THE RIGHT-TO-DIE AND THE COMMUNAL BODY

AN EXAMINATION OF THE MEDIA INFLUENCE, ETHICAL PRINCIPLES AND
STAKEHOLDER ATTITUDES TOWARDS ASSISTED DYING IN NEW ZEALAND,
FROM A SOCIOLOGY IN BIOETHICS PERSPECTIVE

BY

SARAH ELISABETH REVELL-DENNETT

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When I was little, and I thought that children grew up
and parents grew down, so that one day the child became the parent
and the parent became the child,
I had in my head such an impressive idea of what an adult was.
- Sheila Heti, *How Should a Person Be?*

Abstract

This thesis is based on a sociology in bioethics approach which seeks to demonstrate that the current rhetoric being used by parties on both sides of the debate is no longer useful for the realities that people are expressing or living. In sociology, the assisted dying literature has tended to focus on the social, political, economic and cultural contexts within which it is sought, and to understand the range of definitions that are used to conceptualise a good death. Bioethics literature, on the other hand, has removed the socially situated individual from ethical discussions of assisted dying. By engaging with an idea of the communal body, interpreted as a moral community who experience intersubjective realities, this thesis provides a platform to combine these two perspectives. It seeks to examine the range of possibilities for understanding the socially situated and relationally autonomous individual requesting medically-assisted death.

The debate in New Zealand surrounding the right-to-die was brought to the fore in 2015 when terminally ill Lecretia Seales took a case to the High Court. Her argument sought a clarification of the current law, which would have allowed her doctor to provide life-ending medication should her pain and suffering become unbearable. Seales' case was unsuccessful but it, along with the following events, has succeeded in bringing attention about end-of-life choices to the New Zealand public and media. The current *End of Life Choice Bill*, which stands before Parliament and was proposed by Member of Parliament (MP) David Seymour of the ACT Party, will once again provide a chance for these issues to be voted on by New Zealand's elected officials.

A critical analysis of provincial New Zealand media articles, across the time periods between 2002-2005 and 2012-2015, has sought to highlight the ways the media influences public perceptions of the debate and emphasises the limited discourse available. These years represent significant periods during which events in time led the media to variably describe these deaths from murders to mercy killings. Further thematic analysis (TA) of 12 interviews undertaken with stakeholders in the field of medically-assisted dying show discrepancies between lay public knowledge and informed stakeholder views.

Overall, this thesis situates the communal body within the right-to-die argument in New Zealand. The results lend themselves to support a view that the current lack of available discourse has for the most part irrevocably rendered a divide between those who campaign for change and those who do not. In this thesis, I argue that by positioning itself within a

sociology in bioethics approach, the right-to-die debate in New Zealand will be afforded a clearer understanding.

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Preface

I became interested in the idea of a right-to-die following an Honours year paper, taken in 2013, that looked at the sociology of ethics and morality. For my final research essay, I looked into the force feeding of prisoners at Guantanamo Bay. Within this literature I stumbled across the concept of a right-to-die. The very idea that someone could decide when to end their own life and in what manner – and for that to somehow be an active policy for a sovereign government – got me thinking about whether such cases could, and perhaps more importantly should, have a place in medical practice in New Zealand.

The background to this, or why I believe it is important to be discussed in New Zealand in 2018, is that assisted dying is a current political issue. David Seymour's *End of Life Choice Bill* was drawn from the ballot on 8 June 2017 and is currently at select committee stage, following a first reading, before it is voted on again in a second reading in Parliament. At the beginning of August 2017, Attorney-General Chris Finlayson released a report declaring that in its current form the *End of Life Choice Bill* is consistent with the rights and freedoms affirmed in the New Zealand Bill of Rights Act 1990. More than the Bill being drawn from the ballot, this is the bit that excited me because I inferred from the decision a nudge towards recognising the right-to-die, at least within the legal framework.

I am excited to finally share my research with people who are as taken with end-of-life discussion as I am. Dying, as it is for living, is a fundamentally social event with the isolation and loneliness brought on by terminal illness exacerbating, and being exacerbated by, the patient's physical and mental suffering. To this end, our present individualistic medical ethics are isolating and potentially destructive, and it is here that sociology is conducive to bioethical and medical discourse as it situates the individual within a socially embedded environment. My research aims to expand the conversation between a variety of disciplinary discourses. These include moral philosophy, medical ethics, medical practice, social psychology, public policy and legislative practice. So many of these discourses have become viewed as isolated approaches within and around discussion on the end-of-life and assisted dying, but I believe now is the time to bring them into dialogue.

Drawing on contemporary sociological theory, this thesis aims to provide an understanding of assisted dying legislation and its implications within the wider communal body. Such a work presumes, on my part, a tacit awareness of the communal body that constitutes New Zealand

society. It stems from the belief that these moral communities are underlying insofar as they form the social ties that concern the multiplicity of persons experiencing a variety of social lives.

Mildred Solomon (2005), in her article 'Realizing bioethics goals in practice', looked into the idea of a sociology in bioethics and touched specifically on how it might aid in the assisted dying discussion. This work is the first large-scale attempt to consider conversations between the disciplines which relate directly to assisted dying. As such, I suggest that this thesis makes an original contribution to New Zealand research on assisted dying, which until this point has largely maintained a focus on medical ethics and psychology or legal issues.

Current social expectation holds that a terminal patient should act in a perceived way or should constantly endeavour toward curative treatment, lest they be seen to be 'giving up' on life. As Glaser and Straus (1968) discuss, dying trajectories can take many forms but they also need to be culturally appropriate for both patient and whānau. The dying role can then become understood as being a continuation of the living role that they maintained.

Atul Gawande, in his book *Being Mortal* (2014), highlights the range of possibilities that are open to a person over the course of their dying process. In my view, *Being Mortal* should be compulsory reading for anyone planning on dying one day. Gawande not only shows the advantages of having open conversations about death, but questions the overwhelming role of medical technologies and the medicalisation of the dying process.

The constant innovation of medical technologies has further challenged the individual's understanding of health and wellness and what it means to be 'alive'. Technological advancement has allowed those with a chronic terminal illness to continue living with the aid of medical technology. It was my intention within this research to help create a path for further conversation among our moral communities within this interdisciplinary discussion. It was not my intention to attempt to solve the assisted dying problem or find solutions that once and for all provide a kind of revolutionary approach to assisted dying legislation. Instead, I have sought to consider potential new avenues for approaching discourses around assisted dying.

Overwhelmingly, this is a controversial issue, but like a number of these sorts of wicked problems they are not going to go away. Because people often shy away from talking about death, we as citizens are not necessarily as engaged with what form we personally think that the legislation should take. While I guarantee that many New Zealanders are able to give you

their position on assisted dying, such opinions are always going to rely on the social context of the individual and are likely to be informed by mainstream media depictions along with the dying processes that they have seen others succumb to.

No-one really likes having to talk about whether or not nana wants to live on a ventilator, or what happens when mum cannot care for dad, and what if his pain is unbearable? But the reality is that we all eventually get there. In 2002, there was a case in Auckland where 77-year-old Rex Law killed his wife by hitting her over the head with a wooden mallet and then suffocating her with a pillow. It was ruled an aiding of suicide because they had previously made a pact, but I do not really think the fact she knew it was coming makes it any better. What I am trying to get at is that it is important we have these conversations now. Instead of resorting to using a mallet, I want people to feel comfortable with having end-of-life discussions with those around them, including their health care professionals as required. More than anything, it is here that the benefits of relationally autonomous approaches within health care and viewing individuals within their social context and among their social relations could prove to be beneficial for both patient and whānau, and this is considered in this thesis.

Hopefully, my own research has made an attempt to highlight what I believe can be some of the advantages of taking such a path in end-of-life research, along with placing us on that path, but without a doubt I feel there is more research to be done. It is from this point that this research stems, at a crucial time in the history of New Zealand to be making these decisions and having these discussions.

Chapter one: Introduction – assisted dying legislation in New Zealand

Introduction

Throughout the course of this research people would often inquire about what I was studying. As I interacted with those around me and discussed with people the nature of my research I was often struck by the recurrent relaying of stories about the dying process. What I came to notice is that on raising the topic of assisted dying with people within *my own* community, their most common reaction was to provide a story of a family member who had passed away. These were stories of husbands, mothers, sisters or uncles suffering through unbearable symptoms at end-of-life. At other times dementia had meant that the family became strangers to the now deceased. Perhaps most frequently, however, people would relay a story in which their loved one had been dying, whether in an institutional setting or the home, and following an open discussion between medical practitioners and the family the near-dead would have their dose of morphine incrementally increased until they passed away. This anecdote from my own experience is not intended to cast doubt on the collective trust society holds in its medical professionals, or to cast aspersions over family members making decisions at the end-of-life.

In a recent *New Zealand Herald* commentary, palliative care specialist Sinead Donnelly (15 Dec 2017) strongly criticised MP David Seymour for his comment that it is frequently the case that morphine is intentionally given by physicians in large doses at the end-of-life, with the intention of hastening death. In her commentary, Donnelly questioned how Seymour would dare accuse her profession and colleagues of illegal practice. I present this account to highlight my personal experiences of claims that some groups have attempted to denounce as occurring. Furthermore, I believe that this anecdote highlights a need for an open discussion among New Zealanders. The communities that constitute its citizens must engage thoughtfully with the assisted dying debate so that the current covert practices are not left unchecked. Rather, they help to inform the discussion by taking as its starting point an acceptance that this practice is occurring. In doing so, it could follow a process like that seen in The Netherlands whereby the doctors turned to legislation to clarify practices that they recognised as already happening. In this way, such legislative change in New Zealand could be taken as a natural evolution of the law as it seeks to keep pace with the adjustments needed and being brought about by the development of medical technologies and social change.

This thesis therefore situates the question of assisted dying in the context of New Zealand. As such, my view is that New Zealand will enact a form of assisted dying legislation at some stage in the future. This should not be taken to be the effect of a demoralisation within society, but instead as the impact of technological advances in medicine and changing understandings of personhood, a person's goals for their life, and how we understand the body in relation to society. Elizabeth Grosz (2017, p. 2) states that, "The open-ended nature of the future, its capacity to deviate from the present and its forms of domination and normalization, necessarily link an ethics, how one is to live, with a politics, how collectives, and their constituents, are to live and act together and within what protective and limiting parameters". Whether or not New Zealand creates its own legislation – in the short term or at a later date – it follows that such a law must take into account the voices of the most vulnerable and the concerns that they hold with regard to their safety and perceptions of worth so that any deviation "from the present and its forms of domination and normalization" (Grosz, 2017, p. 2) do not further harm, but only benefit, the lives of individuals within New Zealand communities.

Beginning from this stance, and having identified relevant material from sociology and bioethics to assist our understanding, I provide a discussion that will help to articulate the greater range of lives that are being experienced in our communities, through the integration of discourses of the body and self-identity into the assisted dying argument. The research presented in this thesis must be emphasised in its interdisciplinary outlook. Although this work draws on sociological thought and literature on assisted dying, it is concomitantly positioned alongside that from the field of bioethics. Such an emphasis highlights the role that an array of disciplines and fields should have within the assisted dying debate, as its impact on many aspects of social life should not be forgotten. This research therefore draws on legal and medical literature to more fully immerse itself within the range of possibilities open to New Zealand regarding assisted dying.

Precedent has been set for the interdisciplinary research approach presented here, and further details on the relationship between sociology and bioethics can be found in De Vries (2003); De Vries, Turner, Orfali and Bosk (2006); Shaw (2015a; 2017). While sociology can aid in the discussion around assisted dying, it cannot inform all aspects of its application and nor, for that matter, can bioethical, medical or theological frameworks. Starting with the current introductory *Chapter one*, this thesis therefore hopes to further the conversation within this interdisciplinary discussion. This present introduction offers a brief contextual account of

assisted dying in New Zealand. It then considers the nuances in vocabulary used in the debate, as well as defining the terminology to be used in the following chapters. Furthermore, it introduces the reader to some of the prominent groups and persons that are associated with the debate in this country. This chapter ends by providing the research questions and outlines how they will be addressed and answered within this thesis, before concluding with a summary of the chapters to follow.

