicians removing ventilation, this did not equate with euthanasia but that "life-sustaining treatment may be discontinued" (Hamilton, 2002, p. 565). It is interesting that clarification of removing the ventilator did not equate to euthanasia, whether voluntary or not, as the definition of voluntary euthanasia would be comparable to this decision given; and one must consider, therefore, if clarification of this not being equitable to euthanasia was a means of easing the burden of decision making in this instance for both clinicians and lawyers.

This case does not sit in isolation, but does demonstrate the dominance of medicine in coercing the sick and suffering to abide by their constructed paradigms of care. The decision to pursue legal support to continue treatment for some patients upholds the overriding notion of life being sacred, but when compared with the pursuit of removing treatment in the cases of Bland and Lambert questions around sanctity of life appear to be omitted. This situation presents an opportunity to question whether all life is sacred, or only some lives in the contexts of both medicine and law. And if it is only some lives that are sacred, then how do medical practitioners choose between who to save and who they will allow to die? It could be surmised that those individuals who have the knowledge and awareness of their human right to self-determination and, thus, pursue the right-to-die are speaking against the institutional powerhouses of medicine and law. This may result in these individuals becoming victims of the power dynamics at play, as through voicing their preference to die it subjects them to the negative impact of the law, simultaneously placing them in the care of palliative medicine.

Palliative medicine, law and intent

The negotiation between medicine, law and the individual presents a complex dynamic that must be individually considered within the context presented. With regards to individuals pursuing the right to self-determination, however, there may be some suggestion to support these considered postulations of power dynamics at play. These are evident when reviewing the recent case of 42 year old New Zealand lawyer, Lecretia Seales, who had been diagnosed with a brain tumour in 2011. Seales concurred with the right to self-determination, saying that "I am the one who has been inflicted with this disease … so who else but me should have the authority to decide if and when the disease and its effects are so intolerable that I would prefer to die?" (The Dominion Post, 2015, para. 14 & 15).

The public response to her legal bid was that if anyone were to succeed in securing the right to an assisted suicide, a legal professional would be best placed; but again her crusade failed, she lost the battle of both life and the right-to-die. The support for Seales and her bid for personal choice gained strength, however, with New Zealand Prime Minister John Key "saying he would sympathise with the 'speeding up of the process' of death for a terminally ill patient" (Collins, 2014, para. 1); with 74 per cent of New Zealanders polled supporting a change in the right-to-die law (Scoop, 2015). In an era of "growing medical sophistication combined with longer life expectancies" (Hamilton, 2002, p. 565) the medical denial of self-determination in dying remains dominant irrespective of their ethos to 'do no harm', but may simultaneously harm the patient for whom the suffering is unbearable.

This is highlighted with the case of a 30 year old UK woman who had been diagnosed with Eienmenger's Syndrome together with Klippel-Fiel Syndrome and was seeking "medical assistance to relieve her suffering" (Davies, 2007, para. 1); and she had completed a living will or ACP to this effect.[65] The medical team

> "refused her request, arguing that to provide deep sedation would amount to euthanasia" and that "this would involve the doctors in assisting her suicide,

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[65] Eienmenger's Syndrome is a congenital heart and lung condition. Klippel-Fiel Syndrome is a rare congenital spinal condition.

which is unlawful and unethical" but doctors "may give morphine or other medication with the aim of relieving pain and which may have the effect of shortening life" which "is lawful and part of good-quality care, but is different loactiun [sic] taken with the intention of ending the patients' life" (Davies, 2007, para. 4 & 9).

These statements, when combined and read in succession, paint a paradoxical image of medical practice in that on the one hand medications can legally be given that may shorten life in a clinical situation through PST, but when a patient specifically requests sedation to alleviate fear and suffering it is declined. The power dynamic at play demonstrates that the differences in practice are minute and open to the manipulation of language and subjective interpretation in achieving outcomes. This statement demonstrates the blurring of boundaries in clinical practice, and produces a discourse of discord mediated through the specialist knowledge of palliative medicine. This is secured through their institutional and cultural status of power, in that a hastened death and less suffering is offered to the compliant patient, but simultaneously inflicts prolonged suffering on the individual seeking control over their demise. Such decisions are legally biddable and, as such, leaves the non-compliant individual in a compromised position of otherness with little power to challenge their situation, as demonstrated in the cases of Pretty, Nicklinson and Seales.

This power paradox does not serve the needs of the contemporary dying individual but the needs of both medicine and law in that without each other it is difficult to justify some decisions made. Law mediates the needs of the intolerable sufferers through linguistic choices such as these individuals being "tragic" (Epstein & Foster, 2014, p. 1) and thus supports the construct of palliative medicine in determining their fate. Both law and medicine utilise the human rights framework of everyone having the right-to-life as being fundamental irrespective of the suffering incurred, and that choice is restricted through the construction of specialist bodies of knowledge. However, it appears at odds that New Zealand as a nation, for example, allows "the termination of unborn children based on the choice of the Mother, but can't seem to get our heads around the concept of a suffering Human Being [sic] electing to end their own life?" (Nebman, in Slater, 2015, p. 3). This

leads us to question how an individual can choose life or death for a foetus, but one cannot choose death for the self, making an informed decision in light of succumbing to an incurable disease. More specifically, it appears that we cannot be trusted to accept the culturally prescribed trajectory when dying and, as such, medicine and law collaborate to ensure that we remain within the constraints of accepted pathways of dying within contemporary Western societies.

Medicine: retaining power through law

The medical profession, however, is engaging with the right-to-die campaigners through defending its profession, knowledge and opinion (Right-to-life New Zealand, 2015). They are seizing the opportunity to regroup and work towards a more harmonious dying trajectory for the general population. Medical practitioners are being urged to "rise from our slumber" as there "is an international war being waged on the conscience of the medical profession" in a society that imposes a "culture of death" (Right-to-life New Zealand, 2015, para. 1).

This appears a harsh statement in relation to the individual pursuing personal choices and freedoms at the end-of-life. There is no mention of war in the individual cases pursued through the legal systems of the UK and New Zealand, but an expression of determination to secure personal rights over the demise of the self. Moreover, the notion of there being a "culture of death" (Right-to-life New Zealand, 2015, para. 1) opposes the known culture of anxiety and fear around the unknown trajectory and experiences of the dying. Dying may sit in opposition to the medical culture of life saving, but reality must be accorded to the fact that the lifespan of the human being is finite, and the war against it cannot yet be won.

The increasing number of individuals exerting their right to choice appears to displease some medical practitioners, as in a recent UK poll, medical practitioners were asked if they supported the right of patients to assisted suicide, with a 57.5 per cent majority not agreeing (RCP, 2014); and 62.5 per cent thought that improvements in the construct of palliation would suffice to meet the needs of individuals (RCP, 2014). Such statistics reflect the dominant thoughts of medical practitioners, in that palliation is sufficient to manage end-of-life care choices. The reality is that this may be the case, as for some individuals the comfort provided by

palliative medicine is a necessary and welcome distraction from the naturality of dying. It provides the labelling and treatment that offers security when facing the unknown and is engaged with without pressure. For those who prefer not to engage with the constraints imposed by palliative medical practices, the fact that so many doctors are not in favour of physician assisted suicide, and feel their construct of palliation should suffice, paints a substantially negative backdrop against which the self-determined individual must fight for the right to choice.

Through the use of specialist knowledge and language the constructs of medicine and law engage in a form of institutional violence towards those they serve achieved through a "mystical violence" (Shaw & Shaw, 2013, p. 44); with law in particular reflecting such violence as a means of "codification of organised public violence" (p. 44).[66] This suggests that there is a conscious move in the construction of both medicine and law to weave such approaches into the fabric of the institutions as a means to navigate and subjugate the general population, thus, facilitating the "construction of social values" (p. 45). As such, these powerhouses are able to implement their own agendas, histories, sciences and values onto the constructed paradigms within which they work (Shaw & Shaw, 2013). It demonstrates the means through which medicine occupies the life and death of the self (Turner, 1995), achieved "not through overt violence but through a micro-politics of discipline whereby people have been morally regulated into conformity" (Turner, 1995, p. 12); thus demonstrating

> "that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations. These 'power-knowledge relations' are to be analysed, therefore, not on the basis of a subject of knowledge who is or is not free in relation to the power system, but on the contrary, the subject who knows, the objects to be known and the modalities of knowledge must be regarded as so many effects of these fundamental implication of power knowledge and their historical transformation" (Foucault, 1977, p. 27-8.).

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[66] Mystical violence refers to a means through which power is exerted that is not attainable for the general population and is shrouded in secrecy through the use of specialist vernaculars for example.

Such power residing in the dominance of medicine highlights the inequalities in power relations between practitioners and patients. It suggests that the discourses of both medicine and law are manipulated through their respective institutions by means of knowledge "that is considered legitimate and valid in that context" (Oliver, 2010, p. 28) and, as such, permits the professional practitioner to "exercise his or her power and influence in a way that remains relatively unchallenged by others" (Oliver, 2010, p. 29). For those individuals, however, seeking self-determination at end-of-life, they sit in a position of difficulty and, as such 'otherness', in relation to resisting or criticising the dominating demeanour of medicine (Turner, 1995); but simultaneously produce a reflexive form of the self, becoming a "reflexive project of self-governance" (Fox et al, 2005, p. 1307) which, in turn, produces a disciplined self and, thus are able to establish the reflexivity of self-management (Fox et al, 2005).

The power paradigm of medicine and law working in unison to support or deny the dying their rights, is produced through a discourse of power and the creation of "regimes of truth" (Foucault, 1979, p. 30); which in turn are "produced by virtue of multiple constraints [a]nd it induces regulated effects of power" (Foucault, 2008, p. 112). In effect, this enables medicine and law to be "conceptualised in all aspects according to a singular vision which sets out what is true and false" (Shaw & Shaw, 2013, p. 50); with the realisation of truth being constructed through the specialist knowledge afforded to medical practitioners. Subsequently this projects their values and experiences upon the individuals in their care. Moreover, the construct of power within medicine can effectively constitute the production of the docile body or patient, in that the patient is easily controlled to comply with palliative therapies in return for achieving a 'good death'. Although power may not be equated with the disciplined patient, and disciplinary power has strong associations with crime, punishment and the military, the concept can be expanded to embrace health and welfare, with the intention of constructing a society of obedient or docile bodies (Thornborrow & Brown, 2009; Humphreys & Brown, 2002; McGaha, 2000); achieved through the

> "moment when an art of the human body was born, which was directed not only at the growth of its skills, or at the intensification of its subjection, but

at the formation of a relation that in the mechanism itself makes it more obedient as it becomes more useful, and conversely" (Rabinow, 1991, p. 182-3).

Medicine invites the dying patient into its enclave in order to break it down and rearrange it through its "mechanics of power" (Rabinow, 1991, p. 183). More simplistically medicine manipulates and treats the body through the postmodern construct of palliation to manage the dying. Medicine, however, does not invite the dying into their care, but expects that the dying will want palliative care over the right-to-die, whereby their knowledge will not be questioned; thus retaining the exclusivity of knowledge of the dying body while simultaneously commanding the docility of the dying body. Such docility is upheld through the construct of law supporting medicine, when those less obedient dying bodies pursue their rights to choice at end-of-life, challenging the practices of medicine and discourse in their quest to control this final act of living.

A reality remains, however, that the practices of medicine and law, their selective collaboration and the disharmony in responding to the wishes of the individual portray a futility in using the *Human Rights Act* as a framework through which to sequester one's wishes when dying (Schaber, 2013); as it would appear to be applied as an interpretive tool (English, 2001). I suggest, therefore, that despite the propulsion to utilise this framework to seek rights over the self, it is but a broad framework, with little specific impetus to secure its contents for the individual in the face of dominating powerful institutions. Moreover, the human rights framework becomes but a pawn in the negotiation of rights, through which those perceived with relevant knowledge can manipulate its contents to suit the occasion.

Medicine, law and ethics: beneficence and non-maleficence
The use of end-of-life pathways is not the only instance through which medical professionals confound the right-to-life paradigm. Through using their professional knowledge to make decisions on behalf of others there have been, as demonstrated, instances where clinicians have sought to end the lives of patients, albeit legally, based upon the subjectivity of life value. Such opinions, however, do not always

align with the life about to be lost, for the value of life between one individual and the next can differ through the application of subjectivity.

Quality of life cannot be measured through indexes, in a similar manner to formulas to care for the dying, or through attaching specialist knowledge to the disease within a body.[67] Quality of life is a personal and subjective experience, which will differ depending upon whom is asked and at what stage in their lifespan in conjunction with a broad range of other issues. A point to note, however, is that it would appear that the majority of cases whereby medicine pursues the right to remove or withhold treatment relate to patients who are being cared for at the expense of healthcare institutions (Zaidi, 2013), thus, this must be considered in relation to the decisions being sought.[68] Such actions and requests by medical practitioners are considered through the legal lens, whereby clinical knowledge is formally presented to support such applications. This demonstrates how specialist knowledge is held, given and received in return for collaborative decision making in the best interests of the patient, often favouring the clinician (Gillon, 2014; Truog, 2012; Kasman, 2004), irrespective of the patient's own wishes being given sufficient consideration (Gillon, 2014). One must ask, however, how support and sustenance can be withdrawn without autonomous consent of the individual involved, as it clearly contradicts the medical and legal arguments around an individual's right to choice and the sanctity of life concept.

The answer must lie in the collaborative strength, or synthesis, of the two knowledgeable institutions, medicine and law, for which the expectation of achieving desired outcomes rarely fails (McClurg, 2010). It also relies upon the ability of these two powerhouses to achieve such goals through the modulation of specialist language and perceived empirical knowledge, thus applying the *medical gaze* to the body within the context of legal statute. This, therefore, allows the invisible to become "…visible only because one knows the language; things are offered to him who has penetrated the closed world of words, and if these words

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[67] Quality of life refers to the general well-being of individuals, encompassing many aspects of daily living (Constanza, Fisher, Ali, Beer, Bond et al, 2008).

[68] The medical ethics in such situations become expansive, and are not the focus of this research, but remain noteworthy.

communicate with things, it is because they obey a rule that is intrinsic to their grammar" (Foucault, 1973, p. 115).

That is, that despite the perception that the individual has choice over the outcome of their fate a reality that the power ascribed to medicine and law becomes the boundary that prohibits such self achievement. It demonstrates that medical practitioners can deem life as being worthy or not, irrespective of personal choice and, as such, support such subjectivity through the objective lens of utilitarianism, irrespective of philosophies of care. Such decisions when taken in light of the sanctity of life, pro-life and right-to-life frameworks, appear to suggest a selective use of such philosophies and frameworks to fit with the problem in question. The sanctity of life, for example, comes to the fore when individuals seek the right to sedation and assisted suicide, but similarly recedes when medicine deems it appropriate to apply PST or the LCP as fitting care. Often decisions are founded upon the financial implications of continued care, when such funding for one individual could provide care for many more (Cronshaw, 2014), with individualism, autonomy and the sanctioned right to choice being side lined, thus demonstrating a flexibly selective process in founding arguments on right-to-life and choice. A case in question occurred in the UK in 2013 when a 68 year old man

> "walked into his local hospital…with suspected constipation but never left after developing hospital acquired pneumonia and blood poisoning. Within weeks he was in intensive care and was left unable to speak or breathe unaided…the hospital trust – which cannot be named for legal reasons – launched a rare legal action seeking permission to withdraw potentially life-saving treatment" and "won an appeal" (Gladdis, 2013, para.2,3,5).[69]

This particular case made headlines in a UK daily newspaper and one can understand the difficulties faced by those without medical knowledge in understanding what has occurred. That said, the personal autonomy and choice of this individual and his family were not observed, with clinicians seeking legal power to invoke the LCP should his condition deteriorate, with him dying ten days

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[69] It must be noted that the media have not disclosed full details of this gentleman's illness, but this is used to highlight not his care or condition, but the application of medical authority over choice.

after the court case (Gladdis, 2013). This case, however, demonstrates the flexible nature of the *medical gaze* in relation to the needs of the general population versus the preferences of individuals as, according to this man's family he "still enjoyed life and was not ready to die" (Gladdis, para. 5), with his family describing the decision as "legalised murder" (Gladdis, para. 7). This emotive statement, however, directs such reactions back to the notion of families being hysterical when dealing with grief and, as such, presents an unfortunate image when compared with that of the clinician.

Such incidences are not unique and sit within a medical discourse of power over the individual regardless of the theoretical consolation prize of perceived autonomous choice for the dying. For this man his trajectory was one of death regardless of his preferred choice; for those non-consensually placed on care pathways their right-to-life was usurped in favour of what has become considered a fast-tracking means to dispatch the dying (Barnes, 2013). These situations become problematic through the denial of life to these patients, regardless of their situations, and sits juxtaposed to the *Hippocratic Oath* to 'do no harm', the human right-to-life and the promotion of the sanctity of life. Moreover, when considering the ethical implications of the medical and legal collaboration that occurs to agree to medicine withdrawing life sustaining treatments, or denying an individual the right of assistance to end their intolerable suffering, beneficence and non-maleficence become flexible paradigms that can be manipulated to suit individual situations. Such constructs offer modes of power legitimised through the application of specialist knowledge to the situation. They combine "knowledge, power and ethics as necessary dimensions of professionalism" (Turner, 1995, p. 131) and, as such, enable clinicians "to manipulate and control their clients and markets" (Turner, p. 131); thus demonstrating how the expertise of the professional is able to control the body of the self, irrespective of personal autonomy.