The Local Context for Legislation

On 6 June 2017, Act MP David Seymour's *End of Life Choice Bill* was drawn from the ballot box and introduced into Parliament for consideration. This Bill attempts to legislate for assisted dying in New Zealand law and includes safeguards and regulations for its practice.¹

On 13 December 2017, Seymour's Bill had its first reading by the newly-formed government. The last Bill to be voted on by the House was defeated at its first reading by just two votes. The latest Bill saw a quite convincing vote in favour of it progressing to a select committee by a convincing 76 votes for to 44 in opposition. The select committee gathers information and prepares a report on the Bill for the House, including recommending changes to the Bill before they then debate the report and vote for a second time.

A select committee has already convened and produced a report over the issue of assisted dying within the New Zealand Parliament. Established by the previous National-led government, the committee sought to "investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable" (New Zealand Parliament, 2016). This was done following the death of terminally ill woman, Lecretia Seales, who had taken a case to the High Court in 2015 to seek clarification in the law over whether her doctor would face prosecution if that same doctor ended her life [missing word?] medical assistance. Subsequently, Seales' widower Matt Vickers, along with a cross-party group of four MPs, presented a petition to Parliament that called for a select committee inquiry. This petition was delivered and led by Maryan Street on behalf of the End-Of-Life Choice Society of New Zealand.

¹ A full copy of the *End of Life Choice Bill* proposed for consideration by Parliament can be found at www.legislation.govt.nz/bill/member/2017/0269/latest/DLM7285905.html

Groups and Prominent Persons in the New Zealand Assisted Dying Context

The End-of-Life Choice Society of New Zealand became an incorporated society in 2004 following the merging of the Wellington and Auckland branches of national committees dedicated to the same interests. It was previously called the Voluntary Euthanasia Society New Zealand (VESNZ). Former Labour MP Maryan Street is the current President of the national committee. On its website it states that it, “provides information about and the opportunities for open and frank discussion on, the legal rights of people to obtain assistance in ending their lives and the legal alternatives that are available to such an action, when they suffer from, or may in the future suffer from, an incurable disease or condition which they find unbearable”. This group is one of the more outspoken end-of-life care groups in New Zealand, holding events and meetings regularly around the provinces. Their members feature regularly in the ‘Letters to the Editor’ section of regional newspapers as they attempt to further the progression of legalised assisted dying in New Zealand.

Alongside this advocacy group are also three chapters of Exit International which are described as being the “grass-roots, local way for Exit members in Australia, New Zealand and the UK to get to know each other & [sic] come together for information & [sic] support”. They consist of “small, informal, local groups of Exit members who meet for friendship & [sic] support” (Exit International, 2017). Exit International was established in 1997 by embattled Australian doctor Philip Nitschke. It claims to be a leading end-of-life choice information and advocacy group that, “sets itself apart from other aid-in-dying organisations in that we take a Civil Rights [read: non-medical] approach to a person’s right to determine the time and manner of their passing”. It hosts conferences several times a year in their chapter locations.

At the other end of the spectrum are vocal groups that provide the opposition for the above groups. Euthanasia-Free New Zealand is a nationwide society of individuals who describe themselves as being “united in the belief that the *legislation* of euthanasia – voluntary or not – and assisted suicide poses a great threat to the wellbeing of our society” (Euthanasia-Free New Zealand, 2017). This is not to say that their members unanimously disagree with voluntary euthanasia in principle in certain individual cases; instead, they hold diverse reasons as to why euthanasia should not be legislated for. Euthanasia-Free New Zealand instruct, on their website, that they will work with “anyone who opposes the legalisation of euthanasia and assisted suicide, for any reason, and irrespective of their views on other

issues". They also belong to the Euthanasia Prevention Coalition (see Euthanasia Prevention Coalition, 2017 for details and mission statement), which acts in much the same way as Nitschke's Exit International, although advocating on a global scale to ensure that assisted dying legislation is not enacted into law. Renee Joubert is the executive spokesperson for Euthanasia-Free New Zealand and has in recent years become an outspoken critic of the practice, both in this country and internationally.

Euthanasia-Free New Zealand is also a member of the Care Alliance, which brands itself as bringing "together organisations and individuals who want to nurture better conversations about dying in Aotearoa New Zealand" (Care Alliance, 2017). Care Alliance are in opposition to the legislation of assisted dying and were given the opportunity to provide a dissenting voice in the case that Lecretia Seales took to the High Court in 2015. These groups inform a significant segment of the New Zealand lay population, providing voices in the media, writing letters to the media, holding events in favour and against the legislation of assisted dying but, most importantly, ensuring the dissemination of information that informs individuals of their options. In some cases, these groups explore the expansion of palliative and hospice care, viewing end-of-life suffering as an unfortunate but necessary part of life.

Along these lines, such groups often advocate for the use of palliative care and the reliance on medical interventions to eliminate as much suffering as possible. In other cases, they provide the necessary means through which people can end their lives beyond the boundaries of legislation, often by their own hand, and in the absence of friends and family. Such practices remain risky and hold an inherent danger that attempts will not be successful, while also ensuring a gruesome discovery for whoever may happen across the body. Although these groups have a prominent place in the production and reproduction of the assisted dying discourse, the often vehement beliefs of members can often disturb the balance of judgement and allow followers to easily disregard the claims of their opponents. Such arguments are framed by dialogue that is employed to tilt the portrayal of opinions and to represent the various voices bound by lines of socially constructed rhetoric used to advance the cause. A summary of the different definitions and vocabulary used within the assisted dying debate follows in the next section, in order to leave the reader with no doubt as to where the rhetoric used within the following discussions positions them semantically.

Associated Definitions and Vocabulary

Vocabulary associated with assisted dying, and bioethics in general, is often complex. While on the face of it many of the concepts used may appear straightforward, they are often value-laden and can take on an entirely different meaning depending on perspective and context. As is shown in *Chapter four*, many people take for granted the term ‘dignity’, yet doing so can lead to miscommunication. One person’s interpretation of assisted suicide may constitute for another little distinction from traditional suicidal acts, definitionally and morally. Further, and as noted by Joanna Sikora and Frank Lewins (2007), within popular discourse the distinction between active and passive euthanasia is often reduced to the difference between “killing” and “letting die”. However, this reductionist approach can lead to an overlooking of more nuanced characteristics of its application. Therefore, it is important to delineate for the reader how specific terms are understood throughout this work.

Following a Foucauldian approach to the use of the word ‘discourse’, I take knowledge to be constructed through its use. This is not to say that what we know is created by what is spoken, but that the statements upon which the social world is produced and constituted are created by the formations, relations, productions, transformations and rules of discourse. However, that is where the similarities to Foucault end and I take discourse to comprise the statements and opinions that relate specifically to forms of social interaction and which can be characterised by various themes, concepts or values that help to communicate beliefs and opinions of those speaking.

Another of these words is ‘patient’, which refers to the primary recipient of care, taken to be a person suffering from illness or injury. Throughout this thesis, patients are most commonly referred to in relation to their situation at end-of-life and their status being ‘terminally ill’. Those who are terminally ill are taken to have an irreversible (and ultimately fatal) condition, with the disease being either the primary (i.e. cancer) or secondary (i.e. pneumonia) cause of death. ‘Intolerable suffering’, then, refers to either the physical and mental suffering experienced by a patient because of their terminal illness. The suffering being experienced by the patient is taken to be long-standing and irremediable, with only minor respite being offered from the use of medication. It may be marked by uncontrolled symptoms, psychological distress and existential suffering.

In this thesis vulnerable people, as referred to throughout, are characteristic of those individuals who are oppressed through policy choices and discourses of inferiority. Following the work of David Mechanic and Jennifer Tanner (2007), I take vulnerability to mean a susceptibility to harm resulting from interactions between available resources, individuals, the circumstances and difficulties they face, and the communities within which they reside. As Mechanic and Tanner (2007, p. 1220) state, vulnerability can result from “developmental problems, personal incapacities, disadvantaged social status, inadequacy of interpersonal networks and supports, degraded neighbourhoods and environments, and the complex interactions of these factors over the life course”. Thus, the priorities that are given to removing various vulnerabilities reflect the social values of communities and their willingness to address the issues vulnerability may arise from.

As discussed by Elizabeth Hallam, Jenny Hockey and Glennys Howarth (1999), research shows that older people have a tendency to assert their “good health”, even if this is only done following the expectation that being old and being ill naturally go together. Although this may be the case for the public, this thesis starts from the assertion that the two, being old and ill, are not in any way mutually exclusive. When discussing the option of assisted dying for individuals, this research therefore begins from a point of discussion premised on a belief that if legislation is to be enacted it must be done with a restriction on those with terminal illnesses who are within months from death. This excludes ‘old age’ being viewed as a terminal illness, which from certain perspectives may appear apparent owing to the frailty and physical deterioration of older people, but does not necessarily reflect how the elderly internally construct their self-identity.

Difficulties in prognosticating aside, the assurance of the patient’s death being imminent owing to a chronic, life-ending illness provides a safeguard that mitigates against risk for the elderly, disabled or otherwise marginalised communities. This definition also excludes those who are in persistent vegetative states, instead focusing specifically on individuals consenting to their own deaths in an act that actively, as opposed to passively, ends their life. This thesis most notably, however, does not focus on Alzheimer’s disease and various forms of dementia amongst the ageing population. While noting the prominence and significant moral quandaries those afflicted with such illnesses hold regarding assisted dying, the eligibility criteria proposed in New Zealand would not, and I believe at this stage *should not*, provide for the assisted deaths of such individuals.

The term 'euthanasia' can be broadly separated into three different understandings of the ways that a person can be euthanased. For these definitions, I will follow the widely understood conceptions by John Wilkinson (1990). First, there is *voluntary euthanasia*, which is requested by the patient or agreed to by them. Secondly, there is *involuntary euthanasia* where the agreement of the patient could be obtained but it is not. Finally, there is *non-voluntary euthanasia* where the agreement of the patient cannot be obtained because of mental incapacity. Beyond these definitions is a further breakdown into *active euthanasia*, where death is actively produced with deliberate intentions and positive means, and *passive euthanasia*, where death is deliberately produced by withholding or withdrawing the ordinary means of nutrition and/or hydration (Wilkinson, 1990). I will now elaborate on both passive and active euthanasia to explain the practice of active voluntary euthanasia.

The language of active and passive euthanasia can be largely differentiated by delineating between killing and letting die. Many authors, notably James Rachels (1975; 1986), argue that there is little differentiation between active and passive euthanasia when it comes to these distinctions and therefore passive euthanasia is as morally questionable as passively letting a person die. The idea of letting a person die can be quite controversial in the context of medical practice. For the sake of this thesis, however, passive euthanasia will primarily refer to cases where treatment is withheld or withdrawn, where the patient voluntarily stops eating or drinking, or where the patient is terminally sedated until death (Quill, Lo, Brock, 1997). Other scholars believe that the distinction can help in properly understanding when euthanasia could be morally permissible; it is the differences in the two approaches that I would now like to turn to. What is important to note before any discussion occurs is that in both active and passive euthanasia there is an intention to hasten death in the patient's interests. It is on the point of whether this action is intended to hasten death that is of primary issue. I would like to begin to formulate an understanding of what passive euthanasia entails.

Passive euthanasia is widely understood as the withholding of treatment from a terminally ill patient. According to Garrard and Wilkinson (2005) there are three conditions that must be met in order for passive euthanasia to occur. First, they believe that there must be a withdrawing or withholding of life-prolonging treatment. Secondly, the primary purpose of withdrawing (or withholding) said treatment is to hasten the patient's death. Lastly, Garrard and Wilkinson believe that the reason for hastening death must be in the patient's best interests. They therefore believe that the grounds for passive euthanasia are in the interests of the patient where their expected quality of life is so poor that its continuation will be worse

for them than death. What this portrayal of passive euthanasia fails to include is the other situations in which treatment of a patient may be withdrawn or withheld. That is, it assumes that allowing a person to die for other reasons (burden of care, cost, futility of treatment, refusal of treatment, compassion) goes beyond the scope of being passive and is therefore deemed as either active euthanasia, suicide or, at the extreme, murder.