This is a reminder that medicine is a powerful institution which appears to be uncomfortable with power being distributed between the general population. Medicine raises its shields in defence, often through collaboration with law, when it feels invaded or questioned. Medicine prefers to retain its dominance and power, attained and retained through the application of specialist knowledge. Such power,

however, must be questioned when the discussed dichotomous narratives of care are occurring in practice. The DPP (2001) highlighted the need for individuals to "be protected from the state and public authorities" (p. 3), and this dichotomous narrative for the dying is such a case. Although the use of PST and the LCP within the UK is evident from the proliferation of literature discussing the benefits and drawbacks of these practices; the complaints made against practitioners and NHS Trusts were reviewed in the *Neuberger Report* (2013) and, as such, the LCP has since been disestablished and is to be replaced by the new *Priorities of Care* (Stephenson, 2014, para. 2). The new framework is to provide individualised care plans for the dying, although remaining within the biomedical paradigm of care, using the motto "one chance to get it right" (Stephenson, 2014, para. 8).

Conclusion

Protecting the dying is a problematic challenge, in that dying is so obscured through fear and anxiety within contemporary Western societies, that to bring it to the forefront of open discourse is difficult (Gawande, 2014). To be informed of the physical demise of the body, together with what modern medicine can offer to alleviate suffering would be a step in the direction of producing a more equal life event and, as such, presents an opportunity to consider re-conceptualising the *Ars Moriendi* as a means to negotiate the contemporary fear of death. The fear of dying, however, presently paralyses the living into two opposing corners; those who fear dying and acquiesce to the biomedical paradigm of palliative care and those who fear living with intolerable symptoms and challenge the powerful institutions of care and law to assist them in achieving death. Such opposing viewpoints have provided a platform through which palliative medicine has constructed a paradigm of care to support the dying, albeit contextualising this natural event as a medical condition requiring attention. Furthermore, through the construct of medical models of care specifically for the dying, it appears that on occasions the trust placed implicitly in medical practitioners and their knowledge by patients may have been misplaced; resulting in the juxtaposed narrative of some patients dying when they wished to live, some patients having their lives ended through collaboration with law, but simultaneously denying death for those wishing to die.

The routinisation of dying through the application of specialist models of care provides a backdrop to the difficulties faced by patients irrespective of their personal standpoint, for autonomy and choice are difficult to achieve in reality. Medicine through its application of specialist knowledge manipulates the dying to acquiesce with their ideas of the right way to die, but, when medicine is challenged in its practice, or the dying have views and requests that sit outside the currently prescribed medical pathway to death, a selective collaboration with law occurs. The pathway to autonomy and personal choice, irrespective of the legal statutes, human rights frameworks, sanctity of life and the *Hippocratic Oath* is littered with barriers and obstacles, some of which can be overcome, with others proving constraining in achieving a right to self-determination. Thus, the right-to-life and right-to-die debate is constrained, but not enabled, through the application of institutional power and, as such, erodes the reality of choice at present when dying. Thus, the idea that patient choice equates with being an illusion in regard to clinical decision making appears relevant to individuals, as the marketing of and lived reality of choice exposes duplicity in practice through the timely collaboration between medicine and law in regard to end-of-life care; thus positioning those seeking the right to self-determination as other. Ultimately this suggests that true individual choice is elusive and an illusion in practice.

Chapter Six

"Deviance is in the eye of the beholder"

(Anon)

Dying as deviant behaviour

Introduction

Dying remains firmly contextualised within the medicalisation of life discourse, with conformity to palliative medicine expected socially and culturally. These structures constrain the individual whose expectations in death fall outside of the medical framework of care and are subjugated through the application of the *medical gaze* to the dying body, thus, delimiting their personal choices. The result of positioning the self in opposition to palliative care, therefore, violates the perceived norms of British and New Zealand societies, thus transforming the individual from being identified as self-determined towards acquiring a label of deviance. In this chapter I therefore consider the consequences incurred with the act of labelling some individuals as deviant when they pursue the right to choice and death, highlighting the experiences of those who have attempted to traverse this pathway. I discuss the potential for such perceived deviance to become acceptable when framed in a medical context through the notion of being burdensome. Furthermore, I also consider the notion of the deviant palliative patient through the lenses of authoritative power and how such deviance disrupts current social practices.

Deviance: choosing death over life

Within Westernised societies, both life and death have only meanings that we attribute and ascribe to them. Such ascribed meanings may be external, for example 'God's will', or internalised through arbitrary selection of a frame of reference (Vaknin, 2007) and as such only have value or meaning to the individual involved. It is the value that one places on life and death that may, through self-determinism, lead an individual to move away from the socially constructed and controlled norms of dying, choosing an alternative pathway which, in this instance, is the right-to-die.

Such self-determinism violates society's social control structures according to Durkheim (1897), for *anomie* weakens or eradicates such free will, resulting in the malfunctioning of social structures whereby an individual is not adequately restrained by social control mechanisms and the individual is subsequently labelled as being deviant. *Anomie* can be viewed as "the breakdown of the individual's sense of attachment to society" (MacIver, 1950), or in the contemporary setting as one suffering from psychic isolation (Lasswell, 1952); and when related to those pursuing the right today can be considered as a breakdown of, or disparity between personal and group standards and the wider community settings.

It could be considered, therefore, that due to the considerable economic and social advances made in recent decades, the notion of moral deregulation has produced a discourse of self-centricity and the idea that one now has rights over the determination of the self. Moreover, *anomie* could be perceived as occurring in contemporary Western societies, and in relation to the contemporary death, as the values and norms through which individuals have been socialised are no longer valid or helpful in navigating the evolving social world. As such, it could be considered that the right-to-die discourse has been produced as an anomic response to the current ways of dying which do not meet the needs of some individuals, produced through the rigidity of medical and legal practices and in turn produces the deviant individual.

Deviance is considered the violation of social norms to the extent that the majority of society disapproves of such actions (Gerber, 2010). It is not a behaviour, it is a label ascribed by those in power, to maintain their power. Deviance is an ideology, according to Sumner (1994) whereby control is achieved through imperial knowledge and the deviant individual rejects the social norms in favour of their personal choices. Deviance can be criminal or non-criminal. Those individuals, therefore, who choose to deviate from the socially constructed and accepted medical death, do so because they do not see their actions as being deviant, for deviance can means different things to different people (Becker, 1963), but is relevant to their life choices. Society labels such individuals as deviant and, as such, may be a measure by which society interprets their non-conformist life style into an understandable format. The consideration of ending life, either through suicide generally, or other means for those incapacitated by illness, is considered to not only be an unnatural action, but that the

individual concerned should have a social conscience and consider the adverse effects their death may have on the community at large (Vaknin, 2007). This suggests that there is a moral obligation to not choose death over life, and that to seek control of the demise of the self is constrained by the expectation of compliance with societal norms, thus, locating such choice as being morally deviant and 'other' (Clinard & Meier, 2013; Bryant, 2011).

With reference to compliance with societal norms and the alternative of actively choosing death, an interesting case arose in April 2016 of an emeritus professor in the UK who sought physician assisted suicide to end her suffering. Avril Henry, an 81 year old woman, approached Exit International to obtain the medication necessary to end her life at a time of her choosing as "she described her life as becoming a complete misery.[70] She could not lift anything and was living an impossible existence. It got to the point she did not have a life she wanted to live" (Nitschke in Morris, 2016, para. 7). Still of sound mind, she had written a suicide note which Phillip Nitschke, founder of Exit International, accepted as being genuine, however, her original suicide date of September 16, 2015 was postponed following a tip off to Interpol that she had acquired medication and was about to commit suicide.[71] This tip off resulted in her home in Devon, UK being raided by police officers, but no drugs were found (Morris, 2016).

Having attended Henry's property, the police issued a statement declaring that "no criminal issues were highlighted during this incident" (Morris, 2016, para. 24), but concluded by leaving matters in the "hands of medical and mental health professionals" (para. 24). This proves an interesting turn of events, that although suicide is not illegal in the UK, and that Henry was obviously capable independent suicide, she was subjected to criminal, medical and legal investigation. Although the criminal investigation was limited, the automatic referral for medical and mental health support infers that her decision was irrational, despite it being an organised and rational decision (Mendick, 2016). Nitschke highlighted in a statement following

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[70] Exit International was founded in 1997 by Philip Nitschke with the view that dying does not always need to be a medical process and, therefore, supports non-medical interventions to ensure an individual dies in the manner of their choice at a time determined by them (Exit International, nd, para. 2 & 3).
[71] Interpol is the world's largest international police organisation, with 190 member countries.

Henry's delayed suicide in April 2016 that "police need to realise in the UK suicide is not a crime, and mental health authorities need to recognise that not everyone who seeks to end their life is in need of psychiatric intervention" (Morris, 2016, para. 15); yet this is exactly the reaction that occurred upholding the stigmatisation and deviant positionality of those opting for death. However, deviance was not necessarily a new label for Henry, as one neighbour stated that she "could be quite controversial" (Morris, 2016, para. 26).

The power and control of medicine and law, however, encourages individuals to act towards each other in patterns of behaviour that are deemed acceptable, thus enabling medicine the privilege to construct and reconstruct the acceptable boundaries of what dying should comprise; but simultaneously constraining those who refuse to conform to such prescriptive pathways when dying. However, the meaning of deviance differs according to the subjectivity of the individual (Becker, 1963), and the laws of the particular society, the idea to choose death over life becomes necessitated through a desire to determine the outcome of the self at this life point. Yet, to consider the needs of the self over that of the needs of the general population invokes the notion that such individualistic choices are self-centric in terms of narrowness of need, but also in terms of disobedience and otherness. Such a situation propels a compulsion for medicine and law to feel the need to collaborate to protect the general population from the inner thoughts of the self, in that the self appears to want to control the demise of the human body and, as such, control the naturality of dying. This, however, is usurped through the use of some medical practices which appear to support the notion that death can become dutiful or obligated when faced with burdensome individuals.

The deviant death becomes obligated

Pursuing the right-to-die is considered deviant when the intent is individualistic and generally opposed by medical practitioners; however, when death becomes obligated through being burdensome or financially expensive to the institution, the deviant label appears to disappear. An obligation to die, irrespective of the reasoning behind it, opposes the *Hippocratic Oath* and the motto to 'do no harm' by the medical profession, yet in some way the idea to die in order to pacify the needs

of the family, the institution or the state, appears to be able to supersede such ethical undertakings and simultaneously remain legal.

A closer reading of this situation suggests that the right-to-die discourse becomes subjected to the subjectivity of need in relation to the powers of medicine and law and, as such, can be manipulated to suit a given situation. It becomes a convenient tool through which the physical and/or financial burdens of care can be lessened by legitimate means, through implementing the LCP or PST; irrespective of the right-to-die being positioned as deviant when it is considered a lifestyle choice. Despite death being seen as obligatory for some of the burdensome, it is perceived in a conciliatory manner, resulting in such individuals being despatched through the covert application of medical models of care. Such activities, however, highlight that patient choice is lost in favour of the needs of those in power and, as such, suggests that there is

> "an illusion or a self-deception; …that under the present regime the medical profession does not get involved in determining the timing or circumstances of the death of its patients" (Lord Davies of Stamford in The Telegraph, 2013, para. 11).

Such an illusion is notable in the perception that individual choice is achievable when dying, but institutional power and practices suggest otherwise. The idea that the individual is denied the right to choice and, as such, to death at a time of their choosing produces a hypocrisy in that clinicians acquiesce to death when it suits the clinical situation; that is the financial burden of care, bed blocking or even a financial reward for instigating specific models of care. Lord Davies continues his narrative with

> "one doctor put it to me as, 'helping the patient on his way', generally by administering a lethal dose of opiate or perhaps barbiturate" but "this is not talked about because of course it is against the law, so there is a great deal of hypocrisy here, but we should not have any illusion about the truth", that "more frequently in recent years, the patient has been referred to a hospice and there a clinical decision is taken steadily to withdraw the necessary

means of life support: resuscitation, ventilation, antibiotics and dialysis…"
(The Telegraph, 2013, para. 12-14).

If this is what is disclosed to members of the *House of Lords* in the UK, but not directly to the general public, it is concerning that the narrative appears to be so opaque; however, the duplicity is not lost on lay individuals in there being

"some hypocrisy here. Not long ago you had the Liverpool Care Pathway [sic], supported and carried out by doctors – morphine sedation so that patients could no longer eat and drink so they died. Often without anyone's consent and with doctors arguing that only they were entitled to make the decision, like because the patient was OLD [sic]. Yet. To ask for help to die? Forget that." (Sheila, in Borland, 2014, p. Comments).

Such statements demonstrate a greater need for transparency from the institutions of power rather than unobtainable double standards when the individual pursues the choice that they believe they have. The notion, therefore, that the individual has a right to choice becomes invalid, with catastrophic results for these patients, in that they become constrained, and contained, by the collaboration between medicine, law and government. Furthermore, through deviance not being accepted in the schema of social order, the illusion of individualistic power pertains to otherness in the context of social norms and the authoritative elite; thus, illuminating the consequences for those choosing the non-conformist pathway to death.

The 'slippery slope' to obligation
The notion of death becoming obligated is present in the context of journalistic and online social media representations of the assisted suicide and euthanasia debate. Opinions often sit in complete opposition to each other, with some supporting the act of individualism and the right to personal choice and others narrating the dire consequences that are set to implode should assisted suicide become legal in either the UK or New Zealand.

The consequences of perceived obligation is colloquially known as 'the slippery slope' effect, in that once the status of assisted suicide is legalised the flood gates

will open (O'Hanlon, 2013), with everyone who is terminally ill, or tired of living, seeking early redemption from the potential suffering that may occur. More troubling, however, is that individuals may feel forced to die as they are increasingly seen as a burden to the family and the state, and that decision making may not be taken by themselves, but will be made for them in a similar manner to the implementation of the LCP. The voices of those not in favour of having the right-to-die in New Zealand for example, pervade online social media, implying that assisted suicide "would have far-reaching impacts on New Zealand society" (NZ Herald, 2015, para. 1) and, as such "sets a dangerous precedent which will harm society's more vulnerable people" (3News, 2015, para. 6). Moreover, "if [Lecretia] Seale's claim were accepted, it would have implications well beyond her case and would apply to all who have a terminal illness and think their suffering is intolerable" (Heron, in The Dominion Post, 2015a, para. 7); therefore "attempts to fine-tune this approach by creating exceptions have been unsatisfactory and have tended to support the theory of the 'slippery slope'" (Sopinka, 2001, p. 4). These narratives are clear in suggesting that to legalise assisted suicide and euthanasia would be problematic, with an element of truth notable in such claims. This is evidenced when constraints and controls do exist to safeguard the vulnerable, such mechanisms are indeed corrupt, with the 'slippery slope' having the potential to become reality (Ellis, 2005).

These ideas suggest that despite the appearance of transparent guidelines to allow the assistance of suicide, those with power to manipulate such frameworks may not be sufficiently trustworthy to not interfere and amend these guidelines in the future.[72] More troubling, however, is the discretion available when exercising such legislation in practice, as there are examples of children being euthanased in the Netherlands and Belgium with parental consent; and the case in Belgium of Frank van den Bleeken who is a convicted murder and rapist who, doctors have agreed has an incurable psychiatric condition and has been granted permission to assisted suicide (The Guardian, 2014a).[73]

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[72] This refers to a narrative in the *Assisted Dying for the Terminally Ill Bill*, House of Lords, UK, 2005.
[73] The granting of the right-to-die has, however, now been withdrawn as the prison doctors refused to carry out this authority.

The online expressions of mistrust demonstrate distrust in the power of medicine, with people assuming they will be forced to die to suit doctors. They also suggest that the potential for abuse or for further manipulation through the ethical boundaries of medical practice may prove problematic. However, the denial of a 'slippery slope' was upheld more recently in the outline of *Lord Falconers Assisted Dying Bill,* 2015 in the UK, as "in three jurisdictions where it was permissible to assist suicide, there was no evidence of vulnerable groups being subject to any pressure or coercion to seek an assisted death" (The Supreme Court, 2014, p. 18). This viewpoint was "supported by the reports of the two Canadian panels, [that] states that in the Netherlands, Oregon and Switzerland there is no evidence of abuse of the law, which permits assisting a suicide in prescribed circumstances and subject to conditions" (p. 28), and that there is "no evidence of a slippery slope towards putting pressure on people to kill themselves" (Blair in Mason, 2014, para. 2). This is but a small sample from which to analyse the effects of implementing the right to assisted suicide and cannot be taken purely at face value, but if this is the case and there is no 'slippery slope' to be afraid of, why then are many of the other authors in this judgment concerned with maintaining a 'blanket ban' to protect the vulnerable? Is this because previous legislation regarding abortion, for example, has proved that although in legal terms abortion in New Zealand is not available on demand, but in practice is? If so, then the notion of a blanket ban on assisted suicide may be one that can be understood from the perspective of protecting the greater good.

Slippage, however, can and does occur within the context of assisted suicide and has been identifiable in the Netherlands and Oregon for example, and also in Belgium where infant euthanasia is now legal (BBC, 2014b); indicating that what is clarified in law and what actually occurs do not always equate. This suggests that although in some instances it can be demonstrated that allowing assisted suicide or voluntary euthanasia is a well-established practice, it has the potential to become a flexible practice that can be manipulated to suit given situations. It suggests that the weak and terminally ill, the vulnerable, the disabled and the elderly are in need of protection from being consigned to the grave at a point earlier than anticipated (Rady & Verheijde, 2014; Neuberger et al, 2013). Moreover, through coveting a blanket ban on the right-to-die for those suffering it "…can be rationally justified by

the need to protect the weak and vulnerable and was recently affirmed by Parliament in the 2009 Act" (The Supreme Court, 2014, p. 27), with "the only valid argument for resisting change is to protect society. The fear exists that the elderly and disabled could become obliged to seek death rather than be a burden on others" (Western Daily Press, 2012, para. 4).[74]

The concern is, therefore, that the route to choice may be contaminated through the misuse of the legal directives regarding assisted suicide; with this being highlighted in the case of Marie Fleming. Fleming, a 59 year old former lecturer and multiple sclerosis sufferer also failed in her bid for assisted suicide. The court in referring to her application to die ruled that "the aged, the disabled, the poor, the unwanted, the rejected, the lonely, the impulsive, the financially compromised, and emotionally vulnerable" (O'Hanlon, 2013, para. 11) will also become potential targets of the 'slippery slope' effect of the right-to-die, thus not granting this choice to Fleming. Moreover, a New Zealand correspondent suggested this situation would "…lead logically to generalised killing" (Waikato Times, 2013, para. 6).