In their argument, Garrard and Wilkinson (2005) hold that active and passive approaches to euthanasia are morally incompatible. They form an argument based on the ideal that passive euthanasia does not in fact cause death in the same way that active euthanasia does. Garrard and Wilkinson claim that because an omission cannot cause anything, it can therefore not cause death and thus passive euthanasia is not actually euthanasia. In cases of terminally ill patients being taken off life support, or never being placed on it, this causation argument claims that it is not the inaction of attempting to save the patient that causes their death but in fact the terminal disease does. What this view also manages to do is to release the physician from the burden of killing as their omitted act is not the final cause of death. Passive euthanasia from this perspective can be seen as a way for medical practitioners to get around the current moral dilemmas surrounding assisted dying. However, while I understand the simplicity of taking such an approach, I do not believe that Garrard and Wilkinson's arguments go far enough to help solve the quandaries that surround assisted dying legislation and practice.

While I appreciate that there can, at times, be little distinction between killing and letting die, from here on the discussion of euthanasia will refer directly to the active sense of the word. Further, the proposed *End of Life Choice Bill* that has just been voted on specifically relates to the active ending of a person's life by a medical practitioner and thereby highlights the significance of the issue in our contemporary society. For the further sake of clarity, this thesis will also focus only on voluntary and non-voluntary euthanasia as I believe that the use of involuntary euthanasia raises a number of new issues that require more space than this thesis can provide. Developing on the definitions of euthanasia provided herein, this thesis will refer to *the active and deliberate ending of life as requested by a patient to secure the intentional release from pain and suffering, by means of lethal injection when relief cannot be sought by other means.*

In more recent bioethical discussions, the grey area surrounding the definition of assisted dying has moved from consideration of differences between passive and active actions, to a

greater discussion on the distinctions and differences between assisted dying and assisted suicide. Again, due to space limitations, while this thesis does not provide discussion on these differences, clarification of the terms is important for understanding the different approaches that can be taken to end one's life. Although it is acknowledged that people will have differing understandings of the above terms, the topics to be discussed in this thesis fall on the clarity of such definitions and understanding. The importance of them and the way they are understood cannot be overstated enough. Like all discourse, the uses of different terms, which may on the surface seem minor, are employed by proponents on either side of the debate to skew how their claims are interpreted and received and, therefore, how changes are received.

In the following discussion, assisted dying is an overarching term to be used interchangeably with, if not in preference to, euthanasia. In this thesis, and unless otherwise specified, assisted dying will encapsulate the meanings of both medically-assisted dying and assisted suicide. I will therefore not distinguish, when done voluntarily, between whether a medical professional, family member, friend or the patient themselves takes the final action to end life. It is from this term too that we can come to also distinguish between assisted suicide and medically-assisted dying. An example of a legislative change resulting in legally-assisted suicide can be found in the State of Oregon's *Death with Dignity Act*,² whereby patients are prescribed or given the medication by their health care professional but must themselves be the one who makes the final administration of medicine.

In this thesis, suicide is understood as it has traditionally come to be viewed as the intentional taking of one's own life, although assistance is provided in the acquisition of medication to end the life. Medically-assisted death follows in much the same pattern and is defined as a voluntary and intentional act to end the life of a terminally ill patient. Medically-assisted dying can be evidenced legislatively in The Netherlands where the patient requests an end to their life and this is achieved through a prescribed administration of medication by the patient's primary care physician. For the most part in this thesis, assisted dying will be used in place of euthanasia. This is owing to the traditionally held views that people place on such language. In order to move away from the traditional conceptions of the term, many of which foster links to the notion of eugenics, I believe it is pertinent to use a value neutral term to provide the discussion with a clean slate for ongoing dialogue.

² For a more detailed discussion on the main points of this Act please see the next chapter.

Research Questions and Chapter Overview

Specific research questions are detailed in the introductory sections of the eight succeeding chapters. Broader research questions to which this thesis relates are as follows:

- What role can a patient's social death be seen to have in relation to suffering?
- What part can the 'dying role' play in how we approach current understandings of the end-of-life in relation to assisted dying?
- How can relational approaches to autonomy benefit the current assisted dying and bioethics literature?
- How does the communal body affect, and how is it affected by, current claims around a right-to-die?

The present chapter provides the boundaries of the following research and seeks to provide upfront the terms of reference within which this work is situated. This is done to avoid any confusion in relation to vocabulary, definitions or semantics that pertain to the specific use of terminology, the employment of which can variably construct meaning for those involved in the discussion. This introduction chapter also provides a brief overview for the context of the assisted dying debates. This contextual environment is discussed in detail in *Chapter two*, which looks at dying within New Zealand and situates the assisted dying discussion within the current legal and medical frameworks that regulate society. The nature of the various assisted dying legislation that is a feature of jurisdictions worldwide, and can help to inform New Zealand's own debate by providing evidence from valuable empirical experiences, is also outlined in this chapter. This is done to identify variations in the application of the law and possible avenues for New Zealand MPs to consider. This chapter then considers the case of Lecretia Seales, which has been particularly prominent within the media, contemporaneously providing references for many within the lay public who may otherwise know little about the topic. *Chapter two* concludes with an overview of where the current legislative process sits in New Zealand.

Chapter two also provides the backbone for understanding the context within which assisted dying legislation could be introduced in New Zealand. It shows how particular features of health care within this country are provided and the regulatory frameworks that give

guidelines and policies for medical practice. It also considers some of the relevant health and mortality statistics of concern for the development of assisted dying legislation and the nature of ageing and dying within New Zealand. Following the common law of this country, judicial system work is informed by precedent from previous cases that have gone before the courts. Mercy killing cases, murders and assisted suicides make up the cases that are significant in New Zealand for showing how convictions have frequently shown leniency from the courts and these are also discussed. Finally, *Chapter two* concludes by situating New Zealand in mid-2018, outlining the current legislative process for Seymour's *End of Life Choice Bill* and how it might sit within a legislative framework going forward.

The following three chapters turn toward the sociological and bioethical literature that is drawn upon within the assisted dying arguments and the claims proposed on either side. Beginning with *Chapter three*, this looks at the sociological approaches towards death and dying in contemporary society. It situates the discussion amongst the sociological literature by informing the reader of the structural conditions within which modern death and dying is contextualised. This chapter highlights the social nature of the dying process and the ritualistic behaviours that organise social interaction when death occurs within the community. Looking at how medical knowledge has developed provides reasons for the ways that deaths occur within modern western societies. Drawn into this is a discussion of the implications brought about by an increasingly technologised society, which has largely attempted to confine death and the dying process within institutional walls, lest individuals be reminded of its inevitability and fear its contagion.

Chapter four then turns to consider the arguments that can largely be taken to provide coherent moral frameworks on which assisted dying can be debated and decided upon. Within this chapter the fear of encountering a slippery slope should assisted dying be legalised can be taken as forming a significant argument. It draws upon discourses embedded with risk to highlight the danger of at all breaching upon the sanctity of life and the complete prohibition in bringing about another individual's death. This discussion is followed by an overview of the sanctity of life arguments against those who advocate for death with dignity. This then leads into a deliberation of the ambiguity that is the concept of dignity, and the difficulties that this presents for modern day medicine and assisted dying specifically. Bringing this chapter to a close is then a brief consideration of traditional theories on suicide. These should not be conflated with assisted dying, but they remain important for how it is approached as a form of voluntary and self-inflicted death.

The next chapter, *Chapter five*, moves on to look at the principle-based approaches that have traditionally been employed when it comes to the consideration of assisted dying and end-of-life care from a bioethics perspective. It identifies the constraints that result from such an approach drawing on the popular principles of autonomy, justice, beneficence and non-maleficence, and contemplating them as they relate to the assisted dying debate. The shortfalls in their application are highlighted before adopting an alternative ‘sociology in bioethics’ approach to the topic of assisted dying. A sociology of bioethics approach is borrowed from the work of medical sociologist and bioethicist Raymond De Vries (2003), and is called upon as a means by which the contentious issues that formulate the dispute can be mitigated, or at least scrutinised, on the basis of new methods and a recognition of alternative options for end-of-life care practices in future care plans and policy.

Chapter six provides the methodological framework for the thesis, and covers the research design and method of data analysis that is undertaken. This chapter prefaces *Chapter seven* which provides the findings for the analysis depicted in the previous chapter. These chapters represent an original contribution to current research, being the first qualitative studies of their kind conducted in New Zealand. These diptych studies were done across two data sets, the first being a critical analysis of provincial New Zealand media articles across the time periods between 2002-2005 and 2012-2015. This analysis identifies the ways that the mainstream New Zealand media influences public perceptions of the assisted dying debate. It emphasises the limited discourses available to the lay public owing to the narrative illustrations that are portrayed within the New Zealand print news media. As is detailed in *Chapter two*, the years selected for analysis represent significant periods over which time-specific events led the media to variably describe deaths from murders to mercy killings, all the while providing frames to subtly inform readers and construct identities to further a specific agenda.

A further data set is comprised of a thematic analysis (TA) of 12 interview transcriptions. I undertook these interviews during 2014-2016. The participants in this analysis consist of stakeholders who in some way hold an interest in the field of medically-assisted dying through their professional or personal lives. The analysis of these two data sets, when presented side-by-side, show discrepancies between the lay public’s knowledge that is generated by their consumption of mainstream media as a primary news source, compared with that of informed stakeholder views that provide a more balanced and complex assessment of the nuances of the debate.

The list of characters that feature regularly in the newspapers referring to assisted dying were all unfortunate enough to, in some way, be implicated within or by a death. The nature of these articles means that they refer to not only the deceased who had taken their lives, but also the living who were active in bringing about another's death, or passively did nothing to halt it. Analysing the way the media impose characteristics and relationships helps to identify the ways that media influence readers in ascertaining and determining how they should feel about or towards the people involved. Boundaries are drawn between good and bad, or right and wrong, and in doing so frame the moral permissibility of certain actions and imply a moral acceptability of some activities and individuals but not of others. An observable point about the articles referring to euthanasia is that while many of them portray the lives of those implicated in the debate, they invariably leave out the voices of the opposition. The media provides an altogether positive frame around the space that is dedicated to the euthanasia discussion, and this helps to sustain a certain image of it. Favourably viewed, the cases depicted are premised on an underlying moral rightness of the practice.

A sociology in bioethics approach is described in *Chapter eight*, and the chapter poses, alongside such a sociology, the advancement of the debate through discourses of the body that shows how the performative aspect of self-identity and its constitution within the communal body should be seen as the logical progression in the assisted dying argument. The inclusion of such a discourse that takes into account the lived experience of the person in terminal illness is argued to be a beneficial possibility to further advance the positions through which decisions at the end-of-life are informed. Overall, this thesis situates the communal body within the right-to-die argument in New Zealand.

The literature review that follows sets the premise for the empirical research involved in this thesis. As with any literature review it highlights the scope of current literature on the topic and gaps in the knowledge that this informs. The structure of the following work allows the reader an insight into current sociological and then bioethical literature on death and assisted dying. The purpose of this is to highlight the space that this thesis seeks to fill. One of these is by suggesting a sociology of bioethics approach would be beneficial for the assisted dying argument. The other is done through the use of empirical analysis that identifies the ways discourses are currently produced and reproduced among different communities. By identifying the productive forces that construct discourse we are also able to identify where conversations can be expanded and reframed in order to create a more expansive and effective dialogue regarding end-of-life policy.

Having conducted data analysis across two data sets, the results from these, as contained in this research, lend themselves to support a view that the current lack of available discourse has for the most part irrevocably rendered a divide between those who campaign for change and those who argue against it. In this thesis, I argue that by positioning itself within a sociology in bioethics approach, the right-to-die debate in New Zealand will be afforded a clearer understanding. By engaging with an idea of the communal body, interpreted as a moral community comprised of individuals who each experience their own subjective realities, this thesis provides a platform to combine these two perspectives. In summary, it seeks to re-examine the range of possibilities for understanding the socially situated and relationally autonomous individual requesting medically-assisted death.