Although these statements are not reflective of Fleming's personal condition, they do look to secure an emotional response to the situations depicted and are a more extreme manifestation of the argument. However, these statements remain subjective to the rationale of medical practitioner's definition of what is and what is not intolerable suffering in relation to burden of care commitments, either financially or in relation to ongoing physical need in the case of Fleming. That said, there is an assumption that autonomous choice will be rational, independent and not deviant and, as such, not considered under the opinions of others; but choices can be coaxed through manipulation, as indicated in this doctor/patient scenario narrated by a registered nurse in the comments section of the *Nursing Times* professional journal:

> "Heroic measures – NO, not if there is no chance I will ever recover.
> CPR – YES.
> Most people decide against having CPR. Are you sure you want it?" YES.

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[74] This refers to Nicklinson vs Ministry of Justice, 2014, UK.

"But it will likely be very painful. They usually break a lot of your ribs if they do CPR, are you positive want it? [sic]" YES.

"It probably won't work – are you sure that's what you want? Most people never really recover, and it hurts a lot. Many who do have CPR regret it later because of the pain of the broken ribs – are you positive?" YES.

"What if they come in and you are cold and unresponsive, are you sure you want them to do CPR even then?" YES.

'Even if you are unresponsive?' YES.

Finally, she gives up… "well, we can always come back to this decision later…" (Anon in Wollaston, 2014, p. Comments).

This is printed "more or less verbatim" (Anon in Wollaston, 2104, p. Comments) of a conversation between a home nurse and a patient who considered themselves to be in excellent physical health. It cannot be assumed to be completely accurate but does paint a compelling image of individuals being coaxed into compliance with medical protocols when elderly or potentially dying. It alludes to the potential of there being a 'slippery slope' in relation to society's most vulnerable individuals and the naivety in choice being a reality. It creates an image of the powerful and knowledgeable clinician overriding or coaxing the choices of the individual, to fit with the medical framework of acceptable practices. It is, therefore, concerning that the vulnerable and, in particular the elderly, frail, and terminally ill are considered to be a "demographic time-bomb" and, as such, "older people do feel they are becoming a burden – to the state, to society, to their families." (Mumford, 2013, para. 11). In one Australian social media interaction, it is suggested that some "57 per cent of patients listed concern about 'being a burden on family, friends and caregivers'" (Harradine, 2013, p. 22); a view upheld in a research paper in *Medical Online Journal*, which suggests that

"the issue of 'being a burden' [being] one of several themes that arose from our interviews with participants" as "many spoke of their fear of becoming a burden on themselves" in that "they feared becoming someone they did not want to become – someone they no longer recognised" (Malpas, 2012, para. 5).

The idea of not being one's self is a prominent discourse in the changing façade of end-of-life functionality and is an important issue, but being burdensome is not only about the identity of the self, but the reliance upon others to maintain functionality and, as such, becomes problematic in relation to the contemporary self-centric culture. Vulnerable individuals may not say they feel burdensome but may, through fear and anxiety, feel the need to comply with medical directives indicating that treatment will be withheld, or more recently that care will continue, but through the application of end-of-life care pathways (Richmond, 2013). The notion of being a burden is conceptualised through a multi-faceted narrative incorporating "emotional, physical, social, and financial aspects" of care (Johnson, Sulmasy & Nolan, 2007, p. 264). It plays a key role in the emotions of the dying and their concerns for those caring for them; but it is not only located in the physical care but also within the context of seeing how death occurs, therefore, those feeling burdensome may be more likely to acquiesce with directives encouraging withdrawing from treatment plans and being placed on sedation.

The notion of burden provides a key element in the assessment of individuals in that their life value is judged by clinicians in relation to their personal subjectivity, thus, creating an imbalanced perception of the individual in question. This issue is raised in the interactive communication and comments section of the *Telegraph* blog, asking "how can you or I judge another human being's suffering? This will naturally be the excuse used to put the inconvenient old dear out of his or her misery" (Vitaly Klitschko in Odone, 2014, p. Comments). This idea of dispatching the burdensome is also highlighted in the *Palliative Medicine Journal*, where the authors express concerns that

> "where Big Brother comes along and says, 'well, okay…very few people over the age of X, let's call it 90, really make a valuable contribution to society; they take up space and they're a demand and even a drain on the health system; we keep on patching them up but they're going to die in a few years' time anyway and that's a waste of money, so let's knock 'em'. Where's the dividing line?" (Participant 2 in Malpas, Wilson, Rae & Johnson, 2014, p. 356).

When such concerns are highlighted within medical journals it must raise questions about what is occurring in practice because, as previously mentioned, slippage does occur, thus, presenting a blurring image of what really is happening within our clinical institutions. Moreover, what being burdensome is for one individual will be different to others in a similar manner to the subjectivity of intolerable suffering. The ability of the clinician, therefore, to accurately gauge what suffering means to the individual can also be influenced by extenuating factors, such as pressures on inpatient beds or financial burdens of ongoing care (Pauly, McGuire & Barros, 2012). This is reflected in the following journalists extract in relation to the vulnerability of those aged over 70 years, as "our hospitals [using] a scheme designed to help the terminally ill die without pain (the Liverpool Care Pathway [sic]) has been used to bump off old people deemed to be bed-blocking" (Malone, 2014, para. 4).

This statement may be sensationalist but has far reaching consequences, in that any trust that the elderly or vulnerable or dying have had in medical practitioners always considering the best interests of the individual are being slowly eroded through such journalist representations, together with other related online social media communications. This issue, is not directly documented in the *Neuberger Report,* but the report does highlight the problematic nature of caring for the elderly in acute environments, with it raising suspicions that "age discrimination is occurring, which is unlawful" (Neuberger et al, 2013, p. 9) and that financial incentives in relation to implementing the LCP should not be associated so directly with end-of-life care (p. 8). Malone's statement does, however, allude to clinicians using such techniques as PST, under the guidance of clinical pathways of care, often in a non-consensual manner (Neuberger et al, 2013) for specific gains; yet, when individuals want PST it is denied to them as there is no right to sedation or death.

This positioning suggests the existence of a steeply asymmetrical positioning of medical power over that of the individual, and does so with the knowledge of having legal backing when such decisions are made. It is, therefore, the fear of the 'slippery slope' and the eradication of those that are neither terminally ill nor wishing to die that drives a significant component of the debate between right-to-life and right-to-die; with considerable support for the theory that "the so-called

right-to-die all to [sic] easily becomes a duty to die" (Harned, 2012, p. 520). This situation is already evident in Oregon, USA, where in 2008

> "at least two different terminally-ill patients were denied medical treatment under the health insurance plan, and instead were told that the state would pay for the patients' suicide. The message was clear: "we won't treat you, but we will help you die" (Harned, 2012, p. 520).

This formalised duty to die because of the financial burden of alternative care appears sinister in the simplicity of the statements, in that individuals will not receive care to live but insurance companies will fund death. The clear undercurrent of such decision making indicates that a 'slippery slope' effect is already occurring and not in the recesses of practice, but at the fore of administrative management. This situation is reminiscent of the issues already discussed regarding the financial incentives in the UK to implement the LCP and, as such, demonstrates the level of bureaucracy, effective management structures and institutional drivers that converge in relation to clinical practice, health policy, financial restraints and legislation. However, the situation in Oregon has taken a step outside of the framework of the working clinic and is directing such motives from a perspective of purely financial implications, thus equating life value to that of the dollar. If medical insurance will not pay for the burden of care in the USA, what is there to suggest that the same will not occur in both the UK and New Zealand in the future? This has the potential for public healthcare systems to refuse further treatment for some individuals and in turn promote palliation, thus, favouring a quick exit for those deemed no longer of use to society (as reflected in the UK with the LCP).

The narrative of burden is produced, however, through the collaboration of both medical and legal power in order to achieve a utilitarian standard across countries, even if this erodes individual care decisions down to purely financial constraints and incentives. Furthermore, it must also be considered how death, when perceived as being burdensome, is more acceptable than those for whom death is an individual choice. The duty to die as being obligation is highlighted through charitable research findings in relation to clinical funding, in that

"the inadequate funding for palliative care and pain management…" thus contributing "to the despair felt by many who reach old-age, endure frustrating physical limitation, or are afflicted with debilitating conditions" (The Life Resources Charitable Trust, 2011, para. 5).

The financial implications of care are also highlighted in the *Palliative Medicine Journal*, as

"some [individuals] have expressed their concern primarily in relation to financial aspects at end of life … and it was terrible because they were waiting for her to die, and I just thought, there you go, they would have her euthanasia assisted if they could have" (Participant 6 in Malpas et al, 2014, p. 357), and that

"I fear in time, if it becomes allowed, if it becomes legal and financial matters, financial concerns will come into it" (Participant 8 in Malpas et al, 2014, p. 357), and that

"in some parts of America I believe that doctors report they are given financial inducement not to give palliative care because it is an economic burden on society to keep people alive when they're terminal. It is a lot cheaper to turn off the power as it were and stop the whole thing" (Participant 9b in Malpas et al, 2014, p. 357).

These statements demonstrate a medical perspective, and paint a concerning image of the future prospects of end-of-life care, in that life value equates to dollar value. Although the financial burden of caring for the elderly, frail and dying is vast in both the UK and New Zealand, it becomes clear to see how these groups could easily be exposed to the expectation to die to reduce the burden of care. It is advocated that the choice over the self should be made individually, but the reality reflected through social commentary suggests that "it will be your choice at first, then it will be the hierarchy and other peoples [sic] choice, especially if you are vulnerable" (Sealighter in Odone, 2014, p. Comments).

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The notion of choice, therefore, recedes in the face of the combined power of medicine, law and the governmental policies relating to health budgets in particular, as the economic imperatives of institutional settings, such as the acute hospital, appear somewhat stronger than the more independent fields of medicine and law. This situation could, therefore, pressurise the individual to comply with the acceptability that life no longer holds purpose or value beyond that of the self and potentially condemns the individual to death irrespective of individual preference; with this death not being perceived as deviant. The idea that one can choose to live or die becomes obsolete in the face of the power relations at play between medicine, law and governments, in that social commentary suggests that clinicians can easily "end dying patients' lives to spare them suffering" (The Telegraph, 2013, para. 2), but choose to do so to safeguard the general population (Pike, 2011). It presents an image of how the 'slippery slope' effect may occur in relation to death being a convenient outcome of care within the constraints of medical practice in the public healthcare system as "assisted suicide becomes a utilitarian scheme" (Odone, 2014, para. 10) that is acceptable but choosing to die remains other.

Authoritative power

Authoritative power refers to official or authoritative institutions, such as medicine or law that exercise power through rules and regulations, subsequently expecting compliance by the majority and dominate Western societies. Authoritative power is perceived as a legitimate power, not coercive, and is effective through being consensual (Weber, 2009). It can take many guises including being charismatic, in that personal qualities influence outcomes; it can be traditional or hereditary or be presented as institutions that possess power over those subordinate to them (Weber, 2009), and can be reflected in the doctor/patient relationship. As such, this power is familiar when considered in relation to the legal cases already identified in this research and continues to dominate the landscape of the self-determined individual.

Despite the weakness of individual power and the authority of the institution, online social media commentary continues to pursue individual rights at end-of-life, with many narratives focusing on how their lives may end. To demonstrate this, one media representation refers to a 30 year old New Zealand woman with a palliative diagnosis of stomach cancer who feels she has the "right to choose" as "I don't

want my family and friends to see my suffering" (Stuff, 2014, para. 1). Another contributor to an interactive media report expressed concern that "it's our choice not theirs if we don't want to suffer any more and do not want to be guinea pig [sic] for the big pharmaceutical companies" (Kev, Worthing in Borland, 2014, p. Comments). Such comments displace the notion of achievable individual choice, in favour of the authority of medicine and law. Maybe more significant, however, is the contribution of a Melbourne based surgeon who "believes choosing when and how you die is a basic human right" (Chapman, 2013, para. 2). His beliefs have developed throughout his surgical career but were ignited when a young woman in his care "was left in indescribable pain after the disease spread to her spine" (Chapman, para. 4). This provides a significant dichotomy in the medical authority over the subordinate patient, as this individual is in fact a clinician who has experienced the problematic discourse of prolonging both living and dying; however, he currently remains a minority representative within the medical establishment.

In light of this, however, there are those who uphold the Melbourne surgeon's viewpoint, and who feel able to question the authoritative powers of medicine and law. This is ratified again by the 30 year old New Zealand woman with palliative stomach cancer, who asks "why can't I be allowed to have the choice to end my life on my terms, as long as it's made while I'm of sound mind?" She also highlights that "I've spoken to the appropriate doctors and physciatrists [sic]. Why can't I be given that choice?" (Stuff, 2014, para. 10). This appears a reasonable question in light of capacity and suffering, but remains perceived as deviant in challenging the authorities currently in situ; with the challenge again unsuccessful. This challenging of power, however, is further narrated by a 71 year old man who had recently cared for his wife who died from pancreatic cancer. He expressed concern regarding the inequalities at play in New Zealand, in that "all your life you've worked and paid your taxes and you've got no bloody [sic] rights when it comes to the finish. It's just not fair" (Reed, 2013, para. 7).

Despite the sentiments expressed in these remarks, the fact remains that such opinions are at odds with the reality of constraining powers in both the UK and New Zealand. The idea that one has contributed financially to the wealth of country,

or the funding of public healthcare systems that are present in the UK and New Zealand, does not allow you to buy the right to make choices in the healthcare provided at end-of-life. Moreover, the narrative of perceived deviance pervades these opinions, locating them as being outside the accepted societal norms of authority and regime. There are rumblings of changes afoot in the UK, however, following the *Neuberger Report* (2013), with Neuberger publically challenging the government to take action regarding the rights of the self at end-of-life. This challenge poses the possibility of change ahead for those seeking the right-to-die, with there being some "recognition of an individual's right to determine his or her best interests" (Bingham, 2014, para. 17). This statement is very ambiguous in its sentiments, but may prove to be a starting point for further negotiation of individual rights and, as such, removing the notion of deviance from such individuals. It does, however, also indicate that neither choice nor individual autonomy is actually guaranteed as "…autonomy is important [but] it has to be balanced against other principles including public safety" (para. 19).

Despite the right-to-die discourse being perceived as deviant, it continues to engage a strong following within the individualistic, almost narcissistic Western societies in which we currently live. However, through the value now placed upon the worth of the individual by the individual within a context of self-centric existence, many now perceive that the right over the self to be automatic and more so now than in previous eras, despite narratives to the contrary. This is highlighted in relation to the legal case of Paul Lamb, a 58 year old paralysed builder in the UK who suggests that "if people have the freedom to choose how they live, they should also have the freedom to choose how to die…one's body and one's life is one's own property…" (Carey, 2013, para. 2). Yet, through clinicians applying the interiorising gaze to their practices and values the autonomy of the contemporary self remains contextualised within the constraints of authoritative power.

It must be noted, however, that medicine does not hold a monopoly on the practice of the gaze, in that the individual dying patient may also have the ability to interiorize the *medical gaze* onto the self (Crinson, 2007) and, as such, is also "…his own overseer, [with] each individual thus exercising this surveillance over, and against, himself" (Foucault, 1973, p. 155); thus, the individual becomes the

self-centric individual of agency. In understanding, however, that "none of us believes autonomy is absolute, if we did we would have to say that there was no place for law because every single law restricts personal autonomy" (Saunders in Bingham, 2014, para. 20), the views of Neuberger together with the self-centric observation of the interiorising gaze, may prove pivotal as being the first step in re-negotiating the *Ars Moriendi* as a contemporary means to navigate death in the twenty-first century. There is, therefore, a naivety in this assumption that true freedom exists in the first instance and not within the constraints and contexts of authority.

Authoritative power and the ACP

The power of authority remains dominant even in the arena of self-declaration of preferences, and can be witnessed in the promotion of advanced care planning. Despite this document being marketed as a means of securing personal choice when reaching end-of-life, not only is it contextualised within the biomedical framework of care, it still requires the authority of a medical practitioner as a witness to validate it (Borasio & Voltz, 2014). Although such plans are not legally binding (as previously discussed), they appear to have had a positive impact in some arenas, thus, opening a contemporary discourse about death and dying. This has produced a seismic shift in the engagement of patients with this life event, providing reassurance and comfort for many involved (Hospice New Zealand, 2015). This is reflected in Jean Whitteker's narrative. Whitteker is a 91 year old woman who thinks that "euthanasia is a blessing in disguise" (Fairfax Media, 2014, para. 1) and states that through using an ACP she has drawn up

> "…a plan [that] has given her confirmation that she will "die with dignity – my way"…knowing doctors will be legally bound to respect her wishes and not use unwanted treatments to prolong her life has come as a huge comfort" (para. 3&4).