Chapter two: New Zealand – the Context for Legislation

Introduction

The context within which any legislation is introduced and enacted has significant implications for the way that it is understood and accepted by the communities that will be affected by it. Legislation pertaining to medically-assisted dying in New Zealand is no exception and this chapter sets out the social environment into which New Zealand Act MP David Seymour's current Bill is proposed. This is done to highlight the frameworks that legislation has been developed through and to understand the background against which certain features of legislative practice have come into fruition. Legislation adopted globally is able to provide a frame of reference from which New Zealand can forge its own legislative practice. This enables the country to create legislation that is relevant and practicable for the cultural context within which it is being achieved, while also being informed by current international practice.

This country is one that has had its own history, much of it only now identified as being steeped in the colonial legacy left behind by the British. This has meant New Zealand now enacts laws that attempt to be brought more into line with the principles of the Treaty of Waitangi. Health care must also encompass values from within Māori culture and recognise the individual within their role in their whānau³ and the wider social landscape within which it sits. This chapter sets out the situation that New Zealand finds itself in as it looks forward to the second decade of the 21st century. With a mixed-member proportional (MMP) representation model of elected parliament having brought in a left-leaning government in October 2017, New Zealand is now in a place to deal with critical issues. As with anywhere around the world, the option of assisted dying is hotly contested and it still remains to be seen whether or not the New Zealand Government will take up that particular challenge. To understand and make sense of the following chapters, *Chapter two* aims to inform the reader of the circumstances of the New Zealand medical and legal system as they relate to end-of-life care. This chapter should not be taken as a 'background' chapter, but should instead provide a frame of reference that can be used to discern the medical, social and legislative context for New Zealand in mid-2018.

³ In te reo, whānau refers to, "Extended family, family group, a familiar term of address to a number of people – the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members" (Moorfield, 2003).

Ageing and Dying in New Zealand

The colonial history of Aotearoa New Zealand and the ensuing relations between the indigenous Māori population and the British settlers resulted in the signing of the Treaty of Waitangi in 1840. This document, intended on both sides to ensure rights to the land and taonga⁴ of New Zealand, was breached multiple times by a succession of colonial governments resulting in the large-scale dispossession of Māori land (King, 2003). Although the establishment of an egalitarian society was the driving motivation behind the founding of the settler culture and society, such advantages did not extend to Māori. The result of this, along with their wide-scale dispossession, was that by the 1900s Māori found themselves as a socioeconomically disadvantaged ethnic minority living off small pockets of rural land. Although inherently racist in their practice, the egalitarian values encouraged by British settlers still had two significant impacts on the tacit values of New Zealand society (Tobias, Blakely, Matheson, Rasanathan, Atkinson, 2009). The first of these occurred in 1893 and saw New Zealand become the first self-governing nation to give women the right to vote.

The second impact of the push for an egalitarian society was the establishment of one of the world's first welfare states, with health care being a central feature of the system (Cheyne, O'Brien, Belgrave, 2004; Woodward & Blakely, 2014). Early public health services in the 19th century were provided only to Māori and the poor as it was expected that wealthier members of the population would look after their own health care. The end of the 19th century saw large developments in medical technologies that soon transformed the wards of a hospital to the sanitary and benevolent environments that are common in today's societies. These transformations paved the way for New Zealand's first Labour Government (1935-1949) to introduce the world's first universal health care system that came under the *Social Security Act* (1938) (McClure, 2013). Through the scheme public hospitals were free to all with coverage paid for by way of a social security tax.

The *Social Security Act* that instigated this scheme also saw New Zealand introduce an old age pension which provided a means-tested income from age 60 and a universal benefit from 65 (McClure, 2013). This pension is still in place in 2018, although it has since become universal from the age of 65. The most recent data from the 2013 Census (Statistics New

⁴ In te reo, taonga refers to both property and goods as well as treasures and prized objects; it can be applied to anything considered to be of value including socially or culturally valuable objects, resources, phenomenon, ideas and techniques.

Zealand, 2014) reported that there were 307,035 people aged over 65 years who were “usually resident” in New Zealand, the majority of whom were receiving the old age pension. The superannuation and veterans’ pension were also the third most common pensional income source in 2013, with 16.8% of the adult population receiving them as an income source (Statistics New Zealand, 2014). There was also a 2% increase in recipients of the payments between 2006 and 2013.

The constitution of New Zealand households is also reflected in the pension statistics, with 42.1% of people living in one-person households receiving the superannuation or veterans’ pension. In another Statistics New Zealand report released in 2016, it identified that 44% of all of those living alone were aged 65 years or older. This also included 25% who were aged 75 years or older. This report also largely reflects the nature of the ageing New Zealand population as it found that over half of females aged over 75 years lived alone, compared to just 25% of males (Statistics New Zealand 2016). This is a reflection of wider mortality statistics across the country that, much like elsewhere in the world, see women living longer than men. The average life expectancy for females and males in New Zealand for 2014 was 83.19 and 79.48 years, respectively (Statistics New Zealand, 2015). New Zealand stands as having the 15th highest average life expectancy amongst OECD nations.

The topography of New Zealand has historically led to uneven service and resource delivery across the country, and public health care provision has been no exception. It can be seen to contribute to comparative health outcomes across the country with a disparate distribution of resources in rural areas (Brabyn & Barnett, 2004). Rural communities consist of small populations that are spread over large geographic areas, making the achievement of health care provision for these communities a critical challenge. The National Advisory Committee on Health and Disability (NHC) (2010) found that challenges were exacerbated in attempts to meet the needs of those in old age and/or with a disability. Further, they identified higher levels of deprivation among certain rural communities compared with urban areas. Socioeconomic deprivation is a strong indicator of poor health outcomes, which includes higher levels of hospitalisation and mortality, and greater incidences of chronic diseases along with other acute conditions.

Socioeconomic deprivation was also a strong factor impeding access to health and disability services in rural communities, along with transport, telecommunications, the cost of accessing services and service acceptability (Brabyn & Barnett, 2004; National Advisory

Committee on Health and Disability, 2010). In a study by Santosh Jatrana and Peter Crampton in 2009 they noted that significant financial, cultural and geographical barriers to access exist for primary health care (PHC) in certain parts of the country. Health care services in rural areas is what is often referred to as generalist care. Medical practitioners and nursing staff are expected to provide a diversity of services, or ‘general care’, in rural health care settings, straddling disciplines and allowing them to provide a broader spectrum of skills than would traditionally be seen (Williamson, Gormley, Dovey, Farry, 2010). The provision of high quality palliative care is critical in weighing up the safeguards that must be put in place surrounding assisted dying legislation. It is critical that both generalist and specialist palliative staff can help to alleviate a patient’s pain and suffering in the hope it will not come to needing to put the legislation into practice.

New Zealand’s mortality statistics are largely a reflection of the lifestyle choices of its population. Like many western societies these lifestyles are characterised by diets that are low in fruit and vegetables but with a high salt intake, which is paired with an increasing lack of exercise, leaving three in 10 adults with obesity and another three overweight (Ministry of Health, 2016). Mortality from communicable diseases around the globe has decreased significantly throughout the 20th century (Capizzi, De Waure, Boccia, 2015). However, the prevalence of social and health inequalities in lower socioeconomic communities in New Zealand is a growing concern for public health coordinators (Baker, Barnard, Kvalsvig, Verrall, Zhang, Keall, Wilson, Wall, Howden-Chapman, 2012). Like many other nations, the prevalence of non-communicable diseases (NCDs) has increased and is again largely a reflection of lifestyle factors in society.⁵ New Zealand’s mortality data is collected annually by the Ministry of Health (MOH) and collated for publication to assist in policy development and to inform discussion.⁶ The most recent data set available was published in October 2017 and provides breakdowns of New Zealand mortality statistics, into gender and ethnicity, for the year 2014. The following statistics are provided to inform the reader of the current rates of death to understand how these could be implicated in any end-of-life legislation.

There were 31,164 registered deaths in New Zealand in 2012, reflecting a slight increase over time, largely owing to a similar increase in the total population. On the contrary, the mortality

⁵ “NCDs are defined as diseases of long duration and, generally, slow progression, and they are the major cause of adult mortality and morbidity worldwide. Four main diseases are generally considered to be dominant in NCDs’ mortality and morbidity: cardiovascular diseases, diabetes, cancer and chronic respiratory diseases” (Capizzi et al., 2015).

⁶ See www.health.govt.nz/publication/mortality-2014-data-tables for annual data tables.

rate⁷ has shown a downward trend overall, the rate for 2012 standing at 383.1.6 deaths per 100,000 population, down from 393.6 in 2012. Of the registered deaths, there were a higher number of male deaths than female, 15,707 and 15,457 respectively, again a trend that is reflected globally. One in 10 deaths in 2014 were from the Māori population, who can also claim to have a mortality rate that is 1.8 times that of non-Māori. Statistics also reflected a trend which saw male deaths occurring more often in younger age groups when compared to female mortality. On the whole, however, the overall mortality rate for both males and females has been steadily declining from 1980 until the present, with rates halving for the entire population over this period. Alistair Woodward and Roger Blakely (2014) found that at the beginning of the 21st century, while rapid gains have once again been made in life expectancy for all New Zealanders, evidence showed that the most profound reason for this is due to decreased death rates among the population who are 65 years and over, as well as an increasingly likelihood of people making it to over the age of 85. Lifestyle factors play a significant role in mortality rates amongst New Zealanders. As rates of obesity increase among the population the risk of diabetes has increased. However, mortality statistics do not adequately capture its incidence owing in large part to the co-morbidities it often presents with.

These factors contribute dramatically to the population of New Zealanders who are likely to face chronic and terminal illnesses throughout their later life (Brabyn & Barnett, 2004). A popular choice for end-of-life care, although still under-utilised, is hospice and palliative care services. New Zealand was a somewhat late adopter of palliative care medicine after it was established by Dame Cecily Saunders who opened St Christopher's Hospice in 1967. The first hospice in New Zealand was not established until 1979 in Auckland and, nearly 40 years on, the issues that plague the health care system in rural areas have become prevalent with the spread of palliative care (Ministry of Health, 2017). This means that rural populations have difficulty in accessing specialist palliative services. In recent years, the MOH has implemented new guidelines surrounding the care and support of patients at the end-of-life, be that the final hours, days, weeks or months. The MOH *Review of Adult Palliative Care Services in New Zealand* (2017, p. 3) asserts that the preferred approach, where possible, is to provide palliation wherever a patient may be located. Their aim is to ensure that primary palliative care can be provided as an integral part of standard clinical practice by any health care professional. This policy change reflects the deficiency in numbers of palliative care

⁷ Calculated as deaths per 100,000 population.

specialists around the country. It is hoped that it will instead usher in the routine prioritisation of palliation in generalist physicians' care of patients at end-of-life.

Owing to advances in technology and medicine the ability to which physicians can keep patients alive has reached phenomenal degrees. The MOH report of 2017 highlights the changing demands on palliative care services and the implications of the forecasted growth in care provision. Owing to advances in chronic disease management and the impact of the baby boom,⁸ the instance of co-morbidities will be increasingly common. These cases also mean that planning end-of-life care, which would normally focus on a single disease, will be more complex and difficult to predict. The numbers that palliative care will need to provide for are going to face a significant increase, with the MOH (2017) forecasting making predictions for the years 2016-2038. In the MOH report (2017, p. 7) they stipulate that the 2015 Budget provided funding of \$76.1 million for hospice service delivery, which was to include \$24.1 million over four years to support the delivery of new palliative care services in aged residential care, primary care and community settings. The report also states that to date (2017, p. 7), 40 new palliative care positions had been established across the 15 DHBs, which reflects an average of 2.6 positions per area.

The numbers from the MOH *Review of Adult Palliative Care Services in New Zealand* (Ministry of Health, 2017) show an evident increase in the need for service provision, with a projected increase of the number needing palliative care rising by 51% from 24,682 in 2016 to 37,286 by 2038. In line with these numbers, deaths are set to increase by almost 50% from a current rate of around 30,000 per year to 45,000 in 2038. Those dying will reflect a rapid increase in age, with over half of deaths occurring in people aged 85 years and older. By 2038, it is also predicted that a far greater number of patients will pass away under the care of an institution, with projected figures for the need of palliative care (predicted on historic levels of place of death) showing they will need to increase provision by 37.5% in public hospitals, 84.2% in aged residential care, and 51.8% in hospice care.

This will place a further strain on service providers and resource provision across the country with some, especially rural areas, having limited access to specialist palliative care owing to low recruitment and retention rates (Ministry of Health, 2017). Projected figures for New

⁸ The baby boom is generally taken to refer to the period 1946-1965, which owing to social and political factors saw an increased birth rate during these years. Those born in this generation are often referred to as 'Baby Boomers'.

Zealand are also substantiated by studies internationally. One such study conducted by Anna Bone et al. (2017) found that if aged residential care capacity does not increase across England and Wales then deaths occurring in hospitals will start to rise by 2023. In New Zealand, such matters are also compounded by the fact that by 2020, 56% of the current palliative medicine specialists will themselves be over the age of 65. What all this means for New Zealand is that it is going to have a rising population who rely on increased health services as they age. This ageing population is also more likely to be afflicted with chronic illnesses that are brought on by lifestyle, as well as a longer lifespan ensuring more time for illness to develop.

End-of-life Care in New Zealand

The distinction between the passive and active hastening of death has been discussed elsewhere (see *Chapter one*), and as noted above there is no duty to care by medical practitioners in New Zealand if treatment is deemed futile even though it may be life-sustaining. In the same way, patients can terminate their own care at any stage, with the right to refuse to undergo medical treatment upheld in section 9 of the *Bill of Rights Act* (1990).⁹ Naturally this does not mean that end-of-life care is plain and simple and in New Zealand, as in other places, this care offers a formidable process and sometimes challenging final stage of life. There would appear to be a wide range of views from the New Zealand medical community regarding not just aid in dying, but also other complex end-of-life care decisions. In a study considering end-of-life care nursing practices in New Zealand intensive care units by Coombs, Fulbrook, Donovan and Tester (2015), the authors found that over half (55%) of the nurses surveyed disagreed that withholding and withdrawing life support or treatment were ethically the same. There was a general consensus (78%) among the participants that withholding treatment was more acceptable on an ethical basis than withdrawing it, along with an ever greater consensus (93%) that the withdrawal or withholding of treatment were both ethical options (Coombs et al., 2015). The results of surveys remain critical for understanding the positions of individual health practitioners when it comes to end-of-life care legislation.

A strong argument in opposition of assisted dying is the fundamental change that its legislation would make to the doctor-patient relationship and the role of the doctor more

⁹ “Everyone has the right to refuse to undergo any medical treatment” (*New Zealand Bill Of Rights Act* 1990).

generally. What is commonly excluded from arguments is the role of nurses, who have a close relationship between the physician, patients and their whānau, in legislative change. Indeed, Seymour's *End-of-life Choice Bill* is notable for its lack of provisions relating to the role of nursing staff in any changes that are made to end-of-life care. Physicians and nursing staff have a fundamental relationship that sees them interdependent on each other to provide high quality care. It is critical that the integrity of the relationship is not given a chance to falter or be questioned. In an article by Martin Woods and Bickley Asher (2015) concerning Maryan Street's earlier *End-of-life Choice Bill*, they found that while provisions allowed for nurses to play a part in the process through delegation, there was no provision for them should they choose to accept this responsibility. Seymour's current Bill makes an equal provision which, while probably intended to encompass whānau through its inclusivity, places a burden on nurses who it would seem have not been extended the same guidelines or regulations as their physician colleagues.

Owing to its illegality it is hard to gauge the frequency of assisted death in New Zealand. Even surveys that provide statistics from self-reporting doctors on the unintentional hastening of death may not be reliable owing to subjective accounts of experience and the use of varied terminology for certain practices or the possibility of reporting bias. However, a few have been released regarding practice in New Zealand and it would be remiss not to mention them here. In a 2003 study by Kay Mitchell and Glynn Owens, and then followed up by Phillipa Malpas, Kay Mitchell and Heidi Koschwanez (2015), they conducted a written survey and an optional follow-up telephone service to anonymously interview general practitioners (GPs) on their experiences in caring for dying patients. It surveyed GPs on the details of medical decisions that they had made for the last death they had attended in the preceding 12 months. In 2004, 1,255 of the questionnaires returned were usable and 88% of doctors reported having had attended a death in the past 12 months, while 63% of those physicians had also made a medical decision that could hasten death. Ninety-four (13.6%) of the 1,255 respondents also reported that the final actions taken were done partly with the intention of hastening death, while 19% had withdrawn or withheld support to actively hasten death (Mitchell & Owens, 2003).

In the 2013 Malpas et al. (2015) results they found that of the 650 usable surveys returned, 547 of those GPs had contact with the patient prior to death and were in a position to make a medical decision at the end-of-life. Of these physicians, 65.6% or 359 of practitioners

reported to have made such a decision. These ranged from “making decisions to withdraw or withhold support treatment (or intensify the alleviation of pain and/or symptoms) with the probability that death would be hastened, through to actions partly or explicitly intended not to prolong life, or to hasten death” (Malpas et al., 2015, p. 29). The most common procedure, taking into account that it would probably hasten death, was to increase the alleviation of pain and/or symptoms. These actions can be taken as a form of *passive assisted dying* and is legal under the rule of double effect. That is because the intention on the physician’s part is to actively alleviate suffering, not to hasten death, so it becomes an unfortunate consequence of such action.

When making decisions regarding end-of-life care, Coombs et al. (2015) found that when it came to withholding or withdrawing life support the consideration of expected quality of life as perceived by the patient and family was the most important factor in decision-making. In the study by Malpas et al. (2015), they found that in 45.4% of the cases the GP had not discussed with the patient the possibility of hastening death through the actions described above. In 72.4% of these cases it was because the GP deemed the patient incapable of having a discussion, but in 23.3% of the cases despite competence there was no discussion had (Malpas et al., 2015, p. 32). It is such cases that I believe provide New Zealand with a risk if it does not instigate a form of assisted dying legislation within the foreseeable future. With increasing rates of patients spending the final stages of their lives with chronic and terminal illness it is not presumptuous to believe that those in positions to make end-of-life care decisions will also grow. Regulations are therefore needed to ensure that errant practices, which do not currently provide for a categorical form of self-reporting, do not become unhinged before New Zealand has had time to talk about legislation and make an effective decision.

As it stands now, however, medical organisations around the country and the world still dispute legislative practices that support assisted dying. The World Medical Association (WMA) has made four declarations relating to end-of-life care practices,¹⁰ which all maintain the stance that medically-assisted death of any kind is an assault on medical practice itself (World Medical Association, 2015). In New Zealand, the Palliative Care Council of New Zealand (PCCNZ) released a statement in June 2013, having noted the “widespread debate in

¹⁰ Policies include the: WMA *Declaration on Euthanasia* (2015); WMA *Declaration on End-of-Life Medical Care* (2011); WMA *Declaration of Venice on Terminal Illness* (2006); WMA *Statement on Physician-Assisted Suicide* (2015).

New Zealand society about euthanasia and physician assisted suicide”, which they viewed as being “largely based around anecdotal stories of suboptimal care at the end-of-life”. (Palliative Care Council of New Zealand, 2013). A priority of PCCNZ is to ensure that every New Zealander has access to quality palliative care when and where they need it. Their statement says that they strongly encourage the concept of death with dignity and that it should be a high priority for health care in New Zealand. PCCNZ stands whole-heartedly by the belief that while people have the right to refuse life-sustaining treatment, and that decisions around stopping futile treatments should be continuously reassessed, neither of these options constitute euthanasia. They also believe that euthanasia and physician-assisted suicide have no place in New Zealand society, instead advocating for patients to be made aware of options for hospice and palliative care.

This statement position is also held by a range of other organisations in New Zealand, all of which have expressed an opposition to any changes to the *Crimes Act* (1961).¹¹ The New Zealand Medical Association (NZMA) has openly agreed with PCCNZ in opposition to assisted dying. In its submission to the Health Select Committee (HSC) (2016), they state that it is “NZMA’s view that euthanasia and doctor-assisted suicide are contrary to the ethics of the profession”. From its Code of Ethics (2014) it stated that, “The NZMA is opposed to both the concept and practice of euthanasia and doctor-assisted suicide”. These position statements will ensure a range of opposition is made against assisted dying legislation. It is critical, however, to ensure that palliative care is strengthened and retains its importance in end-of-life care in New Zealand.

Standing apart from this widespread opposition is the New Zealand Nursing Organisation (NZNO), who in their 2014 submission to the HSC raised the issue of there being “no universal nursing position on the ethics of euthanasia”. They further agreed that following the International Council of Nurses (ICN), of which the NZNO is a member, “guidelines need to be developed to aid nurses to understand their rights as well as the ethical and legal complications of their actions and making decisions that honour health consumers decisions”. Perhaps most prominently in the NZNO submission, and in line with Woods and Bickley Asher (2015), they also wrote that any legislation needs to clearly state how nurses will be protected from prosecution and indicate professional legal requirements, both directly and indirectly.

¹¹ See, for example, Hospice New Zealand, the Australian and New Zealand Society of Palliative Medicine and Palliative Care Nurses New Zealand Society for additional position statements.

More recently, and in relation to the 2017 call for submissions relating to MP David Seymour's Bill, the College of Nurses Aotearoa, who claim to "provide a voice for the nursing profession and professional commentary on issues affecting nurses", also provided a written statement relating to the *End of Life Choice Bill* before Parliament. In their submission they concede that owing to the split in nursing opinion from their members they "cannot take a position either for or against the End of Life Choice Bill". However, they do follow this statement by providing "important comments on the way forward". Again, much like the NZNO, one of these comments relates to the clarification of the legislation regarding the role of nurses in the practice of assisted dying. Specifically, they also raise the complex issue of conscientious objection among its practising members, which while anticipated for physicians in the Bill, is notably absent when it comes to the nursing community.

New Zealand Medical Environment

The New Zealand medical system is unique in comparison to several other health care systems globally for a number of reasons. This uniqueness makes New Zealand debates about euthanasia distinct from other jurisdictions. First, provisions under the *New Zealand Public Health and Disability Services Act* (2000) have led to a system of publicly-funded health care services allowing "eligible persons"¹² to receive all "core" services free of charge.¹³ Under this ambit, District Health Boards (DHBs) provide health services to regional areas from a centrally-funded tax-based system (Skegg & Paterson, 2006). Along with this, the Government partially funds primary health care services (60% is government funded and works on a co-payment model) and a range of subsidised pharmaceuticals. The system works in line with a number of objectives, which are summarised by Ron Paterson (2006, p. 5) as follows:

1. Improve, promote and protect the health of New Zealanders (a population health focus).
2. Reduce health disparities by improving health outcomes of Māori and other population groups (equity).
3. Ensure community voice in matters relating to personal health services, public health services and disability support services (participation).

¹² Eligible persons include New Zealand citizens and persons ordinarily resident in New Zealand.

¹³ These "core" services, however, do not include aged care facilities or residential homes.

4. Provide appropriate, effective and timely services (access).

As with any publicly-funded good, the provision of resources is limited by constraints in funding and other resources. Considering this, where resources cannot be wholly allocated, the main objectives of the public health system must be sought “to the extent that they are reasonably achievable within the funding provided” (New Zealand Public Health and Disability Act 2000). Further, the National Advisory Committee on Health and Disability provides the Minister of Health with expert advice on rationing systems that are viable under a publicly-funded health care system. Unlike other jurisdictions that provide health care services through insurance providers or are otherwise privately funded, the New Zealand health care model is not funded based on profit generation and therefore is markedly different regarding motive for treatment. This means that most health care providers within the New Zealand system are not profit-driven and therefore do not base medical decisions on capitalist-based incentives, nor are patients affected or pushed out of the market when it comes to costly treatment options. As regards to assisted dying, this is a particularly pertinent point as it means that the cost of health care is not a mitigating factor when it comes to the ending of a person’s life where this takes place in a public care institution. Within the American assisted dying literature this is a particular feature for discussion owing to the insurance-based system on which a large part of their medical care is provided. The provision of health care regardless of cost is therefore a significant feature for the New Zealand medical system and its attempt to maximise universal access to care.