The belief, however, that this procures her wishes is both naïve and misleading as an ACP is not legally binding and, "although such documents [ACP] are in use in Britain, their legal validity is often questioned…" (Patel in Collins, 2013, para. 4). The idea that security is gained from completing such a document sits in opposition

to the authority retained by medicine who are able to override such requests should they be perceived as not being in the individual's best interests, thus increasing the potential for disillusionment that the self cannot be truly autonomous at the point of death.

More specifically, and in relation to the use of the LCP in the UK, it has been highlighted that some individuals are utilising ACPs as a means to specifically express that they "do not want to be placed on a controversial death pathway" (Bingham, 2012a, para. 2). This is an interesting turn of events, in that individuals are not merely expressing their wish to die at home, for example, but are utilising a medically constructed means to disengage with clinical practices. It also suggests that individuals are less trusting of clinicians when frail, elderly or terminally ill, in that they want to be able to decline such medical models of care in advance for fear of losing control over the self.

In responding to this situation, and in support of these fears, an anti-euthanasia group in the UK, *Alert,* has taken a step further and produced wallet sized cards alerting clinicians to patient preferences of care in simplistic terms, as it reads "please do not give me the Liverpool Care Pathway [sic] treatment without my informed consent or that of a relative" (Bingham, 2012a, para. 10). This is a very specific directive, but the fact that it is carried in a similar manner to that of an organ donation card does not equate its relevance or value with the same status.[75] The *Alert* card is a reflection of personal choice and an engagement with the possibility of autonomy, but is potentially worthless in the face of medical power and, as such, is referenced to be used in conjunction with an ACP (Bates, 2012); although there is little evidence of it being actively used in practice. However, such narratives opposing specific medical interventions at end-of-life reflect the increasing engagement of the self with decision making but simultaneously will remain framed as deviant and other.

Access to death, therefore, is only attainable through the authority of medicine and/or law. As such, the use of ACPs in relation to medical power renders them all

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[75] It must be noted that an organ donation card in both the UK and New Zealand refers to the intent of the carrier, with permission still needed from family members by medical authorities (Robinson, 2012).

but irrelevant, but when they are noted, clinicians must prove that the patient is aware of the consequences of the request being made; that is they will die. This is reflected in the process for accessing assisted suicide, where it is a legal option. Through attempting to access the right-to-die, completing the legislation necessary for actualising self-determination is both lengthy and complex. Such pathways reflect the complexity of authoritative power and, therefore, may be one reason why the numbers of individuals accessing assisted suicide is actually quite limited. Such convoluted and intricate routes to self-determination can be seen in the recently defeated *Lord Falconers Assisted Dying Bill* (2015), in the UK, which outlined the medicalised route to assisted suicide. This comprised of a declaration of intent to die being

> "countersigned in according with subsection (3) by- (i) the registered medical practitioner from whom the person has requested assistance to end their life ("the attending doctor") and (ii) another registered medical practitioner ("the independent doctor") who is not a relative, partner or colleague in the same practice of clinical team, of the attending doctor" (Assisted Dying Bill, 2014, p. 3).

This is only a small section of the rules designed to safeguard potential problems with assisted suicide in the UK, but consideration must be given to the fact that if the individual were sufficiently able bodied they would not need to consult with, or gain permission from any medical team member to commit suicide and, therefore, not be subjected to medical authority with regard to self-determination. Moreover, this is a lengthy process if the individual is experiencing intolerable suffering and, as such, it must be questioned whether such a process is in fact a deterrent in its own right? The right to commit suicide is legal in both the UK and New Zealand with 7.4 per cent of UK suicides involving terminally ill patients (The Telegraph, 2014); with no such data available in New Zealand at the present time (Ratine, 2016). But according to one UK lawyer, the UK *Suicide Act* (1961) is "discriminatory because its effect was to prevent the disabled, but not the able-bodied, from committing suicide" (Pedain, 2002, p. 513) and, as such, reflects the dichotomous picture already exposed in this research.

Such discriminatory mandates would be less tolerated if it were not related to the taboo subjects of death and dying, let alone taking one's own life; so this double standard remains upheld, together with the perceived sanctity and value of life irrespective of subjective suffering. This, however, is not an individual injustice, but is reflected through the authoritative power of judicial numbers involved in cases, in that it was "three senior Judges [who] rejected "right-to-die" appeals by the family of Tony Nicklinson…and Paul Lamb" (Gibb, 2013, para. 4) albeit with the expert knowledge imparted by clinicians, thus, indicating the supremacy of such decision making that can prove almost impossible to permeate.

This has been described by Raymond Tallis, a previous chairman of the *Committee on Ethical Issues in Medicine at the Royal College of Physicians (UK)* as being a "clinical, ethical and legal fudge – in which ploys such as continuous sedation [PST], and starvation and dehydration, are used to get round the prohibition on assisted dying" (Tallis, 2009, para. 13), thus suggesting "that this boundary is also blurred when it comes to the administering of drugs" (Hay, 2014, para. 7). Furthermore, James Mumford who has recently worked for a Westminster Think Tank suggests that in this situation "…we run the risk of being naïve about 'choice'" (Mumford, 2013, para. 8), in that we can express our dying wishes through formal channels such as ACP's, but in reality thinking that an ACP will achieve our desires confers the existence of patient naivety in relation to the overriding powers of medicine and law (Khan, Mirza & Rauf, 2011; Willison, Keshavjee, Nair, Goldsmith & Holbrook, 2003).[76] Patients, however, may not be as naïve as perceived in this statement, as they currently feel able to express their concerns about futural hospital admissions and the potential power of others over their self.

Fear of institutions and hospitals

The risk of being perceived as deviant through not wishing to align individual wishes with medical expectations has produced a perceptible fear in some vulnerable patients when having to enter hospital situations. This fear is particularly related to the use of the LCP and is palpable when reading through readers'

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[76] The Westminster Think Tank refers to a public policy research institute that influence decision making both nationally and internationally (University of Oxford, 2016).

comments and experiences of end-of-life care in response to media articles. This is evident in one narrative with an individual expressing that "…old people and the disabled are too scared to go into hospital in case they get put on this care pathway…" (DoNotTouchMyNanna, 2012, Comments, para. 2), and that "…this [the LCP] has made patients terrified that the hospitals supposedly taking care of them may try instead to kill them – and that their relatives feel they must defend their loved one from the medical staff" (Phillips, 2012, para. 20).

Such narratives depicting a culture of fear regarding hospital admissions for the elderly follows the story of an 86 year old man in Scotland being admitted to hospital following a fall, but was then placed on the LCP for end-of-life care. The narrative does not define his condition completely, however, infers that he was not imminently dying. Those commenting on this story expressed fear of hospitalisation in that "I'm nearly 70 and I'm absolutely terrified of ever going back into hospital" (Sdewolfe in Daily Mail, 2012, comment 13) and "don't go into hospital if you are over 80 even for a trivial problem; your chances of coming out of hospital will be slim" (ny250w250th in Daily Mail, 2012, comment, p.2). This sense of fear of not surviving a hospital admission in old age is further highlighted in a daily blog comment that the

> "perfectly healthy over-75s, as well as patients with conditions that put them at risk of needing to go into hospital unexpectedly, are being targeted by NHS England. They're asked a number of fairly innocuous questions before the district nurse bowls a bouncer about resuscitation" (Glover, 2014, p. 15).

This documented fear is not a response to myths but founded in experience according to the *Neuberger Report* (2013), which suggests that the right-to-life does not stand up in the face of such allegations. The findings of this report have concluded that for some individuals their lives may have been ended prematurely, in that they were placed on medical pathways inappropriately according to their condition or prognosis and, for some, without consent (Neuberger et al, 2013; Watt in Barnes, 2013a, para. 11). Such narratives support the tangible fear that presides over the elderly, in the UK in particular; which serves to deter the unwell from seeking medical attention and through doing so, and the desire to avoid the LCP

places them in positions of otherness. Moreover, such situations reflect the ability of medical power in overseeing the frail body, perceived through the *medical gaze*, as being the dominant discourse in outcomes for these individuals.

There are some individuals, however, that have been successful in countering medical authority and, as such, refusing the LCP or similar models of care in relation to the withdrawal of medical support, with one example being Simon Fitzmaurice. Fitzmaurice is an award-winning writer and film director who developed motor neurone disease. He experienced

> "respiratory failure, caused by his Motor Neurone Diseases (MND), [which] resulted in his being ventilated in hospital. A doctor he had never met, came to his Cork hospital bedside and in front of his wife and mother, told him "It's time to make the hard choice' i.e. to die. He was told he could not go home on a ventilator essentially because medical policy in Ireland was not to ventilate patients with MND. Simon fought, won and went home to his wife and three children, with the aid of a ventilator" (Fitzpatrick, 2013, p. 577).

This particular encounter occurred in 2013, with Fitzmaurice clearly outliving his original prognosis of death within four years of diagnosis and continues to live well some eight years since the original prognostication (McCarthy, 2016). He attributes his continued ability to live, albeit with no independent physical functionality, to his addiction to work and his love of film making. Fitzmaurice states that "I never stopped working. It was a solace to me. I would be in these nightmare situations, really sick in hospital with doctors all around me and I would be thinking about shots and scenes" (Lavin, 2015, para. 7). For Fitzmaurice, his work provides liberation from his suffering, in that

> "the film has really surprised me. I didn't expect it to be life-changing" but "it gave me a freedom from MND which I never thought possible. It's hard to explain. I suppose just being focused utterly for 12 hours a day liberated me from MND which tries to define me, every second" (McCarthy, 2016, para. 7&8).

Film making provides Fitzmaurice with purpose that was not envisaged by those suggesting that he had to choose between a life in an institution or death. Clinicians were unable to foresee that this individual had capabilities beyond those of the physical self and, as such, prescribed a pathway to death. Fortunately for Fitzmaurice he had the articulation and confidence to question the authority and power of his overseers, but this may not be occurring in every encounter. This particular case provides, therefore, opportunities for learning for many factions, as Fitzmaurice demonstrates the confidence needed in making individual choices when faced with the immediacy of potential death due to the inflexible directive of institutional drivers. He also demonstrates that life value is subjective and may not coincide with that of the clinician, as for Fitzmaurice to be alive, albeit with physical incapacity, has allowed him to lead a productive and fulfilling life, producing an award winning film and fathering two more children; with his situation representing a shift from being labelled as a deviant individual for wishing to continue living on his terms, to a life now celebrated.

This almost compulsory withdrawal of treatment and being placed on the LCP is also evident in relation to the previously noted 86 year old man in Scotland, as Arthur Oszek was placed on the LCP without his or his daughters consent. In this instance, however, and "after 20 hours of discussions, doctors agreed to restore his food and drink" (Daily Mail, 2012, para. 6). This man did not have an ACP, however, the situation demonstrates that discussions are often not equitable but with a large degree of negotiation cases can be overturned in some instances, but require stamina and confidence when challenging such power regimes. Furthermore, these examples reflect the inequality in status between patient and clinician in that "the unwashed general population are far too ignorant or gullible to defend their own interests, unlike the professional elite" (Floreat-d in Odone, 2014, p. Comments) and so having the knowledge that choice should be equitable can be the difference between survival and not.

These cases highlight that the right-to-life is not a given right, even under human rights legislation or through documentation in an ACP, but is at the discretion of the powerful elite. It is the clinician's decision to guide the patient and family towards death, but in doing so appear to override the fundamental right-to-life on some

occasions. This then presents a juxtaposed position of being able to curtail life in some instances, but prolong dying in others and, as such, it

> "does seem odd that the State [sic] is willing to spend thousands of pounds and requires that a Judge [sic] is needed [to] allow the withdrawal of treatment from a patient in a PVS, but the same doctor can withhold any treatment from the same patient if they consider it to be 'futile'"(M, in English, 2012, p. Comments).

This comment highlights the paradox that is occurring in the saving of some lives and not of others and appears dependent upon the subjectivity of those involved in specific cases. It indicates that the right-to-life is not automatic, but an illusion and has to be fought for, and highlights the crux of the debate in that medicine has a varying ability and power to give and withhold treatment according to their ethical practices or personal opinions. There is, however, limited consistency in such practices. This is visible in a comment on one of Seales' blog pages, in that it is "these people who wish to deprive others their rights – by FORCE [sic] if necessary – to achieve their own personal views" (Clark in Lecretia's Choice, 2015, p. Comments). This reflects the notion that personal subjectivity and the positionality of those with power do attach their values and opinions to the wishes of others, even if this is not a conscious move but that of the subconscious, but in doing so they condemn others to suffer, often unnecessarily.

In opposition to such negative outcomes for some individuals, there are some clinicians who use their power and offer passive euthanasia which goes unnoticed and under the radar, yet there are others who refuse to sedate dying patients even when they have expressly asked for it, as these wishes are perceived as deviant (Lynoe, 2014). This diversity in practice represents the power held by the clinician over that of the individual, thus informing us that choice becomes problematic if our choices do not align with that of our caregiver and more specifically when clinicians question the absolute right of the patient to make individual choices (Boyd, 2002). The absolute nature of this power is precarious as clinicians have fallen back on legal statute when challenged by informed individuals in order to bring the issue to closure. This demonstrates how the individual cannot request

assisted suicide as it is illegal, but simultaneously cannot insist on treatment or on their express wishes for withdrawal of treatment to occur and, as such, leaves the patient in a vacuous space of inertia from which it is difficult to escape. This presents a negative prospect for the dying patient in that their rights and choices are but illusions captured in a moment of time, sometimes in writing, but become worthless in the face of the power of the medical institution.

Disruptive practices and medical power

Governments, as producers and products of society, govern through the political forms created within Western societies and, as such, can support or oppose societal factions in the constraining or containing of proposed changes. Governments, however, do not have the ability to simply change the power relations that have built up over time, with medicine and law becoming powerful agencies in their own right, thus inferring that change is only permissible through legislative amendments. Furthermore, although power can be found everywhere (Foucault, 2014) and is infused in discourse, the power that emanates from the construct of palliative medicine is so strong it evaporates the notion of individual choice; but simultaneously "freeze[s] the relations of power…so that a certain number of persons get an advantage, socially, economically, politically, institutionally" (Foucault, 2014, p. 5). This produces an inflexible paradigm of prescriptive care, however, such inflexibility may be malleable when considered through the lens of social disruption, in that rules become constituted through the exceptions to them (Vollmer, 2013). Thus the movement of the individual to seek autonomy over their body, as opposed to the dominance of the *medical gaze* when dying, suggests a disruption in the social order of social practices.

The dying individual who seeks self-determination is articulating their self-interest into the arena of medical knowledge and, as such, conspires against the natural order of compliance and social obedience. Such disobedience to the societal norms manifests in an alteration in the relationship between clinician and patient, thus disrupting the considered norms of social order in relation to death and dying. This ensures that those sitting on the periphery of society become a symbol of constraining violence, even if that violence is symbolic. Although the self-determined individual is complicit in their awareness of the symbolic violence

occurring as they disrupt the current order of social practices when dying, they do so by engaging with the changes occurring in the world.

The extinguishing of individual choice, however, should not occur through the power of medicine and law; neither should power "be defined as a constraining act of violence that represses individuals" (Foucault, 2014, p. 4) as power is not always equitable with hierarchical status as power does not always work from the top-down. In this instance, however, medical and legal power does uphold this stance if the cases of Pretty, Nicklinson and Seales are considered. These individuals were forced into compliance with medical and legal statutes to prevent them attaining what they sought and, therefore, endured their greatest fears (BBC, 2002; Laville, 2002). Symbolic power is, therefore, repressive in these instances and exists to maintain the equilibrium of social order within British and New Zealand societies. This suggests that the "voice of the elite is often the voice of the corporate or institutional master" (van Dijk, 1989, p. 23) and, as such, can never be truly equal with the patient, as "the relation of power is an inequality" (Foucault, 2014, p. 5).

The dying patient, therefore, when exerting the notion of personal choice and thus autonomy over the self becomes a problematic factor in the encounter between clinician and patient; in that when the individual attempts to disrupt the culturally accepted social order, even in a basic functionalist capacity, medicine requires the backing of the resolute power of current laws. This power leads to the individual becoming a victim of power relations, in that true choice and autonomy over the self is very difficult to actualise. Power is an ideological status that is formulated through the compliance and obedience of the general population with social norms and sanctions of a given society; however, if the individual is to succeed in attaining autonomy over the self, it would suggest that it is medicine that may need to adapt and integrate into the evolving and increasingly self-centric culture of the twenty-first century.

Considering, therefore, the nature of the self-centric contemporary individual it is not unrealistic that a change in practice or ethical conduct by medicine, through a review of their current norms and values, would encourage a degree of realignment with the forward movement of increased monitoring and marshalling of the self that

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is occurring. Such individual monitoring is achieved through the wide range of medical and health related literature available online (Ma, Ziao & Blonstein, 2013), but does not always equate with improved individual outcomes regarding healthcare decision making (Eckersley, 2006). This movement provides an opportunity for medicine to engage with the changing demands of individual autonomy over the self, but instead has produced a discourse whereby the profession has receded into its protective construct of expert knowledge in order to retain control of the dying trajectory.

True equality in the doctor/patient relationship is, therefore, unlikely to occur let alone succeed, suggesting that medical domination will inevitably remain prominent in this disequilibrium (Foucault, 2014). This leads to an imbalance of power relations, and a disquiet expressed by some individuals. In particular, they are concerned that "doctors are the persecutors and enemy of the public" (Shuttleworth, 2013, para. Comments), and that "…it should be my choice, not some ideologically driven busybody's" (bunyrab1t in BBC, 2015a, p. Comments) in relation to healthcare decision making.[77] These statements may appear strong in intonation, but suggest a frustration with the lack of flexibility or negotiation available between individuals and clinicians, or the interference of others in the context of individual choice. It demonstrates strength in the discourse of power of the large institution and that medicine is not simply a symbolic demonstration of being powerful but is tangible in the exercising of symbolic violence over the deviant self who wishes to die. Yet, the choice to die becomes problematic, as previously noted, in the medical discourse, as the convenience of death may outweigh the sanctity of life framework.