Secondly, and along with Australia, New Zealand doctors do not have a ‘duty to treat’ in cases where treatment is deemed futile, even if it might be life-sustaining (Willmott, White, Downie, 2013). Decisions regarding the withdrawal and withholding of treatment are based on whether doing so would constitute a breach of the criminal law duty to provide the necessities of life. In the case of life-sustaining treatments, however, court rulings (see *Shortland v Northland Health Ltd* - [(1997) 1 NZLR 433], for example) have judged that even when treatments may be a necessity of life, such a withdrawal is still lawful if it could be considered “good medical practice” to not provide medical treatment in the circumstances the patient is in (Willmott et al., 2013). The precedent set by previous cases that have gone to court show that the issues faced within other medical systems regarding the withdrawal and withholding of treatment are not relevant to the assisted dying argument within New Zealand

because, even without consent from the patient or their substitute decision-maker, a doctor can still end treatment that they deem futile and not in the patient's best interests.

Thirdly, New Zealand has a 'no-fault' system whereby under the *Accident Compensation Act* (2001),¹⁴ any physical injury that results from negligence of a health professional ("medical error") as an adverse consequence of (non-negligent) treatment, or where physical injury meets the statutory requirements of seriousness and severity ("medical mishap"), civil action cannot be taken against doctors and other medical professionals (Skegg, 2008). Instead, what is provided to patients is "an administrative system of compensation without the need to prove fault" (Davis, Lay-Yee, Scott, Briant, Schug, 2003, p. 79). The 'no-fault' system has the effect of easing the path of compensation for the patient and reducing the threat and cost of litigation to the doctor. It also encourages them to disclose errors that may have occurred within medical practice (Davis, Lay-Yee, Briant, Scott, 2003). In terms of medical practice overall, this is an interesting system and a point of difference within New Zealand as it allows doctors to take what could be seen to be riskier measures and options for treatment without the fear or burden of potential law suits being brought against them. Where in other jurisdictions, as noted by Sheila McLean (1999), there has been a shift of power from doctors to the courts in some cases of medical decision-making, the lack of legal indemnity for doctors in New Zealand means that this country has not seen this same shift.¹⁵ Further, in the case of *Auckland Area Health Board v Attorney-General* [1993] (1 NZLR 235) it was stated that, "Generally speaking, the courts certainly will not wish to intrude upon what they ... perceive to be the legitimate province of the doctors and their patients. Undoubtedly, the courts will be slow to respond to any invitation to resolve an issue which is essentially a clinical or medical decision".

Numerous accounts of the 'good death' highlight that many people believe this is an event that occurs at home surrounded by loved ones. However, the continued institutionalisation of medical care means that this is not often the case. While New Zealand, like many other western countries, has an upward trend of death within hospitals our rates of dying in these institutions are relatively low in comparison to other jurisdictions. Between the periods of 2003-2007 in New Zealand it was found that just 34% of deaths occurred in a hospital while 22% occurred at home. A further 31% occurred in residential care while 6% took place in a

¹⁴ Previously titled the *Injury Prevention, Rehabilitation, and Compensation Act* (2001).

¹⁵ Most notably, the cases of Tony Bland and Nancy Cruzan highlight this shift where doctors have asked the courts for clarification for fear of litigation.

hospice setting. What these statistics show is that the fear of dying while hooked up to numerous machines is not in fact a reality with New Zealand, yet. As will be shown in the following section the impact of ageing on the future provision of end-of-life care is likely to be expansive.

New Zealand Legal Environment

Although a few mercy killings came before the courts, it has largely only been within the last 20 years of New Zealand Parliament that debates about the legislation of euthanasia have been prevalent. In 1995, then National Party MP Michael Laws introduced his *Death with Dignity Bill*, which proposed to allow the people of New Zealand to decide on euthanasia by way of a public referendum. The Bill, however, was voted down by Parliament 61 votes to 29 before it came to the referendum stage. It was then not until 2003 that the topic was brought back into the spotlight by then New Zealand First (NZF) Deputy Leader, Peter Brown. Brown's *Death with Dignity Bill* was drawn from the ballot in the wake of New Zealand's most infamous case of euthanasia, Lesley Martin's attempted murder of her mother, Joy Martin. The high-profile media attention that Martin received for the case again brought the assisted dying debate back into the public eye, with her declaring that it caught people between "legislation and love" (Life Resources Charitable Trust, 2011). While Brown's *Death with Dignity Bill* was once again voted down by Parliament there was a far closer margin in 2003, with 60 yes against just 58 no votes.

The killing of another person is illegal under New Zealand law, as stipulated in sections 158 and 160 of the *Crimes Act* (1961), which rules against homicide and culpable homicide, respectively. Further, section 63 forbids a person from consenting to their own death and section 179 prohibits the aiding and abetting of suicide. Prior to the Lesley Martin case, there had been a number of cases in New Zealand legal history of aiding and abetting suicide and manslaughter that due to the circumstances can be viewed as euthanasia (see *R v Novis* [1988] unreported; *R v Albury-Thomson* [1998] NZCA 367; *R v Karnon* [1999] unreported; *R v Simpson* [2001] unreported). There are also three particularly notable cases in relation to this thesis within New Zealand that have made it into the courts. These have subsequently been deemed by the respective courts as 'mercy killings' and therefore punished accordingly. However, calls have followed each case that the law needs to be brought into line with law enforcement (Webb, 1994). It is in these cases that there is evidence of the fine line that is towed within arguments around medical aid in dying.

The first case relevant to this study is that of *R v Stead* [1991] 7 CRNZ 291, which was described by Webb (1994, p. 450) as a “disturbing comedy of errors” in which the defendant, following his mother’s failed attempt at suicide by an overdose of sleeping pills, attempted to end her life by way of injection of sedatives. This attempt also failed, following which the defendant tried to poison her with carbon monoxide by attaching a hose pipe to the car exhaust. This too failed leading him to smother her with a pillow. Having been unsuccessful in all these three attempts he subsequently repeatedly stabbed her to death with a kitchen knife. Although the defendant was cleared of murder he was subsequently found guilty of manslaughter and sentenced to three years’ imprisonment. The court report of this case highlights an unusual instance of coercion. Unlike what is often feared in end-of-life care where a person feels coerced by family members to be assisted in ending their lives, the opposite coercion here occurred by way of a mother imploring her son to end her life. What was further noted by the courts in this case was that it was “very significantly more than an aiding of suicide; it is more akin to a mercy killing with the unusual feature of persistence in the attempts” (*R v Stead* [(1991) 7 CRNZ 291 (CA)]). However, it was also noted that, “There is no established sentencing pattern for that [aiding suicide] in this country, still less for mercy killings and the like”.

The second significant case in New Zealand case law is that of *R v Ruscoe* [(1992) 8 CRNZ 68 (CA)] in 1992. In this case, the deceased and the defendant agreed on the methods by which death would be procured. The deceased was a tetraplegic friend of the defendant who voluntarily swallowed 50 sedative pills, which were placed in his mouth by the defendant. To then secure death the defendant proceeded to smother the deceased with a pillow after he had fallen asleep. While at first sentenced to nine months’ imprisonment for his role in aiding and abetting the commission of suicide, on appeal the court decided that a non-custodial sentence of one-year supervision would be more appropriate. In their sentencing the presiding JJ Cooke P, Hardie Boys and Gault stated that they were satisfied the actions of the defendant were motivated solely by compassion, recognising the grief he would have suffered watching his friend become helpless and threaten to starve himself to death. What is interesting to note about this case is that, as noted by the court, following the death of his friend the defendant developed alcohol and psychological problems and subsequently attempted to commit suicide. Although complicit in the decision to end the deceased’s life, which as highlighted by the judges was done out of compassion, this is a potentially significant issue with regards

to assisted dying legislation as it highlights the unknown effects of wilful killing which could be detrimental to those who carry it out.

The third case, *R v Law* in 2002, came just three years after Martin's assisted death of her mother. The difference in this case to the two previously outlined was that it was ruled an aiding of suicide as opposed to a mercy killing. Mr. Law, at the age of 77, had ended the life of his wife who was 73 and suffering a developed form of Alzheimer's. Mr. Law had given his wife sleeping pills, hit her on the head with a wooden mallet, and then suffocated her with a pillow before trying to end his own life. The defendant himself pleaded guilty to the murder, but due to the extenuating circumstances of the case Randerson J., the presiding judge, ruled only a sentence of manslaughter with imprisonment of 18 months (with leave granted to apply for home detention). In his closing statement Randerson J. stated that, "The taking of a life, even for the highest and best motives, is not permitted under our law and, for good reason, murder is ordinarily regarded as the most serious crime in our statute books" (*R v Law* [(2002) 19 CRNZ 500]). He then continued on to say, "The court would be sending the wrong message to the community if it were prepared to allow the deliberate killing of someone suffering from such a disease [Alzheimer's] or other affliction to go unpenalised, even in the tragic circumstances of a case like this". In his verdict it becomes clear that eight years after Webb's (1994) call for the law to be brought in line with the enforced punishment this still has not occurred, and thus judges face difficult decisions when it comes to upholding the law and sentencing accordingly.

Following the rejection of *Brown's Bill* in 2003, the subsequent Martin court case drew much media attention, not only following Joy Martin's death but again in 2004 when Lesley Martin was charged and sentenced. Charges were not initially laid against Lesley Martin as the Police could find no proof that the morphine overdose that killed Joy Martin was in fact intentional and not the result of a case of double-effect. In an 'off the record' and confidential statement made to a Police officer following the death, Martin admitted to the purposeful taking of her mother's life. This remained unproven until Martin released her book *To Die Like A Dog* (2002) which related to matters surrounding the death and were viewed by the courts as an admission of guilt. The media attention to the case threw the issue of euthanasia back into the spotlight with Martin (2002) describing her book about the ordeal as, "The personal face of the euthanasia debate". It was the Martin case, in particular, that threw

assisted dying into the spotlight in New Zealand and for many highlighted the plight of those suffering slow and sometimes painful deaths.

It also worked in drawing the attention of medically-assisted death to the New Zealand public, the surrounding issues of which many had not considered before. It was not to be the last time that the publication of a book would bring assisted dying back into the spotlight in New Zealand. In 2006, in a similar case to that of Martin's, Sean Davison took his mother's life after a terminal illness. It was again not until he published a book regaling his story and the story of her illness in 2009 that problems arose. The publishers had omitted the section in which Davison narrated the death in which he supplied his mother with an overdose of morphine, but the original manuscripts were leaked to the Police. The result was that the Police arrested Davison on a charge of attempted murder based on the unpublished section. In November 2011, Davison pleaded guilty to a revised charge of counselling and procuring suicide and was sentenced to five months' home detention.

Just months following Davison's sentencing, a case bearing similarities to that of Law again came to the attention of the public. The death of Rosemary Mott in December 2011 became a popular topic for the media as Mott's husband, Evans Mott, was charged with assisting her suicide. Rosemary Mott, who was 55 at the time, had been suffering from primary progressive multiple sclerosis (PPMS) for four years prior to her death. According to the sentencing notes of the case Ms Mott, "hated the indignity of her condition and made the decision to end her life" (*R v Mott* [(2012) NZHC 2366]). Mott did not keep this decision to herself and instead engaged with her husband, daughter and niece about her determination, as well as making a farewell video explaining the decision. Contentions in the case arose owing to Evans Mott's involvement with the equipment that Rosemary had secured to end her own life. Evans was also found to be complicit when he understood the actions that his wife was going to take when she asked him to leave the house.