Conclusion
The idea that the dying individual has choice over the self produces a narrative that is both dichotomous and unreliable. The perception of choosing death over life not only contravenes the sanctity of life principle, but produces the potential for that individual to be perceived as deviant or 'other' and, as such, the repercussions that such labelling can incur. The idea that the dying can control their demise and end their lives at their biding becomes an unreality or an unachievable ideal, in that the

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[77] It cannot be assumed that user IDs represent identification of individuals.

constraints inflicted upon us all produce a paradoxical display of overt and covert power over the individual, thus removing the reality of choice in practice.

With the action of choice being perceived as deviant it does little to deter the potential for the 'slippery slope' effect to occur, in that having the option to choose death would open the flood gates, with the burdensome being obligated to die. Medicine has played a role in removing those perceived as being a burden, or whose lives are declared futile, through the application of medical models of care, thus, hastening death (Wrigley, 2015). This paradoxical situation presents the inequality in the relationship between the individual and the powerful institutions of medicine and law, under the guidance of government, in that individuals cannot die when they want to, but can die if the state or their disciples of power sanction such actions as acceptable.

Choice in relation to choosing death over life produces a paradigm of deviance and otherness for this patient cohort and, as such, they become the pawns in the game of authoritative power relations. These individuals function through the disruption of normative and acceptable cultural practices and, as such, endure the symbolic violence of powerful institutions when negotiating responses to the rights fought for. The notion of self-actualisation and the self-centric ability to choose becomes obsolete in the face of the power of medicine and law, with these powerhouses able to diminish the thoughts of individual choice and cast them aside into the realms of otherness.

This situation produces not only an unequal power status in light of the manufacturing of equity in choice relationships, but also a lack of transparency in practical policies when referring to the dying individual and the experiences of suffering. It produces a narrative that lacks trust by the individual of the clinician, in that many individuals are now distressed when attending public hospitals for fear of euthanasia. Equally, however, the choice of the individual is eroded through the potential obligation to die when inconvenient to society; but simultaneously becomes a deviant subject positioning when death is a lifestyle choice.

Chapter Seven

"The art of living well and the art of dying well are one"

(Epicurus)

The artful death: vernacular and anonymity as loci of power

Introduction

The *Ars Moriendi* was an interpretation of religious guidance in how to die well, and is a transformative piece of literature that has remained relevant for many centuries. Although subjective, the need to attain a 'good death' remains prominent within contemporary Western societies and, as such, it may now be more profitable to revisit the art of dying through a contemporary lens. There is no reason why the art of dying concept cannot be sufficiently malleable to meet the needs of twenty-first century living and, as such, moulded to incorporate the notion of individual choice. In considering a new approach to an old narrative, the new *Ars Moriendi* may provide the opportunity to actualise the right to choice at end-of-life through Western societies accepting the naturality of dying and implementing the letting go discourse. The idea that we can re-utilise a well-used historical narrative to develop a discourse of individual choice at end-of-life, however, is not as straight forward as may be indicated. Medicine has developed such a far-reaching presence in overseeing the process of dying which is continued in the manifestation of a specialist language of communication and, as such, proves influential in retaining control of this life event.

Simplistically, language can refer to "a system for possible statements" (Foucault, 1972, p. 27) through which propositions or statements become discourse itself (Foucault, 1972). Discourse in relation to medical practices presents an image of competence and knowledge and a mode of differentiation between the clinician and the patient, thus, representing both hierarchical power and subordination simultaneously (Foucault, 1972). To narrate subject matter outside of a discourse is

almost impossible as, for example, Foucault explains that to abolish the prison is unthinkable, partly because we do not have the words to describe any alternative as the prison remains central to the modern discourse of punishment (1979). In a similar manner, under the current discourse dying must be located in a medicalised setting and, as such, has produced a narrative of power and dominance through the application of the medical vernacular, thus, locating the dying patient in a position of vulnerability in achieving their individual wishes. In this chapter I now consider the role of the medical narrative in relation to individual choice and the curtailing of moving toward an inclusive representation of the contemporary death, together with the need to implement the discourse of letting go in the twenty-first century and how this may influence the futural role of the *Ars Moriendi* in the contemporary narrative of individual choice at end-of-life.

The medical vernacular

The medical vernacular produces clinical discourse in which the expertise and knowledge of clinicians has been embedded, thus, producing and protecting the power of medicine and the clinical institution to the exclusion of others (Talbot, Atkinson & Atkinson, 2003). Medical discourse delimits the intensity of emotion associated with dying through applying medical knowledge to the dying body, thus, suggesting that to medicalise dying removes the unknown and feared. Moreover, it contextualises the finality of the body within a discourse of separation, locating the dying body as otherness, whereby the power relations of the medical institution de-personalise the rhetoric of nature (Whitney & Smith, 2010).

Although the outcomes of medical investigation can be imparted to patients in lay terms, the choice to protect such knowledge through the development of a specific vernacular suggests a power dynamic through which status and control can be maintained. Rather than allowing the individual to clearly understand what is occurring to their body, clinicians use highly specialised language to impart knowledge; thus, presenting a situation of exclusion whether intended or not. This resource of power, however, is changing through the advancement of technology which can empower the individual if they have the cultural and social capital to

pursue such information.[78] The ability of patients to access medical information through social media communications, or through requesting access to personal medical notes in the UK and New Zealand, ensures they procure the capital to engage with medical conversations. This, however, has resulted in the clinician developing "a system of power which blocks, prohibits, and invalidates this discourse and this knowledge" (Foucault, 1977, p. 207). This is achieved through clinicians being "agents of this system of power" (Foucault, 1977, p. 207) and, as such, converse in a discourse that protects their interest as experts and excludes those without the appropriate forms of capital to continue engagement. The development of such an exclusive language "establishes a singular relationship between power and interest" (Foucault, 1977, p. 215), thus, marginalising the patient through inequalities in capital resources.

Capital resources are interchangeable agents that are not necessarily related to economic status but are inscribed in objects or subjective structures (Bourdieu, 1986). Capital, whether objectified or embodied, is not automatic but takes time to develop and accumulate and, as such, can be seen in the gaining of medical knowledge through the specific vernacular used by clinicians. The cultural capital of education undertaken by clinicians, in conjunction with the social capital produced throughout the course of such higher degrees, transforms their power mobility to produce a discourse of unequal power relations with the majority of patients. This status of clinicians demonstrates the embodied nature of their capital resources that remain unobtainable for the general population, with such social and capital culture not being easily replicated without exposure to the embedded product of the institution in the first instance. Thus, the product of this power relationship not only produces a balance of inequality between clinicians and patients, but it also ensures the dependence of patients upon the expert when making decisions and choices at end-of-life, in that the desire for power "exists and circulates in a web of social interaction" (Talbot et al, 2003, p. 2); but simultaneously remains exclusive.

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[78] Social capital is a termed coined by Pierre Bourdieu and refers to the social connections that can have the potential to be converted to economic capital.

The medical vernacular, when considered in relation to the power/interest relationship, demonstrates the use of specialised language as a means of closed communication between clinicians which generally the lay population cannot comprehend. Such exclusive practices retain and maintain a position of power by medicine over patients, thus removing the potential for an autonomous and artful death to occur; and, as such, represent expert knowledge as being a form of symbolic capital. This indicates that knowledge and, therefore, prestige become important resources and, as such, function as an influential embodiment of cultural value (Bourdieu, 1978), and is embedded in the socially dictated significance of medical expertise.

Symbolic capital obtained through medical knowledge and the prestige it is afforded results in the attention of others being given to clinicians as a form of respect, but can simultaneously refer to medical power being reproduced through social channels. With the continuing revelation of new discoveries in relation to the human body, the potential to increase life expectancy, the body of specialist knowledge and, therefore, power are continually produced and reproduced to satisfy the needs of the individual; but simultaneously secure positional power for the clinician. The symbolic capital of the clinician's knowledge can, therefore, be understood through the social positioning of medicine as an expert institution and the beliefs and values upheld by this (Moore, 2008). Such privileged knowledge remains secure through the monitored and closed society within which is circulates, thus, preventing the dying patient from accessing accurate information.

These closed information networks present a further barrier to dying patients when making care decisions, in that clinicians not only possess the expert knowledge of the dying process and communicate this through the medical vernacular, but in doing so embed the symbolic value of that knowledge in a format that is opaque to the individual. Power, therefore, becomes obscured from the patient's perspective as care is given, but reality pertains that the individual is unaware of the depth of knowledge that has been given or withheld. This is upheld in the layperson's context and was discussed in the interactive comments section of a professional healthcare journal, with one contributor suggesting that "… 'specialist language' often gets in the way of conversations, both between laymen and professionals and

also between different types of professional…there is very little place for 'jargon' in end-of-life care" (Anon in Nursing Times, 2014, p. Comments). This demonstrates that if professionals are already aware of the problematic nature of such communications, then there should also be a means of rectifying the situation to produce a more equal engagement.

All professions use jargon or acronyms within the context of practice (Fenske & Fortney, 1986) and can be considered coded communication. It would be agreeable to consider the use of such codes as unnecessary and possibly obstructive in ensuring timely and appropriate care, but reality remains that codes, jargon and the specialist medical vernacular dominate medical discourse, even when liaising with the dying. Although the medical vernacular, or clinical discourse, should be restricted to intra-clinician conversations, reality suggests it can be used as a form of power; as the symbolic capital of medical knowledge positions the clinician in such a way that although information is imparted, decisions remain difficult for those unable to understand such conversation. This demonstrates how

> "…the symbolic elite and its discourses that control the types of discourses, the topics, the types and the amount of information, the selection or censoring or arguments, and the nature of rhetorical operations. These conditions essentially determine the contents and the organisation of public knowledge, the hierarchies of beliefs, and the pervasiveness of the consensus which in turn are potent factors in the formation and the reproduction of opinions, attitudes, and ideologies" (van Dijk, 1989. p 25).

This statement when considered in relation to the medical vernacular supports the notion of clinicians being elitist in the imparting of their knowledge base and, thus, converting the clinical discourse into one of advantage over the dying patient. As such, this produces a power dynamic of unequal proportions, therefore, disadvantaging the dying individual. Such discourse, however, can sit juxtaposed in the relationship between clinician and patient in that some patients feel secure and more confident when their doctors communicate their conditions and options in medical language as this assures them that the doctor is competent and knowledgeable in their field of practice (Brayne, 2010), even if they do not fully

understand the conversation. Moreover, the reliance upon medical language by patients results in them not only "latching on to medical language to try to make sense of what is happening" (Brayne, 2010, p. 14), but also enables the individual to give a medical answer to a non-medical question.

This lay understanding of the medical vernacular is problematic, however, as it suggests that individuals understand the conversation occurring irrespective of this being factual, but also that the dying are comfortable to position the self within the structure of medicine at this life event. This situation removes the naturality of the dying process and replaces reality with an often indecipherable dialogue of discussion, thus, potentially delaying the imparting of delicate information. It is, therefore, clinicians lack of ability in advising that death is imminent to individuals and other family members that produces a discourse whereby the untouchable word 'death' is continually sidestepped; thus, continuing to uphold the narrative of fear and anxiety that is currently palpable.

For the majority of dying patients, however, the use of lay terminology, not laced with medical jargon, produces improved doctor/patient interactions and outcomes together with a relationship of *fiduciary* (Ludwig & Burke, 2014).[79] Direct language produces a narrative of confidence and trust in the clinician by the individual. Yet, through using comprehensible language as opposed to non-understandable specialised language, ensuring that the phrases used are "familiar and comfortable" (Robinson, White & Houchins, 2006, p. 75) the interaction between clinician and dying patient could be interpreted as patronising, suggesting a position of superiority and power by the expert. Some individuals may be offended by the use of lay language, preferring to try to converse at the same level as the clinician, thus, attempting to equalise the power relations occurring. This produces a situation in which the clinician can never win in relation to communication methods used.

The use of lay terminology can produce a further inequity in the doctor/patient relationship as the notion of familiar language can be lost in translation as familiar can become derogatory. In a study of day-to-day life on an NHS ward in England,

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[79] *Fiduciary* derives from the Latin word for 'confidence' or 'trust'. (Ludwig & Burke, 2014).

researchers observed that although some patient/healthcare professional interactions were "meant to be friendly [they] ended up being patronising" (Tadd in Adams, 2012a, para. 8), with some patients being referred to as "sweetie" or by "pet names" (para. 8). The researchers concluded that due to the high workload on the ward, clinicians did not realise the impact the use of language had on patients and reflected the inability of practitioners to see the individual in their care.

The use of terms of endearment may be meant well, however, they reproduce the inequity of power relations at play. The use of 'sweetie', for example, by a healthcare professional that the patient has never previously encountered has been uninvited and does not reflect the true status of the individual, but categorises them as patients and, therefore, immediately subordinate in the relationship unfolding. The idea that language must be familiar produces a narrative of dependence rather than a focus on context and the individual and, as such, represents a lack of a culture of care. This does postulate whether it would be so difficult, or time consuming, to identify how patients would like to be addressed, to at least acknowledge individuality on a basic level? All patients have the right to such individualistic care and dying patients, in particular, have a right to clarity of information in terms that they can understand, as we only have one chance to get this care right.

The fact that patients emerge from a diverse range of social stratifications with differing levels of social and cultural capital does not appear to deter clinicians from taking a patronising stance when imparting delicate clinical information with regard to dying, thus, ensuring that such information is "…couched in the language of compassion" (Tennant, 2012, p. 34), rather than being factual and more direct. This is exemplified in the omnipresent use of end-of-life care jargon, and clarified by Dr Fiona Stewart in relation to the debate on allowing voluntary euthanasia, confirming that patients are often advised that clinicians can "make you comfortable" (Stewart, 2012, p. A43), as opposed to informing the patient that they are dying.[80]

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[80] Dr Fiona Stewart is the wife of Philip Nitschke and is the former executive director of the pro-euthanasia group Exit International.

The assumption, therefore, that the individual cannot be trusted to cope with the finality of life, and that death is impending, removes any status of equity from the individual and firmly places the power of the relationship in the hands of the clinician. Moreover, the use of euphemisms distances one from the reality of the situation, whether that be a natural death or an assisted one, as comfort replaces dying to produce a narrative of security for contemporary individuals. Identified by the *National Institute on Aging in America*, it is suggested that it is a well-known fact that the "main goal of both hospice and palliative care is to keep you comfortable" (National Institute on Aging, 2015, p. 3), but this does not necessarily convey the activities that occur. As previously discussed the notion of comfort can reflect one of sedation to remove intolerable suffering, yet the language used is soft, delicate and non-confrontational. Comfort is used to convey the actions of the medicalised death through the application of "…medicines that can help to control symptoms" (Cancer Research UK, 2014, para. 16); thus, producing a paradoxical narrative that indicates that those dying have symptoms that need control, but that dying is achieved through the discourse of comfort.

Comfort, therefore, produces a soft approach in that clinicians may be perceived as being supportive to the needs of the dying but can simultaneously infer a degree of mystique and superiority in that clinicians do know what awaits the dying individual; whether that is through natural causes, the application of medical models of care or that of assisted suicide, but it is concealed from the patient. Such concealment of the trajectory for the dying lies again in the symbolic capital of expert knowledge and, as such, continues the cycle of the medical vernacular as a vessel of power; as it continues to emit power over the individual, not only through the non-understandable clinical discourse, but through the omission of detail of the future trajectory of death.

To shroud end-of-life care, irrespective of how this occurs, with soft words and phrases demeans the value of this life event, and produces a narrative that becomes detrimental to the dying individual through the lack of clarity of information. As such, this places the dying at a point of disadvantage when pursuing the right to choice and equity at end-of-life. To be uninformed of the immediacy of death removes the opportunity to pursue or engage with the right to self-determination at

this life event; or the opportunity to engage in activities that may be important to the individual, for example, farewells, the restoration of relationships and necessary last words. Moreover, it negates the element of choice through the dichotomous practice of conferring information in a vernacular that is unfamiliar to the dying or through the withholding of factual information in favour of couching the natural event within the sanctity of soft emotions; yet, this narrative is upheld through the discourse narrated by media interpretations of a 'good death'.

The media, language and medical models of care

The use of specific language is not solely contained within the medical vernacular used in interactions between clinician and patient, but is pertinent in the representations made through the media to both dying per se and to medical models of care. As dying has become removed from the community to that of the institution it has simultaneously removed any experiences of how one dies from common knowledge, resulting in the current knowledge base being gained through the representations made by the media in newspapers, online, news bulletins and television programmes (Brayne, 2010). Such knowledge, however, is polarised with dying being portrayed through rose-tinted glasses as being a romantic affair where the dying simply close their eyes or alternatively death being achieved through horrific circumstances, whether that be murder or war (Scarre, 2012). The reality of dying, however, sits somewhere between such oppositional insights, in that it can be uncomfortable both physically and emotionally but equally can be sedate, dignified and almost pleasant (Scarre, 2012). This central point makes dying ordinary in that the natural end to living is less harrowing than the media would suggest (Brayne, 2010), but being ordinary does not sell newspapers or add gravitas to such a situation (Brooks, 2015); leaving individuals with an untrue perception of the futural reality of this event.

The media have also played a role in the demise of the LCP for example, in that it portrayed the use of some words as being dualistic in meaning. Specifically, it references the word pathway in the LCP document as inferring that the care delivered is a one way road to death (Borgstrom, 2013). The word pathway has, therefore, not been perceived as a positive journey and, as expressed in an article in the *BMJ,* can be considered in a metaphorical sense as it "appeals to an irreversible

journey of decline" and, as such, "being 'placed on' a pathway alludes to exertion of medical control and swallows the patient's voice when individual choice in healthcare is overtly promoted" (Borgstrom, 2013, p. 4957). The use of pathway, however, was initially considered a comforting or neutral term, but has become a euphemism in and of itself, as it does not hint at what the LCP will look like, and cloaks rather than reveals this information. This is but one example of the interpretations given to the use of the use of the word pathway in relation to end-of-life care and, as such, its usage has proved hugely problematic for clinicians, destroying some of the trust or *fiduciary* that is necessary when care decisions are being made.

The disquiet occurring in relation to trust and confidence has produced a tidal wave of effects not only for the dying patients, but palliative medicine and the conduct of clinicians. The standardised, one size fits all use of the pathway has produced a narrative with *fiduciary* removed, therefore, locating clinicians in a previously unknown position of vulnerability, raising questions about the routinised clinical care of the dying. The use of pathway not only clinicalises the care regime of the dying, but places it objectively in a process that is not objective, as the only objectivity in dying is death itself, but the journey to death should be individualistic and relative to the subjectivity of the dying individual. The word pathway lacks emotional or personal connotations and describes a solid one-way street to a specific point, in this instance death.

Despite the negative connotations of the word pathway there are those clinicians identified in some professional journals who defend its use irrespective of "…its assassination by the media" (Brewerton in Nursing Times, 2014a, p. 2) and suggest that it is not the document or the language that is problematic but its' portrayal in the media and subsequently in the *Neuberger Report* (2013). This has opened up a further negative narrative around the use of language, albeit by clinicians sitting in opposition to the 'assassination narrative', through replacing 'Liverpool' in the LCP with alternative suggestions, for example it being "…dubbed a 'death pathway'" (Wrigley in Nursing Times, 2014a, p. 2), or through media commentary in that "I am getting more concerned about this 'death pathway' that is coming" (Devlin, 2009, p. 3).

The use of the phrase 'death pathway' highlights the problematic nature of labelling trajectories in medical care, in that such language can be manipulated to suit the position of the writer. Through intimating that the pathway leads to death it presents a problematic discourse for patients and relatives alike, in that such reference removes any potential good that may be provided by its implementation. The use of pathway has, however, produced further problems for clinicians, as highlighted in the *BMJ*, in that the use of this medical model of care is not

> "reflecting people's expectations of dying" but that "health professionals were seen to be interacting with forms rather than people" (Borgstrom, 2013, p. 4957). This viewpoint has been furthered with some clinicians reflecting that the LCP became "robot care for [a] robot pathway" (Carson in Nursing Times, 2014b, p. Comments), and that you will "get a robotic nurse if you want to use a robotic pathway!" (Anon in Nursing Times, 2014b, p. Comments).

There is not necessarily a correct or incorrect means through which to view the use of this language, but the *BMJ* warns that limitations inferred through using "terminology like 'pathway' can in practice become a protocol – a literal pathway to follow" (Borgstrom, 2013a, p. 4568) and, as such, enhances the narrative of fear in the lay population through such symbolic language (Bolinger, 2014). The result produces a situation whereby the original function of providing transparency at end-of-life is usurped and that further amendments to the LCP, for example substituting 'plan' for 'pathway', may prove ineffective as the LCP is already tainted with suspicion. Yet, this discussion around the use of specific words in relation to medical practice although relevant, does not remove the need for clarity of end-of-life care choices in relation to the right-to-die, which too is couched in a misleading vernacular.

Media representations: the problem of 'dignity'
Language choices produce directed outcomes and, as such, media representations of the dying, the right to self-determination and the right-to-die are manufactured and couched within the context of constructing a death with dignity. Dignity, however, relates to "the state or quality of being worthy of honour and respect" (The Oxford

Dictionary, 2015, para. 1); and while respect and honour of each individual is a virtuous characteristic to uphold, it does not reflect the reality of what is being conveyed, that choice in death is what is really being pursued. It must be asked, therefore, why dignity has usurped choice in the fight for the individual to choose outcomes at end-of-life? And that it may again be related to our inability to deal with the reality of the wishes for those who choose death over living. The use of dignity, therefore, becomes problematic in the canvassing discourse of many of the charities and agencies supporting the right to choice and the right-to-die, in that they shroud their petitions in the metaphor of dignity.

This is visible in the values of the charity organisation *Dignity in Dying* campaign group in the UK, who canvas to "legalise assisted dying, with upfront safeguards, for terminally ill, mentally competent adults" (Dignity in Dying, nd, p. About us), through having

> "choice over where we die, who is present and our treatment options; access to expert information on our options, good quality end-of-life care, and support for loved ones and carers, and control over how we die, our symptoms and pain relief, and planning our own death" (Dignity in Dying, nd, p. About Us; Our Vision).

Yet, the values of the *Dignity in Dying* group, while commendable in ideology, do not equate with the singular use of the word dignity as headlined in their name. The heart of their campaign is located in advocating for the right-to-die as opposed to a dignified death and, thus, produces a confusing narrative. Through using dignity instead of assisted suicide or the right-to-die, or individual choice, for example, it suggests a softer approach to the harsh realities actually being pursued; that of voluntary euthanasia. Dignity blurs the boundaries between the medical contemporary death and the pursuit of assistance to die with choice, for choice is really what is being advocated in the policy statements mentioned above. The use of dignity, a grand and noble word, is aligned with the fact that contemporary individuals fear death and dying and, as such, find it difficult to relate to the idea of suicide, irrespective of means even when been actively sought. Dignity, therefore, masks the harshness of pursuing the right-to-die by shrouding the reality in a

framework of honour and respect, when respect for the individual already exists in the foundation of medical care, or should do.

Canvassing, therefore, for 'dignity in dying' rather than assisted suicide has, unfortunately, developed a misleading discourse by the campaign groups with the general media doing little to enhance an open engagement with the fact that the human race is mortal and that death is the inevitable end to living. The signals given with the use of dignity reduces the effectiveness and power of the goals being sought, as language usually seeks power to "designate, to name, to show, to reveal, to be the place of meaning or truth" (Foucault, 1972, p. 125) with regard to the matter in hand. Therefore, if the right-to-die campaign groups took notice of Foucault's interpretation of power in relation to language they would be more open and transparent in their quest for such rights.

The use, therefore, of prestigious yet indirect language misguides the individual into believing that dying with dignity differs from dying with assistance, or having the right to choice. The language used produces an opaque barrier in a similar manner to that of the medical vernacular, thus, reducing easy access to the issues at hand and in turn potentially reduces the power of the self in relation to individual rights at end-of-life. The paradoxical use of soft language in conjunction with the medical vernacular and the nobility of dignity produces an ambiguous yet dichotomous situation which the individual must navigate through at a time which is already loaded with emotive issues; thus leaving them vulnerable to the power relations present in obscuring the individual death in favour of the accessible medical death.

Social media: the power of anonymity in power relations
Medical professionals may appear to have secured power over the general population in relation to the contemporary death through a variety of means; however, through the emergence of online social media as a means of mass communication, changes may be afoot. Clinicians remain powerful through the acquisition and selective imparting of knowledge towards patients using a medical narrative which, until now, has been relatively unchallenged on a consistent basis. Through the popularisation of online social media as a means of collective communication, challenges are now being made towards not only medical practices,

but to all aspects of the contemporary existence (Pattenden, 2014). This has resulted in practitioners from all professions, not only medicine, becoming less obscure and aloof and, as such, become answerable for practices and decisions which would have not occurred previously (Sherrington, 2013); thus, indicating that the barriers to choice and the potential for clarity and transparency in practice has the potential to come to fruition. This move is not necessarily negative, but does mean that all practices can be targeted without repercussions for the anonymous questioner.

Although anonymity on social media has existed since the early days of the Internet, its use has been noted to have increased in recent years and particularly in relation to sensitive subject matter (Correa, Silva, Mondal, Benevenuot & Gummadi, 2015). Through the development of thousands of forums, personal blogs and interactive journal articles, the general public has gained a voice in relation to all subjects and, as such, allows the projection of individual opinions into the global stratosphere. This is evident in relation to the contemporary medicalised death and those seeking individualism at end-of-life (Pattenden, 2014), and in particular in relation to the responses to the media representations regarding the use of the LCP in the UK and the promotion of the individual's right-to-die.

This represents a shift in the power status of the lay person in relation to the doctor/patient relationship, in that the individual dying patient becomes empowered to speak of matters that were previously brushed aside; and is witnessed in the emancipation of thought and wishes to secure the right-to-die when suffering becomes burdensome. This power shift, however, may prove less potent if the voice resonates from an unidentifiable source, as invisibility equates with a reduced power status as one is not answerable to comments made, thus decreasing the potential to achieve equity in the power relationship. This is evident through the vast majority of online responses to such sensitive and delicate subjects are either posted anonymously or via usernames through which the individual cannot be identified (Correa et al, 2015).

The purpose of anonymity is to give the individual voice the confidence to make statements that would otherwise be omitted from face-to-face communication (Suler, 2004), and can be demonstrated through some of the comments already used

within this research. Yet, the ability to vocalise concerns or wishes anonymously does not result in achievement of those desires, as anonymity may provide a voice for the individual, but simultaneously presents a shield between the voice and actualisation. The result of this in relation to the doctor/patient relationship suggests that this relationship may now be in a state of flux as "…all those on whom power is exercised to their detriment, all who find it intolerable, can begin the struggle on their own terrain and on the basis of their proper activity (or passivity)" (Foucault, 1977, p. 216).

Interpreting Foucault's statement in relation to the discursive use of the Internet together with anonymity, it suggests that the power relations between the clinician and the dying patient may become unstable. It allows the individual, and the general population, to challenge the practices of the medical elite in a new form, thus divesting power towards the subjugated general population; albeit a population that is unable to clearly demonstrate the social and cultural capital upon which their suppositions are founded. Moreover, the power of the anonymous internet voice produces an accessible and repeatable voice through the ability to easily share information, thus having the potential to be heard on multiple platforms. This is evident in the media representations regarding the LCP in the UK which resulted in the undertaking of the *Neuberger Report*; and demonstrates how vocal anonymity is a powerful tool when exercised through online social media, in that the secrecy it guards with regard to the identity of the writer produces a platform through which the marginalised, persecuted and stigmatised can be heard, as "secrecy can breed publicity" (Tonkin, 2014, para. 7). Moreover, it has been suggested that the use of anonymity allows the individual to produce more aggressive narratives and "exhibit disinhibition" (Correa et al, 2015, p. 19) than when meeting in person and, as such, may produce a narrative that is less valuable than that which is accountable.

This shift in communication platforms produces the potential for a less uneven power dynamic in the clinical relationship and has the potential for the dying patient to be able to shift from the position of subjugation to that of equal. However, the true possibility of this is negated through the social media narrative being conducted in an anonymous manner, thus meaning that the dying may voice their opinion but the debate may not produce transformative outcomes for dying

individuals or equality of voice. However, as such communication mediums move forward there is always potential for equality to be achieved through "the revolutionary movement of the proletariat to the extent that they fight against the controls and constraints which serve the same system of power" (Foucault, 1977, p. 216).

When considering this statement in relation to the dying patient, it suggests that the dying patient has the potential to produce a discourse of individual choice in the future, should the online social media voice continue its ability to raise awareness of a multitude of issues and create the conditions for social change. This potential shift in the doctor/patient relationship demonstrates that power is not necessarily a "one-way" (Talbot et al, 2003, p. 2) system, but can become a multi-directional, and not necessarily hierarchical, concept through which the individual can succeed in their quest for autonomy over the self when dying. Such multi-directionality does not necessarily produce symbolic capital for the patient in a similar manner to the power and knowledge possessed by medicine, as the power over the self is not so much symbolic but physical in the attainment of individual desires. Symbolic power does not translate to being similar for the dying patient, as medicine will still retain such symbolism regardless of the increased equity in decision making and choice for the self at end-of-life. This is achieved through the retention of specialist knowledge in relation to the human body and the use of the medical vernacular; despite the dilution of some aspects of medical power in relation to the formalising of patients' rights in healthcare settings. Moreover, as power is defined "…in terms of interests" (Deleuze, 1977, p. 214), the interest of the dying patient is that of the autonomous self with regard to the death they choose and is, therefore, of importance to the individual; whereas that of medicine currently remains one of power over the general population in order to control the body from before birth to beyond the grave.

Anonymity can, therefore, be considered as a powerful tool through which the individual voice can create a disturbance in the present equilibrium of medical discourse and the inter-relational power between clinician and patient. However, it can also be argued that anonymity produces a weakened source of power as non-identification can be related to the production of poor behaviour, together with an

aggressive and potentially bullying narrative (Crozier, 2009). Power resides in the ability to annunciate and argue your point, but equally requires the ability to produce knowledge and resources that have accountability, thus, suggesting that despite the increasing presence of the individual voice on social media, power will remain within the construct and context of the expert clinician, through the application of knowledge and language together with the ability to demonstrate appropriate social and cultural capital.

Consideration must also be given to the idea that the interests of medicine are not always aligned with those of the individual. Often medicine considers the needs of the general population (Cameron & Pimlott, 2015) in conjunction with law and the government, over that of the dying individual and this can be seen in the continuing refusal for the individual's right to choice when dying. Moreover, despite the rise of the anonymous voice requesting the right to choice at the end of living, it would suggest that the individual voice is no more than a mere indentation on the armoury of the medical profession; as when clinicians are pushed to become more equitable in their relationship with patients, they default and, thus, rely upon the interrelationship of law as supporters of their case. Such collaboration produces an exertion of power relations which, if harnessed, could produce a new and more functional contemporary artfulness in dying, through embracing the finality of life

The 'letting go' discourse
The death denying culture of contemporary Western societies is tangible as previously discussed, and the propensity to engage with the prolongation of life and death discourses does little other than encourage engagement with the narrative of fear. Yet, as the life continuum is finite, and that we should remember that we are 'being-toward-death' from the moment of birth (Heidegger, 1962), to engage with the 'letting go' discourse may prove beneficial (Gawande, 2010). Atul Gawande is an American surgeon who has embraced the finality of life, albeit from a positivist surgical perspective where there is always something else that can be done to prevent death, and narrates the 'letting go' narrative as a means of engaging positively with death.

To let go of a loved one is often to admit defeat in the face of death and, as such, "if you don't give up, if you fight, if you search hard enough, if the doctor is good enough, if the hospital is the best, if you are willing to spend enough – there is always something that can be done" (Gawande, 2010, p. 3). Reality, however, is that death will come eventually, it cannot yet be beaten, but as a collection of Western societies we need to engage with this fact. Yet, this is not a simple exercise to achieve. We are fed information, often through our acquisition of cultural and social capital, that we are invincible and that we can overcome a multitude of diseases, thus, suggesting that the social status of achieving longevity outplays the idea that to die well, at home, or in control is no longer an essential element of the argument to choice.

Social status holds priority for many individuals (Mannheim, 2002), even if such status is achieved through prolonging both life and death. The notion that status can be accorded with longevity even if individual suffering occurs, appears a dubious position of prestige, yet is notable in the context of preserving life through equating endurance with the sanctity of life. This leads to the reinstatement of the sanctity of life argument in light of medicine's ability to keep the human body alive, irrespective of the consequences to the individual. Social status equates with the subjectivity of the individual and must, therefore, always be considered within the context of the subjective, as this differs between individuals and between doctors and patients. This suggests, however, that social status has been accorded to the prolongation of life through consensual acceptance of, and engagement with, the "expensive, [and] unlimited state of the art medicine" (Fields in Payne, 2013. p. Comments) available to keep individuals alive.

Professor Sheila Payne of the *European Association for Palliative Care* suggests that a

> "new social status [has developed as] more people live longer with advanced disease that will or may ultimately cause their death" as "the pattern of dying therefore is more likely to be prolonged, with bouts of illness…which may mean the spectre of death becomes closer" (Payne, 2013, para. 4 & 5).

As such, the individual's increasing engagement with the medical profession throughout the lifespan produces a narrative through which disengagement with the clinician at the end-of-life becomes abhorrent, thus opening the pathway for the subordinated medicalised death. Yet, Gawande suggests that the disengagement with the medicalisation of dying is an important factor in encouraging engagement with the naturality of this life event. There are moves afoot with the opening of discussions around ACPs as a small step towards our ability to let go, but the notion of letting go should not merely be about declining medical interventions, but should be about the encouragement of active engagement with individuals' preferences at end-of-life.

There is comfort in individual choices being acknowledged and engaged with and, as such, produces a narrative that has the potential to dispel many of the anxieties that exist around death and dying. In engaging with equality in decision making with clinicians and having the confidence to take ownership for the natural path of dying, it disengages from the symbolically violent associations of prolonging life irrespective of life value. It allows the use of cultural and social capital to make choices that are necessary and, as such, produces a discourse of support for all involved. Gawande engages with the idea of the *Ars Moriendi* in that the artful death in contemporary societies exists and is attained through the use of hospice supports at this time; with some suggesting that the shift towards hospice care is de-institutionalising death and dying (Howarth, 2006).

This idea, however, sits opposed to the 'letting go' ideology for which he advocates but is a viewpoint upheld by Lydia Dugdale (2015) who also takes a bioethical overview of the art of dying in contemporary society. Yet, despite these attempts to reconceptualise dying from being an over-medicalised life event, the notion that hospice has become the vehicle for change appears misplaced as hospice remains a medicalised discourse of care at end-of-life and, as discussed throughout this work, engages in practices that are not always aligned with the individual wishes of the dying; despite suggestions that the clinicians are no longer the overseer of the dying, but more of a guide sitting alongside patients and negotiating with them (McManus, 2015). I would argue, however, that this clear transition from overseer to negotiator is too linear from a real world perspective as some clinicians remain

reluctant to engage in meaningful negotiations that may detract from their authority and power.