Unlike the other cases discussed above, following Mott's trial he was discharged without conviction. His case is significant, however, in highlighting a view echoed by French J. when discussing section 179 of the *Crimes Act* (1961) that, "there is no sentencing policy ... because the circumstances of this crime are infinitely variable". The discrepancies in charging and punishment for the crimes mentioned above will be discussed further in *Chapter four*. In 2017, legislation and precedent are yet to be set regarding these issues. In

fact, a push for legislative changes did not enter the New Zealand Parliament again until 2013 when Labour MP Maryan Street's *End-of-Life-Choice Bill* was drawn from the ballot. Following political pressure in a pre-election year, however, Street reluctantly withdrew the Bill promising that it would return post-election. Further, in 2013, in an unprecedented move following the suicide of an elderly Lower Hutt woman, Wellington Chief Coroner Ian Smith called for Parliament to make up its mind on its stance towards euthanasia.

Medically-Assisted Dying Legislation Globally

There are now over a dozen jurisdictions around the world that have introduced various forms of legislation that allow for assisted dying to occur although through differing means. The different approaches to legislation worldwide emphasise the specificity of the varying rhetoric and definitions that were discussed at the beginning of this thesis (see *Chapter one*). Each of the legislative approaches highlight the range of moral boundaries that societies set for themselves and believe to be ethically permissible. The different jurisdictional approaches demonstrate the varying aspects of what the policy-makers in each place hold as important and the intentions and motivations behind legalising a form of assisted dying. Among the different jurisdictions with forms of medical aid in dying there are strong themes of moral judgement being made through the different legislative practices. Imbued within the different forms is a sense of the moral permissibility and action that is expressed in the decisions that were made regarding what should and should not be allowed to feature. What follows is a brief overview of the different measures that specific jurisdictions have taken when allowing assisted dying and the regulations, guidelines and safeguards that exist to ensure patient support.

Australia

Most recently, in late October 2017, the Victorian Parliament of Australia passed legislation through its Lower House after a debate lasting four days (see Parliament of Victoria, 2017 for details). The Bill was then debated by the Legislative Council and a number of amendments proposed. Finally, after a number of the proposed amendments were made, the final version of the Bill went before the Legislative Assembly who approved it on 29 November 2017. The legislation is due to come into effect in mid-2019 to allow the proper implementation of a

number of safeguards.¹⁶ In passing this legislation Victoria became the first Australian territory since 1995 to have enacted a form of assisted dying legislation. On 1 July 1995, the Parliament of the Northern Territory enacted the *Rights of the Terminally Ill (ROTI) Act*¹⁷ which allowed patients meeting strict criteria to end their lives with medical or pharmacological assistance (Street & Kissane, 2001). However, after the deaths of seven people, the Federal Government of Australia overturned the *ROTI Act* by passing the *Euthanasia Laws Act* in March 1997 that effectively rendered *ROTI* useless in terms of having any legal effect (see Australian Government, 1997 for details). This means that the Victorian state's [missing word?] having passed the *Voluntary Assisted Dying Bill*, is a significant development for New Zealand owing to its strong political ties to Australia and the current population of New Zealanders resident in Victoria.

Europe

Switzerland has some of the broadest laws worldwide that allow for assisting in the termination of another's life. There was also one of the earliest, with a comment by the Swiss federal government on the first penal code in 1937 stating that, "In modern penal law, suicide is not a crime ... Aiding and abetting suicide can themselves be inspired by altruistic motives" (Hurst & Mauron, 2003). This is still the basis for the Swiss penal code, which under Article 115 considers assisted suicide a crime only if it is motivated by selfish actions.¹⁸ This form of rational suicide does not require that a patient be terminally ill or that there is physician involvement in bringing about death. When prosecutions rarely occur, they are raised on doubts surrounding a patient's competence in making an autonomous choice (Hurst & Mauron, 2003). While aiding or abetting in a suicide is legal, "murder upon the request of the victim" remains illegal under Article 114 (Swiss Federal Council, 2017), although the severity of sentencing differs from that made against the will of the victim (Hurst & Mauron, 2003).

The Swiss Academy of Medical Sciences (1995) holds in its ethical recommendations that assisted suicide is "not part of a physician's activity". While this conventionally means that physicians should not, and do not, engage in assisted suicide, they have the same freedom to do as any other citizen of Switzerland (Hurst & Mauron, 2003). Perhaps, most notoriously,

¹⁶ The *Euthanasia Laws Act* will have no effect as it only relates to the Australian Capital Territory, Northern Territory and Norfolk Islands owing to their laws surrounding self-government.

¹⁷ See Australian Legal Information Institute (2010) for details on the repealed Act.

¹⁸ See Swiss Federal Council (2017) for text of the Criminal Code.

these Swiss laws tolerate for what has been dubbed as “suicide tourism” as they allow for citizens of other countries to secure their own deaths (Gauthier, Mausbach, Reisch, Bartsch, 2015). These deaths are carried out at clinics established by right-to-die societies. There are six of these organisations nationwide and four offer assisted suicide to people who are neither Swiss citizens nor resident in Switzerland (Gauthier et al., 2015).

The Netherlands has what can perhaps be seen as the most naturally developed assisted dying laws. Until the early 1990s, assisted dying and assisted suicide by a physician were illegal. However, prosecutors were lenient on giving out punishments if physicians could show they met certain requirements, such as the patient being terminally ill and suffering unbearably (Van der Heide, Onwuteaka-Philipsen, Rurup, Buiting, van Delden, Hanssen-de Wolf, Janssen, Pasman, Rietjens, Prins, 2007). In 1993 came an official establishment of a reporting procedure, the regulations surrounding which were again updated in 1998. At this time came the requirement for multidisciplinary review committees to advise the public prosecutor as to whether requirements had been met or not. Finally, in 2002, the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* was passed. It provided formal regulation for physicians ending the life of patients who were suffering unbearably or without the hope of relief. Under this legislation the basis of review committees also changed, whereby they were only required to forward to the prosecutor the cases that had not been considered as meeting the *due care criteria* (Van der Heide et al., 2007).

Regional review committees (RTEs) are considered one of the strongest safeguards in Dutch-assisted dying legislation. An RTE is comprised of five regional committees with the committee appropriate to review the case being determined by location. Committees are made up of a physician, an ethicist and a lawyer, who also holds the chairperson position, along with a lawyer who acts as a secretary and attends in an advisory capacity only. When a physician provides a patient with a medically-assisted death they must notify the municipal pathologist who in turn forwards the notification to the review committee. The committee is then required to review and determine whether the physician and independent physician's actions were warranted under the *due care criteria* as set out in the Act (see Regional Euthanasia Review Committees, 2017 for more details). If a committee finds that the physician did not meet the *due care criteria* the review is sent to the Board of Prosecutors General and the Healthcare Inspectorate, which can impose criminal and professional disciplinary charges, respectively.

In 2002, The Netherlands' neighbour Belgium also introduced a *Euthanasia Act* and has since become touted as having some of the most permissive euthanasia laws owing to its legislation, also including assistance in death for those with psychological suffering (The Associated Press, 2017). A push for legislation in Belgium began in 1995. At the time it was being debated by the media, scholars, the Official Advisory Committee on Bioethics and the Belgian Parliament. Raphael Cohen-Almagor writes that during 1995-1996, four members of Parliament submitted Bills to the senate calling for legalisation. The Belgian Comité Consultatif de Bioéthique (Consultative Committee on Bioethics) was established to advise the federal and community governments and parliaments on bioethical issues, and their first task was to provide advice on the proposed euthanasia Bills (Cohen-Almagor, 2008). Up until this time euthanasia was illegal and was considered as intentionally causing death under criminal law. However, prosecutions were rare and the practice was considered tolerable.

It was not until 2001 that the Euthanasia Commission of Belgium's Senate voted in favour of proposed legislation. This would see euthanasia becoming exempt from criminal prosecution provided that certain criteria were met (Cohen-Almagor, 2008). Patients had to be over the age of 18, and suffering from unbearable physical or mental pain and have no hope of recovery. Like the Dutch provisions, the patient must have been fully informed of their state of health and life expectancy. They are also required to make repeated requests, one of which must be in writing. If this is not possible, an adult of the patient's choice who must not benefit from the death can act as a proxy for the written criteria and must be done in the presence of the physician. As in The Netherlands, Belgian physicians are also required to report all assisted deaths to the specially created Federal Commission for Euthanasia Control and Evaluation.¹⁹

In 2008, Luxembourg, neighbouring both The Netherlands and Belgium, adopted its own version of assisted dying reform when the Chamber of Deputies put forward *The Right-to-die with Dignity Law*. This permitted both assisted death and suicide within the country. Like others it sought standard requirements of the treating physician and patient. The law required the establishment of a National Commission of Control and Evaluation, which is required to assess the implementation of the law. Within four days of taking part in an assisted death a physician must notify the Commission. As with other jurisdictions, Luxembourg also held that if a physician morally objects to the practice they are in no way obliged to take part.

¹⁹ For the latest report for the year 2014-2015 see European Institute of Bioethics (2016).

Following a second reading the law was enacted on 16 March 2009. Similarly, all physician-assisted deaths are to be reported to the Monitoring and Evaluation Commission, which reviews the deaths and acts accordingly in the place of wrongdoing.

United States

Oregon was the first state in America to adopt a form of assisted dying legislation. The move for Oregon to enact an assisted dying Bill followed two citizens' initiatives by the constituency, meaning that a majority of voting Oregonians believed that persons afflicted with terminal illness should have the legal right to hasten their deaths (Oregon Health Authority, 2017). Following a tumultuous few years the *Death with Dignity Act* was finally brought into practice in 1997. It allows terminally ill Oregonians to end their lives using physician prescribed, but voluntarily self-administered, lethal medications. The law states that the patient must be over the age of 18, a resident of Oregon, capable of making their own health care decisions, and diagnosed with a terminal illness leading to death within six months (Oregon Health Authority, 2017).

The patient must first make two oral requests separated by 15 days to their attending physician. This must be followed up by a written request signed in the presence of at least two witnesses. The attending physician and consulting physician must confirm the prognosis, determine the competency of the patient to make the decision, and ensure that they are aware of alternative care options. Following the 15-day stand-down period between written requests the physician must offer the patient an option to withdraw the said request. Physicians need not be present at the time of death and they may choose not to provide prescriptions if they have moral objections. Physicians must report all prescriptions for lethal medications to the Oregon Health Authority (OHA), and also inform pharmacists of its ultimate use. The Act also requires that the OHA annually collect information about patients who participate, and they then analyse the data before releasing an annual report.²⁰ Since the first introduction of this Act there have followed another five American states that have taken up similar legislative practices.

In 2008, Washington followed Oregon in bringing their *Death with Dignity Act* into law. The requirements of this Act reflect the law adopted in Oregon. This law followed a previous initiative that had been brought in 1991. While Montana does not have an enacted law, a

²⁰ Annual reports can be accessed from Oregon Health Authority (2017).

Montana Supreme Court ruling in 2009 meant that an end-of-life option was legal. In *Baxter v Montana*, judges ruled 5-2 that there was nothing in the state law to prohibit a physician from providing a terminally ill, mentally competent patient's request by prescribing medication to hasten that same patient's death. Under the state's *Rights of the Terminally Ill Act*, which governs a patient's rights to withdraw and withhold treatment, they ruled that there was little difference as a matter of public policy between passively taking a patient off life support and providing them with a prescription for lethal medication. The court therefore found that Montana law permits medically-assisted dying under the circumstances set out in *Baxter v Montana*. In 2013, Vermont became the first state to enact an end-of-life choice Bill by way of legislative action (Vermont General Assembly, 2017). The Act itself (*Act 39*) again follows a very similar framework to that of Oregon. It was meant to move into Phase II in 2016, which would have seen it drop legislation to become part of standard professional practice (Tucker, 2013). This clause was overridden in 2015, which thereby brought medical aid in dying solidly into law.