Furthermore, although it is known that "hospices specialize [sic] in the art of pain control" (Muehlenberg, 2010, para. 7), and that there are those who consider that "nursing the dying is an art, as well as a science" (Carter in Ford, 2014, p. Comments), I suggest that although Gawande has some promising thoughts in relation to letting the dying die as they wish, he simultaneously contextualises his thoughts within the constraints of medical practices. This, therefore, offers an opening in engaging with a new art of dying framework, but does little in reality to shift the dying from the current medicalised paradigm of care.

Re-presenting the *Ars Moriendi* as individual choice at end-of-life
Dying is not predictable, nor is it containable despite the attempts of medicine to do so. It cannot be controlled or tamed, however, it can be managed but only in relation to the subjectivity of the individual involved. Medicine has attempted to manage the dying, thus, creating a situation whereby comfort is now produced through the "anatomo-clinical gaze" (Foucault, 1973, p. 179). Such manoeuvres produce a triumphant discourse through which medicine, with the support of law, control all but those who are capable of the individual suicide of the self.

In considering, therefore, how the artful death needs to change in order to be relevant within the self-centric, individualistic societies of contemporary Western cultures, we have to look at how such values sit in relation to the dominant power of medical practitioners. Moreover, we have to consider what it is that is wanted in the twenty-first century that was less visible in previous eras, and that refers to the autonomy of choice over the demise of the self. The idealised, medicalised and peaceful death is not a reality for many on this trajectory and, as narrated by Payne, "death is often a lot less serene than one might think. Death can be like life – a bit messy and awkward – some people die as they lived – 'at odds with the world'" (Murphy in Payne, 2013, p. Comments) and, as such, "people's fear of death has long been the ultimate instrument of power" (Petrov, 2013, p. 353); a situation that has become the focus of medical discourse in recent decades.

The medicalisation of dying, despite its visibility shrouding death with invisibility today, is not supported by all individuals and, as such, has led to the self-centric individual seeking rights over the death of the self. It has set in motion a campaign to allow the engagement of the self in decision making either at end-of-life or when experiencing intolerable suffering. Yet, through the collaboration of medicine and law, the right to self-determination at this life stage remains elusive. Choice is all but an illusion in regard to individual wishes at end-of-life, and the re-presentation of the *Ars Moriendi* as a construct contextualised by, and contained within the medical structure does not illuminate the pathway to improvements in end-of-life choices. I disagree that hospice provides the new art in dying and suggest that we take the *Ars Moriendi* and use it to facilitate the right to individual choice at end-of-life, whether that is a medicalised death or the right to assisted suicide in our death denying culture.

More specifically, to date I suggest that those who have attempted to re-define the *Ars Moriendi,* or consider it in a new light have done so within the context of medical practice alone; with Dugdale and Gawande being good examples of this. Unfortunately, these then appear to end up being just further versions of the palliative model of dying, thus offering limited contributions to changing the face of end-of-life care choices. Drawing upon my professional palliative care experience in both the UK and New Zealand, the notion that hospice is the new *Ars Moriendi* is limited, as the work remains under the jurisdiction of medical professionals, with 'enrolment into the programme' a requirement. What is needed is the embracement of cultural diversity, perceptions, preference and needs, many of which sit exterior to the boundaries of clinical practice, with my intention of including the *Ars Moriendi* in this research as being a suggested starting point in redefining futural end-of-life care that is not contained within, or constrained by medical authority. In trying to define a new framework for dying, with individuality being the central focus, it does not suggest that individuals will be isolated, more that their choices will not be deviant but accepted within mainstream discourse in an open-minded format; with the possibility of social media presenting a means through which a new *Ars Moriendi* may be presented.

The art of dying, therefore, should no longer be prescriptive, and should be considered outside as well as inside the medical model of care. We must consider and treat the dying as true individuals who represent the lives led. A means of doing this may be to embrace the *doula* who walks alongside the dying, supporting them and their family as they traverse the unknown trajectory, as one component of the futural art of dying.[81] Re-presenting the *Ars Moriendi* offers an opportunity for it to become a vehicle for change and, if engaged with, provides a framework through which individual choice and equality in decision making may be achievable, giving us an image of how dying may appear in the future. This is not to say that medicine and their practices should be ignored or excluded, but clinicians and holistic practitioners should work in cooperation to ensure the contemporary death is the one sought, and not necessarily the routinised one of prescription. This image of dying being located outside of the sphere of medical care, however, promises the possibility that we can take back our deaths in the future, but simultaneously means that death becomes an ordinary (if difficult) feature of our life course rather than a hidden extraordinary event. The contemporary art of dying in turn becomes a narrative for individual choice at end-of-life, thus enabling access to the subjective 'good death'.

Conclusion

In considering the medical vernacular as a locus of power, language presents a challenging and compelling argument in the inequalities at play in the doctor/patient relationship at end-of-life. It demonstrates how the cultural and social capital of individuals systematically and systemically overrides the voice of the individual, even when that is actualised through the use of anonymity on online social media. It represents the power of the institution of medicine and, as such, the ability to remove choice as a reality for the dying patient. Furthermore, the medical vernacular obscures patient choice and, therefore, access to individual rights.

Yet, contemporary reality is demonstrating that there is potential for individuals to become equal with clinicians in decision making at end-of-life, if we move forward and engage with the self-centric nature of contemporary cultures and, as such,

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[81] *Doulas* (*Doulahs*) are a relatively new concept in end-of-life support and provide a holistic approach to care. They are non-medical, but supportive and open to the notion of the self (Elliott, 2011).

utilise the historical framework of the *Ars Moriendi* to provide an opportunity for individualism and choice. Moreover, if we embrace the principles of the ACP and deconstruct the security shield of the medical vernacular, together these values could provide the foundation for the re-conceptualisation of the *Ars Moriendi*. The new *Ars Moriendi* would, therefore, no longer be a prescriptive tool guiding the individual towards the collectively perceived 'good death', but would facilitate individuality, thus continuing to offer the medicalised death for those who prefer this pathway, but also offering the opportunity for those seeking the right-to-die to do so, with assistance if necessary, without prejudice. The new, contemporary art of dying would, therefore, produce a narrative of supported individual choice within a safe framework of operation in Western societies.

Conclusion

"The act of dying is one of the acts of life"
(Marcus Aurelius)

Introduction

It would appear that end-of-life care discourses in both the UK and New Zealand are currently in a state of flux, through the discord present in relation to the competing viewpoints on how a 'good death' can be achieved within contemporary Western cultures; with the traditional *Ars Moriendi* all but invisible in the twenty-first century. Currently the course of palliation sits alongside that of the right-to-die narrative and, although the means through which death is achieved appears similar in each instance, palliation is legal and assisted suicide is not. Contemporary dying is currently constrained by the omnipresent belief that medicine can meet all the needs of those at end-of-life or who are experiencing intolerable suffering, thus containing the experience within the boundaries of clinical practice. The assumption that conformity with the medicalised discourse of dying will be automatic and acquiesced to without question is proving difficult to ratify, through the movement for self-determination and the right to choice at end-of-life.

The notion of choice being attainable is a key factor in the lives experienced over the past 50 years or more, and no more so than in the contemporary self-centric Western societies. Yet, despite the marketing of individual choice within the realms of healthcare and the trajectory of dying, as this research unfolds it demonstrates that choice proves difficult to achieve through the selective, but timely collaboration between medicine and law to ensure the dying remain constrained by, and contained within the remit of medicine. However, with medicine becoming reliant upon legal statute in clinical decision making, it demonstrates that a weakness exists in the practice of medicine, one that cannot be filled through the medicalisation of care and, as such, may prove pivotal in moving forward and embracing patient choice as being equitable with clinical knowledge. Moreover, such a weakness may be significant in re-invigorating the *Ars Moriendi* as a means of engaging with and accepting the individuality of the contemporary individual.

This research adds to the body of sociological knowledge on death and dying from the perspective of individual patient choice at end-of-life, contextualised within the movement towards the right-to-die within contemporary Western societies, and the UK and New Zealand specifically. It offers the opportunity to engage with the potential shift that is occurring in the power status of medicine and that of the individual, in relocating the routinisation of dying from the clinic towards one of individual choice. This research also considers this shift within the context of the *Ars Moriendi*, and how the art of dying may be re-invigorated to produce a contemporary framework in order to move forward and engage with the self-centric individualistic lives led within Western societies, thus offering individual choice at end-of-life.

This final chapter considers, therefore, the key findings of this research and the interrelationship and intersectionality of these outcomes, the limitations of the research and recommendations for future study.

Key findings

Patient choice as illusion

Individual patient choice is an idealised construct. It has been promoted as a means of engaging with, and the management of the self in relation to healthcare outcomes and the trajectory of dying when this life stage eventuates. The imagery of being able to achieve actualisation of preferences when dying produces a potent illusion of equity in decision making that remains unachievable in reality. The expert knowledge of the clinician, together with the upheld principles relating to the sanctity of, and right to, life dominate the landscape of patient care.

The *medical gaze* remains dominant in the context of the dying individual, however, I have demonstrated that when this gaze fails to secure the conformity of the dying patient with the preferred models of care at end-of-life, or individuality is sought, medicine collaborates with law in order to ensure their dominance in decision making prevails. This is significant in relation to the self-determined individual seeking the right-to-die, as choice becomes an illusion in reality due to the powerful combination of medicine and law acting together to maintain the current equilibrium in dying care. More specifically, there appears to be a blurring

of boundaries in medical and legal practices with the selective ability to apply models of care in some circumstances but deny them in others. The waters are muddied in relation to consensual use of the LCP and PST for example, and appear dependent upon the subjectivity of intent and the individual it is applied too. However, when such practices are actively pursued, they are retracted as not being legally applicable to such individuals, thus, suggesting that there are no hard and fast rules in end-of-life care, and the implementation of such care models is wholly dependent upon intent of use. However, this problematic discourse could be eased if clinicians and lawyers synthesised their practices to produce transparent narratives of care, thus allowing at least a modicum of understanding of where the self is positioned in relation to achieving the death of choice.

Individual choice, therefore, is problematic as this research highlights that at present it is unachievable in reality. More specifically the voice of the clinical and legal elite produces a vacuum of illusion in that the marketing of patient choice is no more than 'smoke and mirrors'. This suggests that patient choice is 'prescribed' for its placebo effect, thus, ensuring that the doctor/patient relationship remains one of inequity, with medicine maintaining control and power over the individual at end-of-life.

Patient choice as deviant

Through non-complicity with the sanctity of life principle and the right-to-life discourse, this research portrays an image of the self-determined individual as being considered deviant and 'other'. Behind this labelling, the narrative records that such individuals sit outside the currently accepted paradigm of end-of-life care and that control of the self at this life point is an unreality. Moreover, such disruptive individuals highlight the paradoxical display of power regulated through the selective collaboration of medicine and law, in that the appearance of stability in end-of-life care practices presents an imagery of equality in the doctor/patient relationship. However, such equality is, in reality, not identifiable when considered in light of the paradoxical implementation of medical models of palliative care to eradicate the burdensome, and simultaneously removes autonomy for the self-determined individual. The right to choice, therefore, does not necessarily equate

with a narrative of acceptance of such choices, particularly when they are considered as deviant behaviours.

The resistance, however, to the contemporary medicalised 'good death' fails to produce a positive discourse at present for those pursing the right-to-die. Such resistance produces a situation of conflict, with opposing parties unlikely to be brought together in light of current legislation and medical preferences to continue overseeing the dying process. However, through the power articulated through medical practices, and the removal of perceived competence in those pursuing non-complicit means at the dawn of their death, resistance and deviance become labelled as otherness, thus burdening such individuals with monolithic barriers to achieving their chosen goals.

A weakness in the construct of medical practice

Medicine dominates the lives of the contemporary Western individual, offering advice and support for all of life's eventualities regarding health and wellbeing. It produces solutions to ailments and pathways for the living and dying. The dominance of medicine, however, is less resolute than previously thought when considered through the lens of the self-determined individual at end-of-life. Contemporary individuals have begun to question the dominance of medicine over the outcomes of the self in relation to dying through the lobbying for the right to choice and the right-to-die at end-of-life, or when experiencing intolerable suffering. Such questioning has produced a situation whereby medical practices and medical models of care have been scrutinised and determined as not being relevant to the lives led by some individuals; in that they do not meet with their desired outcomes when dying.

More specifically, it is the enforced reliance upon palliative medicine by the dying when individuals are no longer able to commit suicide that proves problematic, in that their right to end life is no longer attainable and, as such, conformity with the clinical death is assured. However, the right-to-die discourse has unsettled medical dominance at the point of death. I highlight this through medicine either inferring that those who are at odds with clinical practices are hysterical or deviant, or medicine reverts to seeking the assistance of law in securing their position of

control over the dying in these situations. The notion that the individual has the right to self-determination at end-of-life and, therefore, the right to avoid the route of palliation, appears unpalatable for the contemporary clinician; but in disapproving the notion of individuality, medicine exposes a frailty in its construct.

Such frailty is reflected in medicine's reliance upon law when individuals do not embrace the contemporary medicalised pathway to death, but embark upon the route to individual choice and autonomy; even if such choice is never actualised. This weakness, however, positions medicine beneath the construct of law in the hierarchies of power, illustrating that medical practice does indeed have a permeable frontier; with the frailty of the medical construct becoming porous in response to the advocates of choice and self-determination at end-of-life.

The UK and New Zealand comparison

A further outcome of this research is the assumption that the UK and New Zealand healthcare practices are similar. Having worked in both countries in roles relevant to end-of-life practices, the outlook for patients at end-of-life is in fact quite dissimilar. My findings suggest that although the implementation of end-of-life care pathways in the UK has been hugely problematic, with significant repercussions across the healthcare sector and the mistrust of patients in clinical practices, these have been acknowledged, with new measures being introduced to address these issues. Interestingly, however, despite New Zealand often following in the footsteps of UK practices, on this occasion it has not done so. Instead, New Zealand continues to roll out the LCP as a means of good practice in end-of-life care, and remains resistant to acknowledging that any issues exist with its use.

More specifically, the Ministry of Health in New Zealand presents an opaque image that there are no issues with the LCP in New Zealand, despite its extensive use in this country. Although the Ministry does acknowledge there have been some complaints regarding end-of-life care standards in New Zealand, it refrains from being specific about this point. However, given the fact that over 85 per cent of institutions now use the LCP in New Zealand, it is possible to consider through the laws of probability, that some complaints must be relevant to this care pathway. There appears, however, little awareness of the LCP as a model of care in New

Zealand, thus, it follows that debate is limited, if existent at all and reflects a very different position to that of the UK, where open debate and formal inquiries occur. This is significant, as to keep such information within the closets of parliament continues the theme of power residing in knowledge and, thus, sequestering such information removes the possibility of choice away from the individual.

With regard to individuals seeking the right-to-die, there are a number of notable cases in the UK, as discussed in this research, all of which have been unsuccessful in their aims of actualising assisted suicide. Similarly in New Zealand, the few cases that have been attempted in this country have also failed, with Lecretia Seales being the most recent of these. This suggests that there are indeed some similarities in some practices at end-of-life between these countries, and simultaneously demonstrates the continued reliance upon law by medicine in such cases. There does, however, appear to be a more open and forward thinking trend in the UK to embrace the notion of the right to choice and the right-to-die, albeit with strict guidelines in place and is demonstrated through the repeated attempts to present this issue to parliament. There have been some attempts in New Zealand, but these appear to have less support than those in the UK.

The UK and New Zealand, therefore, present differing but equally similar images of end-of-life care, in that the dying are currently sequestered into the enclaves of medical care and palliation, and those seeking individualism remain as 'other'. Yet, in order to move forward and embrace the notion of individual choice at end-of-life, transparency is needed with regard to problems encountered in implementing the medicalised death; with this being particularly pertinent to New Zealand at present. It is unknown whether there is financial gain in implementing the LCP, or similar models of care in New Zealand, although as previously noted a price tag has been equated with individual needs at end-of-life, however, financial incentives should not be part of individualised care per se, and certainly not at end-of-life. The practices in the UK have highlighted a significant failing on the part of the healthcare system, but simultaneously presented clinicians as being complicit with the directives from the institutional drivers, with devastating consequences not only for the lives lost and the potential loss of trust in clinicians, but the ongoing

repercussions regarding the rights to individual choice at end-of-life; and is tangible across both countries.

A further outcome of this research suggests that the potential to embrace the right-to-die appears a distant possibility and certainly not a reality in either country at present. To reconfigure and reinvigorate the contemporary death, clinicians in both the UK and New Zealand need to embrace the reality of the self-centric contemporary individual and engage with the notion of patient choice at this life point. I suggest that the reliance not only upon law to support the palliative model of care at end-of-life demonstrates a frailty in the composition of medicine, but the continued promotion of the sanctity of life and presumed life value, over the wishes of the individual are becoming less relevant to the lives currently pursued. The culture of choice is almost one of expectation within contemporary Western societies and, as such, becomes problematic in the context of individual choice at end-of-life and is demonstrated in the medical and legal resistance to introducing the right-to-die for those who seek it.

Re-presenting the *Ars Moriendi*: the contemporary art of dying as a narrative for individual choice at end-of-life

The final outcome of my research is to consider how a 'good death' looks in the present and futurally within the UK and New Zealand, and within Western societies more generally, given the assumption of individual choice being almost expected in the twenty-first century. I highlight in this research that despite the prevalence of, and conformity with the medicalised death by the majority, there are an increasing number of individuals who do not visualise this pathway as being relevant to their needs or wishes at end-of-life. This has motivated individuals to engage with their perceived human rights and advocate for the right-to-die when terminally ill or enduring intolerable suffering through engaging with clinicians and lawyers alike. But with the omnipresence of medicine and law dominating the current pathways to death, at present these petitioners fail in their bids.

With the active marketing of individual choice, however, together with the uptake in pursuing choice through whatever means are currently available by those at end-of-life, it presents an opportunity through which medicine, law and the individual

may be able to collaborate futurally to develop a new, more meaningful and less routinised trajectory for the dying. If medicine and law are able to collaborate at given times, and despite the elevated status accorded to these two professions, the interjection of the articulate voice of the individual should become a welcome addition to the negotiations afoot, in the UK in particular. However, the needs of the individual will always be contextualised, at present, within the need to ensure the safety of the majority, thus collaboration and identification of specific issues will almost certainly prove problematic, given the subject positioning of the parties involved. Moreover, through the dominance of medicine at this life point, to shift the parameters of need from that of the clinic to outside this sphere will become a point of contention, as consideration must then be given to where those seeking the right-to-die will conduct this process.

When considering the disciplines involved in developing a new strategy to encompass the rights of individuals and the right to choice at end-of-life, a framework for change may prove pertinent in achieving actualisation. Given the divergence of skills and knowledge of those to be involved in such negotiations, and the inclusion of the individual, I propose that engagement with the 'letting go' discourse is relevant to the new trajectory for dying and that the purpose of the original *Ars Moriendi* is resurrected to become equitable with the self-centric needs of the contemporary individual. It should not be focused on religion or medical practices specifically, but be utilised as a symposium of broad ranging thoughts in order to provide guidance at end of life, and reduce the contemporary anxieties that pervade Western societies regarding death and dying; and be achieved through locating this reinvigorated framework outside of the medical model of care to ensure inclusion, while simultaneously incorporating the medical death for those who prefer it. I propose, therefore, that the *Ars Moriendi* be assimilated with the needs of the contemporary Western individual, through being restructured, reinvigorated and re-presented as a means through which individual choice and self-determination at end-of-life becomes incorporated into the mainstream of daily life; with those seeking the right-to-die no longer defined as other.

Limitations of the research

In this research I have specifically addressed the issue of individual patient choice at end-of-life in relation to the medicalised death, the use of medical models of care at end-of-life and how medicine and law collaborate to extinguish the right to choice and right-to-die for some individuals, irrespective of the similarity in practices either occurring or being requested; all from a sociological perspective. Therefore, the findings of my research address these issues specifically and, as such, give an indication as to what is occurring for individuals who are toward end-of-life within the UK and New Zealand specifically and more generally across Western societies. It must be noted, however, that I have not engaged with the issues of gender, race and ethnicity specifically in this study for the reasons previously identified, however, these are important fields of research that require further exploration and work in the future.

In addressing this issue explicitly it must be noted I have not examined in detail the notions of vulnerability, the arguments for and against the right to assisted suicide, nor the issue of institutional drivers. While many of these issues are acknowledged within this research, they are not engaged with in detail as to focus upon them would displace the emphasis I have sought to bring to the fore; but simultaneously note not only their significance in relation to contemporary dying per se, but that these issues would provide excellent backdrops for further engagement with this field of study.

Recommendations for further research

The opportunities for further research into the field of medical power, patient choice and human rights at end-of-life are both numerous and necessary to expand the body of knowledge and literature, particularly as we move forward and encourage the embracement of individual thought.

As a starting point in engaging with the futurality of the contemporary death and to provide a more in-depth analysis of the issues from the perspective of the individual, conducting one-on-one interviews could prove valuable. To obtain empirical evidence from such a resource would add a depth and richness to the analysis and outcomes. As such, to interview individuals following the medicalised

pathway to death, together with those seeking the right-to-die and those with experience of specific medical models of care would be enlightening. Furthermore, an in-depth analysis of the components of intolerable suffering, from the perspective of the individual as well as clinician and lawyer would provide a focused backdrop from which an understanding can be gained regarding the desire to end life at a chosen time or the inclination to prohibit this choice. In extending these recommendations, I would also suggest that engagement with the paradoxical use of PST, and how this sits in relation to euthanasia would prove enlightening, and would provide further detail in regard to the practices occurring at present within contemporary Western societies.

My final recommendation would be to consider a more profitable trajectory of research in place of the emergent narrative of the good patient/bad patient discourse which suggests the relationship of subordination between patients and medical practitioners be subverted in order to examine the role of the practitioners in terms of good and bad. Such research would engage with the opposite perspective of the domination/subordination narrative, to examine the role of medicine in developing this as a means of power.

Final thoughts
This research has presented a potent image of inequalities in the power relationships developed when individuals are faced with their life's end. The interrelationship of the power elites and their mutual interdependence suggests that the road to achieving individual choice will be neither straightforward, nor welcomed in either the UK or New Zealand. Although the locus of power remains at present within the field of medicine; through medicine's need for legal support on occasions, the weakness it exposes may prove pivotal if change is to be forthcoming for the future forward individual. Given the value of the autonomous voice through engaging with social media as a means of communication, it has exposed medical practices that would previously have been concealed within the jurisdiction of clinical practice or scholarly activity and, as such, has the potential to shift the locus of power away from medicine towards one of equity with the individual.

The right to choice at end-of-life and the right-to-die currently remain constrained by the notion of otherness, and to overcome such a burdensome label, a framework for change is required. Yet, the frailty of the medical construct and the pervading dominance of a culture of individual choice, produces a weakness that may transcend the boundaries of current practices, thus, encouraging clinicians and lawyers to engage with the individual seeking control at end-of-life. The idea that these powerful elites can engage in some clinical practices that appear not dissimilar to those sought in the right-to-die campaign poses a problematic discourse both for clinicians and individuals. It presents a situation of dichotomous practices that are apparent but untouchable at present, through the virtues acknowledged in this research. Yet, such matters provide a tangible starting point from which to move forward to renegotiate the contemporary death for the self-centric individual. It is, therefore, the potential engagement with re-presenting the *Ars Moriendi* as a futural, non-religious means of facilitating individualism and dispelling anxieties that appears to offer a more equitable, futural narrative of death and dying.

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Appendix 1: Databases

1. Australia/New Zealand Reference Centre
2. British Periodicals (1681-1970)
3. Canadian Newsstand Complete
4. ERIC (1966 – current)
5. GenderWatch
6. Humanities & Social Sciences Collection (Informit)
7. International Bibliography of the Social Sciences (IBSS) (1951 – current)
8. PAIS International (1914 – current)
9. Periodicals Archive Online
10. Pharmaceutical News Index
11. ProQuest Australia and New Zealand Newsstand
12. ProQuest Criminal Justice (1981 – current)
13. ProQuest Education Journals (1988 – current)
14. ProQuest Health & Medical Complete
15. ProQuest Health Management
16. ProQuest Newsstand (1984 – current)
17. ProQuest Political Science (1985 – current)
18. ProQuest Research Library
19. ProQuest Science Journals
20. ProQuest Social Science Journals
21. ProQuest Sociology (1985 – current)
22. ProQuest Historical Newspapers: The Guardian and The Observer (1791 – 2003)
23. ProQuest Historical Newspapers: The Irish Times and The Weekly Irish Times (1859 – 2012)
24. Sociological Abstracts
25. Sociology (Sage full-text journal collection):
a. Cultural Sociology
b. Current Sociology
c. Ethnography
d. European Journal of Social Theory
e. International Sociology
26. Social Theory:
a. Zygmunt Bauman
b. Michel Foucault
c. Jean-Paul Sartre

Appendix 2: Key words and phrases

1. "Assisted suicide" and "*human rights*"
2. "Assisted suicide" and choice
3. "Assisted suicide" and death or dying
4. "Assisted suicide" and law
5. "Assisted suicide" and medicine
6. "Assisted suicide", law and euthanasia
7. "Assisted suicide", medicine and euthanasia
8. "Continuous deep sedation"
9. "Continuous deep sedation" and euthanasia
10. Court papers
11. Court papers and "*The Liverpool Care Pathway*"
12. Court papers and medicine
13. Death and choice
14. Death, dying and "acts of parliament" UK
15. Death, dying and "acts of parliament" New Zealand
16. Diane Pretty, Tony Nicklinson and Paul Lamb
17. Diane Pretty, Tony Nicklinson and Paul Lamb and Debbie Purdy
18. Diane Pretty, Tony Nicklinson and Paul Lamb and Lecretia Seales
19. Dying and choice
20. Euthanasia and "assisted suicide"
21. Euthanasia and dying
22. Inquiry "death pathway"
23. Inquiry "death pathway" and court
24. Inquiry "death pathway" and legal
25. "*Liverpool Care Pathway*" and "assisted suicide"
26. "*Liverpool Care Pathway*" and "human rights"
27. "*Liverpool Care Pathway*" and "no consent"
28. "*Liverpool Care Pathway*" and "right-to-die"
29. "*Liverpool Care Pathway*" and "right-to-life"
30. "*Liverpool Care Pathway*" and court of legal appeal
31. "*Liverpool Care Pathway*" and euthanasia
32. "*Liverpool Care Pathway*" and law
33. "*Liverpool Care Pathway*" and legal
34. "*Liverpool Care Pathway*" and stealth
35. "*Liverpool Care Pathway*"
36. "*Liverpool Care Pathway*", euthanasia and control
37. "*Liverpool Care Pathway*", euthanasia and stealth
38. "*Liverpool Care Pathway*", medicine and control
39. "*Liverpool Care Pathway*", medicine and stealth
40. Medicine and law
41. Medicine, law and "assisted suicide"

42. Medicine, law and "The Liverpool Care Pathway"
43. Palliative care and choice
44. Palliative care and euthanasia
45. Palliative care and "right-to-die"
46. Palliative care and "right-to-life"
47. "Palliative sedation therapy"
48. "Palliative sedation therapy" and euthanasia
49. Paul Lamb
50. Tony Nicklinson
51. "Right-to-die" and choice
52. "Right-to-die" and "*human rights*"
53. "Right-to-die" and law
54. "Right-to-die" and medicine
55. "Right-to-die", medicine and law
56. "Right-to-life" and choice
57. "Right-to-life" and "*human rights*"
58. "Right-to-life" and law
59. "Right-to-life" and medicine
60. "Right-to-life", medicine and law
61. "*Liverpool Care Pathway*"
62. "Tony Bland" and "*human rights*"

NB: For Google UK and NZ searches, 'blog' and 'forum' were added to each phrase.

Google UK Search 2010 - 2015

Key words and phrases (Appendix 2)	Total Blogs returned	Duplicates from previous searches, not included in 'blogs used'	Blogs used	Total forums returned	Duplicates from previous searches, not included in 'forums used'	Forums used
1	142	4	55	141	8	29
2	101	13	40	151	18	13
3	103	31	24	150	33	14
4	114	49	18	156	39	6
5	104	44	19	95	28	9
6	95	52	7	123	35	11
7	92	51	6	104	43	3
8	21	1	9	21	4	5
9	19	9	5	11	8	0
10	188	0	0	53	0	0
11	118	11	23	99	9	6
Court Papers & LCP only	195	19	14			
12	176	1	1	126	0	0
13	212	7	7	167	5	3
14	153	1	1	170	0	0
15	33	0	0	28	0	0
16	15	0	6	10	3	0
17	10	3	4	7	6	0
18	0	0	0	0	0	0
19	139	22	8	157	12	6
20	98	62	1	130	49	3
21	108	31	14	170	39	3
22	39	4	9	21	4	2
23	27	10	2	13	6	0
24	36	11	2	21	5	2
25	61	14	7	42	5	1
26	87	13	5	110	10	0
27	30	3	4	19	6	0
28	44	5	4	31	3	2
29	30	6	2	18	4	2
30	77	10	2	59	6	0
31	72	25	2	78	13	1
32	113	26	6	235	16	1
33	114	30	5	235	17	1
34	26	4	2	11	5	0
35	114	26	10	229	15	2
36	69	21	4	62	12	1
37	14	4	1	6	4	1
38	115	22	1	248	13	1
39	27	6	1	10	3	0
40	169	2	0	110	1	0
41	113	62	4	86	40	0
42	145	37	4	211	15	2
43	126	15	12*	201	3**	3
44	101	35	9	129	20	1
45	103	14	27	88	19	22
46	79	11	11	65	7	6
47	4	0	0	4	1	0
48	5	0	1	7	0	0
49****	163	14	11	122	8	1
50	125	22	16	100	17	9
51	133	26	16	171	26	7
52	85	27	15	161	20	4
53	115	44	11	176	40	5
54	123	42	13	165	27	4
55	112	52	7	178	36	4
56****	159	8	1	258	5	1
57	105	12	3	234	1	1
58	71	8	4	233	8	3
59	99	15	11	225	6	5
60	150	10	9	230	11	1
61	114	37	14	234	23	6
62****	28	11	3	14	6	1
	5758	**1155**	**533**	**6919**	**826**	**86**

APPENDIX 3   Google New Zealand Search 2010 - 2015

Key words and phrases (Appendix 2)	Total Results Blogs	Duplicates from previous searches, not included in 'blogs used'	Blogs used	Total results Forums	Duplicates from previous searches, not included in 'forums used'	Forums used
1	44		17	33	4	8
2	49	9	19	44	11	8
3	68	26	11	59	13	13
4	64	30	18	65	26	8
5	56	40	12	54	29	5
6	68	53	8	53	37	3
7	57	52	5	50	33	3
8	4	0	4	0	0	0
9	9	4	2	0	0	0
10	135	0	0	154	0	0
11	7	1	6	0	0	0
Court Papers & LCP only	12	7	1			
12	21	0	1	12	0	1
13	189	11	15	154	8	4
14	19	0	1	10	0	0
15	22	1	1	16	1	0
16	0	0	0	0	0	0
17	0	0	0	0	0	0
18	0	0	0	0	0	0
19	182	25	17	144	18	8
20	64	57	6	61	45	2
21	90	44	24	99	39	10
22	1	0	1	0	0	0
23	78	1	0	0	0	0
24	0	0	0	0	0	0
25	8	4	4	3	2	0
26	8	2	0	7	7	0
27	0	0	0	0	0	0
28	5	2	2	0	0	0
29	2	2	0	0	0	0
30	9	4	0	14	2	1
31	12	9	2	7	7	0
32	13	10	1	16	4	0
33	16	12	1	15	3	0
34	1	1	0	2	1	1
35	19	13	1	24	2	1
36	10	10	0	2	2	0
37	6	2	2	0	0	0
38	51	12	3	1	1	0
39	1	1	0	0	0	0
40	153	3	10	99	2	2
41	60	50	7	50	30	3
42	33	14	1	17	5	1
43	91	29	15	117	17	8
44	67	41	16	55	24	7
45	34	24	5	22	18	0
46	28	14	4	23	14	0
47	1	0	1	0	0	0
48	11	0	0	8	0	0
49	0	0	0	0	0	0
50	10	5	2	3	1	0
51	53	33	8	33	16	7
52	41	22	6	22	12	2
53	61	37	4	46	29	0
54	52	31	5	32	18	0
55	49	31	1	35	21	1
56	53	39	2	33	22	0
57	87	8	7	74	3	2
58	82	15	4	91	19	1
59	77	17	3	30	10	1
60	42	11	2	64	20	0
61	20	16	0	25	3	0
62	1	0	1	0	0	0
	2506	**885**	**289**	**1978**	**579**	**111**

Key Code for Appendix 3

*   about specific trust aims

**   strategies not interactive forums

***   no authorised to access website

****   abortion & disability

Appendix 4: Emerging themes

1. 'A good death'
2. 'Art of dying'
3. ACP
4. Active euthanasia
5. Advanced care directives
6. Advanced care planning
7. Animals have more rights
8. Anxieties of death
9. *Ars Moriendi*
10. Assisted suicide
11. Autonomy in choice
12. Bad medicine
13. Brittany Maynard (Oregon)
14. Brittany Murphy (Oregon)
15. CDS
16. Choice
17. Choice becomes duty
18. Choice becomes obligation
19. Continuous deep sedation
20. Control
21. Culture
22. Death taboo
23. Denial of death
24. Deviance
25. Diagnosing dying
26. Dianne Pretty
27. Dignity
28. End-of-life care
29. End-of-life care hospital
30. Ethics
31. Euthanasia
32. Euthanasia by default
33. Euthanasia in palliation
34. Fear of death
35. Futility
36. Hastening death
37. History of death and dying
38. Home deaths
39. *Human rights*
40. Humane choice
41. Hunger strike to die
42. *Iatrogenesis*
43. Identity
44. Illusion

45. Institutionalisation of right-to-die
46. Knowledge
47. Language
48. Law
49. Lecretia Seales (NZ)
50. Limits to a free society
51. Live too long through science
52. Media representations
53. Medical models of care
54. Medical power
55. Medical power and control
56. Medical social control
57. Medical technology
58. Medicalisation
59. Morality
60. Narratives
61. Other/otherness
62. Palliative care
63. Palliative care disrespects the natural law
64. Palliative sedation therapy
65. Passive euthanasia
66. Paul Lamb
67. Prolonging death
68. Prolonging life
69. PST
70. Purdy
71. Reform *human rights* to save *human rights*
72. Right-to-die
73. Sanctity of life (too far)
74. Self determination
75. Sleep until death
76. Stealth euthanasia
77. Suffering and animals
78. Suffering is not beautiful
79. Suicide is painless
80. Technology
81. *The Liverpool Care Pathway*
82. Tony Nicklinson
83. Two sides to the debate
84. Unbearable suffering
85. Withdrawal of nutrition