In November 2016, Colorado enacted *Proposition 106* or the *Colorado End-of-Life Options Act*, which was modelled off the Oregonian legislation. It joined a number of states that have now passed end-of-life care legislation, most of which have followed the lead of Oregon's laws. Just four months earlier, on 9 June 2016, California adopted the *End-of-life Option Act*, which allows for the provision of physician-assisted suicide following the Oregonian model of legislation as regards its criteria and the process that the patient must undergo to obtain such a death. It requires that cause of death be reported on death certificates as being a result of the underlying terminal illness. This Act also requires the California Department of Public Health (CDPH) to provide annual reports, the requirements for which are set out within the California Health and Safety Code.²¹ Information is collated from reports provided to the CDPH by physician reporting form, which shows information on individuals who were prescribed aid-in-dying medications.

Canada

A case in 1993 began Canada's change for medical aid in dying when the Supreme Court ruled against a woman, in *Rodriguez v British Columbia (Attorney-General)* ([1993] 3 SCR 519), who had amyotrophic lateral sclerosis (ALS)²² and who had asked the courts to allow a

²¹ See California Department of Public Health (2017) for annual reports along with further information.

²² Also known as motor neuron disease.

physician to assist in ending her life. Section 241(b) of the Canadian *Criminal Code*²³ says that everyone who aids or abets a person in committing suicide carries out an indictable offence, and section 14 says that no person may consent to death being inflicted on them. It was this part of the code that was upheld by the majority view in *Rodriguez v British Columbia*. Following a failed appeal, it was not for another 22 years that Canada would again be faced with the question of assisted dying in its courts. In 2012, the Supreme Court of Canada heard *Carter v Canada (Attorney General)*, in which the laws prohibiting medical aid in dying were challenged as being contrary to the *Canadian Charter of Rights and Freedoms*. The court ruled in favour of the *British Columbia Civil Liberties Association* (BCCLA) who brought the case on behalf of a number of parties, including the family of Kay Carter who had a degenerative spinal disease, and Gloria Taylor who had ALS (BCCLA, 2015). The court suspended its ruling for a year, in which time it required provincial legislatures to enact legislation that upheld the “fundamental human rights” of the ruling (BCCLA, 2015).

The Canadian House of Commons assented to law *Bill C-14*²⁴ on 17 June 2016, and it amended the *Criminal Code*, which provided exemptions under the sections mentioned above. Patients and physicians who make use of these exemptions must meet specific criteria to avoid prosecution, which serves as a form of safeguarding against exploitation and abuse. They also provide for the Minister of Health to make regulations that they consider necessary, respecting the provision and collection of information relating to requests for and the act of medical aid in dying. Reporting in a timely manner, and using and disposing of information, falls under the ambit of this regulation. Information is required from medical and nurse practitioners, and pharmacists, who must also follow a series of regulations regarding the prescription and dispensing of lethal medicines. The pharmacist who dispenses medicines must be informed, by the medical practitioner, of the purpose of the substance and the patient’s intention.

Canada’s enactment of law providing for medical aid in dying is, alongside the Australian state of Victoria, probably of most significance in relation to New Zealand. Both countries currently have a publicly-funded health care system, which provides all core resources and services free of charge. Unlike, for example, the United States, this means both New Zealand and Canada do not face the same issues regarding a patient’s personal resources and wealth when it comes to end-of-life care. That is, unlike the United States, medical aid in dying

²³ For further information on the *Canadian Criminal Code* see Government of Canada (2017).

²⁴ Details of the amendments and final Bill are available from Parliament of Canada (2016).

should not, at least to the same extent, be motivated by a lack of resources to pay for treatment or the fear of burdening the family post-mortem. Significantly also, it was on the same grounds as in *Carter v Canada* that Lecretia Seales brought her case to the New Zealand High Court.

These legislative changes in jurisdictions condoning assisted dying are able to provide a model for New Zealand for legislation, should it come to that. However, there have similarly been a selection of countries that have rejected various legislation and that also provide practical reasons as to why legislative change should not occur. Just as states in the United States are passing legislation, so too are they rejecting it. In February 2017, a House of Representatives Oversight Committee in Washington DC voted down a Bill that would have allowed for the practice of physician-assisted death in that state. Jason Chaffetz, a republican member of the committee, stated he was worried, “that assisted suicide will create a marketplace for death”.

Noticeably as well for New Zealand, which has set much of its legal precedent off the British code, the United Kingdom rejected a Bill to change assisted dying legislation in 2015. Although the vote on the Bill was evenly split by MPs in Parliament at its first reading, by the second reading there was a discernible shift in opinion that saw it being voted down by 330 MPs against it continuing, to 118 in favour of its further progression (for documents relating to the Bill see House of Lords, 2014-2015). Similarly, MPs in the Scottish Parliament on 27 May 2015 voted to halt its own *Assisted Suicide (Scotland) Bill* following its first reading. Prior to this, the Bill was scrutinised by the Health and Sport Committee, who were to report to Parliament on the general principles of the proposed legislation. Their report concluded that “the Bill contained significant flaws and that these flaws presented major challenges as to whether the Bill could be progressed”. Following this, and upon its final reading in the Scottish Parliament, just 36 MPs voted in favour of the Bill, with 82 voting against it.

The Case of *Seales v Attorney-General*

This thesis is contemporarily situated and aims to make sense of the changes that are occurring legislatively surrounding assisted dying in New Zealand. A strong impetus for this change has been the publication of assisted dying cases, both nationally and internationally, that have garnered the attention of the public, along with the scrutiny of both supporting and opposing parties. The cases that have made the news media recent years have become high

profile, with the names of those fighting for the right-to-die used unequivocally in debates seeking for changes in legislation. As detailed above, there are already relevant cases that have set precedent in New Zealand without needing to cover the cases of other countries. Instead, I would like to briefly consider the case of New Zealand woman Lecretia Seales. By all intents and purposes, Seales was not your typical patient who accesses aid in dying laws, which can perhaps highlight the significance of terminal illness not discriminating by age.

Portrayals of assisted dying in the mainstream New Zealand media not only occurred within the realm of news, but have also become popular storylines for fictional realities. The TV show *Shortland Street* is a long-standing medical soap opera taking its name from the hospital in which it is set and holds the prime-time TV spot in the country, as it has since 1991. It has become known for its depictions of socially significant events on the small screen. In recent years, they have portrayed scenarios that reflect stories from New Zealand news and remain relevant in their representations of everyday current events. It was therefore not surprising to see art imitate life, two years after Seales' death and soon after the selection of MP David Seymour's ballot from the box, when in 2017 *Shortland Street* portrayed the sudden onset of terminal brain cancer in their longest-standing character and lead heart throb, Chris Warner. In this storyline, the audience sees Chris tended to by a nurse, who is shown to be "trouble" owing to the suspicious circumstances of her husband's death. The nurse's willingness to help Chris and allow him to self-medicate with morphine during his darkest time leaves for several weeks a cliff-hanger over whether he will 'go through with it'. Adding to the storyline are Chris' children, one of whom is also a doctor. All of them are loving and supportive, but unsure of their resolve to keep him alive while watching him endure such pain.²⁵

New Zealand faced its own right-to-die issue when Wellington woman Lecretia Seales took a case to the High Court (*Seales v Attorney-General [(2015) NZHC 1239]*). In March 2011, Seales had been diagnosed with a brain tumour and following surgery, chemotherapy and radiation therapy was advised that the cancer was terminal. When Seales filed her case on 20 March 2015 she was expected to live for a further three to 18 months. However, as noted above, it is difficult making estimates about people in terminal conditions. On 1 April 2015, Seales began further chemotherapy to slow the growth rate of the tumour, but suffered adverse side reactions and was recommended by her oncologist to discontinue treatment. At

²⁵ Readers can be comforted by knowing that Chris remains alive as of mid-2018.

this stage, she shifted into palliative care. By the time the hearing began Seales was paralysed down the left side of her body, visually impaired and dependent on others for many day-to-day needs.

A lawyer by profession, Seales had by all means a “very satisfying and fulfilling life” (Collins J, 2015), but with the development of her cancer she became concerned about what it could do to her mind and body. She stated in an affidavit for the proceeding, “As my death has become more inevitable, I constantly worry that it could be slow, unpleasant, painful and undignified. I worry that I will be forced to experience a death that is in no way consistent with the person that I am and the way that I have lived my life” (Collins J, 2015). It was on these grounds that Seales took her case to court, arguing for the right for her physician to end her life by lethal medication should her pain and suffering become unbearable. Following the ruling in *Carter v Canada* (2012), Seales argued that by impeding her right-to-die, sections 8 and 9 of the *Bill of Rights Act* (1990), the right-to-life (not be deprived of life) and the right to not be “subjected ... to cruel, degrading, or disproportionately severe treatment”, were being breached as she could otherwise end her life prematurely while she still had the ability and was not yet suffering unbearably.

As mentioned, Seales was an altogether unlikely candidate to fight for her right-to-die. At just 42 she had no children but did have a loving husband who would be financially secure when she died. Seales’ parents, while obviously saddened by her condition, were supportive figures throughout her trial. The New Zealand media publicised her case. While it certainly would have set a precedent for change, in one newspaper article Seales’ lawyer was quoted as saying that she was not looking to create a change in the law and that she was only after a personal declaration by the courts (The Dominion Post; The Press, 22 Apr 2015). Seales’ case drew fascination from around the country – here was a ‘good Kiwi girl’ who managed to engage both sympathy for her plight and heroism for going against the state at the end of her life.

On 2 June 2015, Justice Collins (the presiding judge) notified Seales of his decision, issuing an order prohibiting the publication of the judgement until 3.00pm on 5 June 2015. Seales passed away within just hours of receiving the decision. Having heard amongst others, from a range of oncologists, palliative care specialists and interest groups, Collins ruled that he could not find in favour of Seales as he did not believe that the state was breaching her rights under either section 8 or 9 of the *Bill of Rights Act*. He also found that her physician would be in

breach of the *Crimes Act* (1961) under section 179 if they supplied Seales with a fatal drug and section 160(2) (a) and (3) if they took it upon themselves to end her life. In his final judgement Collins made note of the significance of the issues to New Zealand society that had been raised by the case. He concluded by saying that, “The complex legal, philosophical, moral and clinical issues raised by Ms Seales’ proceedings can only be addressed by Parliament passing legislation to amend the effect of the Crimes Act” (Collins J, 2015). By midway through 2015, New Zealand had had its own dealings with assisted dying which, while some came close to making a change in legislation or setting precedent, never quite made it over the mark.

New Zealand as it Stands

A fortnight after Seales’ death another bid for legislative change was made, this time with the handing over of a petition calling for a select committee inquiry into assisted dying. The petition, which had 8,974 signatories was put forth in the name of Maryan Street and the Voluntary Euthanasia Society (New Zealand Parliament, 2016). It was delivered to Parliament with cross-party support from Act Leader David Seymour, Iain Lees-Galloway of the Labour Party, Kevin Hague of the Greens and Christopher Bishop of the National Party. It was then announced by then New Zealand Prime Minister John Key that Parliament would be launching an HSC inquiry. The committee was to be chaired by then Health Minister Jonathan Coleman. Following the petition the committee were to *investigate fully the public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable* (Health Select Committee, 2017). The HSC called for submissions from 27 August 2015 to 1 February 2016, with the final report stating that the long submission period would allow time for those interested in the subject, both in New Zealand and internationally, to make submissions. The terms of reference set out the that overall the intent of the committee (2017, p. 6) was to:

“Undertake an investigation into ending one’s life in New Zealand. The committee will investigate:

1. The factors that contribute to the desire to end one’s life
2. The effectiveness of services and support available to those who desire to end their own lives

3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation
4. International experiences".

In total, the HSC received 21,000 written submissions from individuals and organisations with over 1,800 submitters initially indicating that they also wished to appear before the HSC. To do so they were invited to Wellington, Christchurch and Auckland, or to appear by teleconference if they were unable to make it to one of these locations. The HSC heard from 944 submitters in the end with over 108 hours of hearings, over nine months, from 24 August 2016 to April 2017.

The HSC found that 80% of submitters opposed any change to current assisted dying legislation, while the remaining 20% favoured law change. The final report also provides that one of the submitters had done a statistical analysis of all the public submissions, according to which the (2017, p. 16) majority of those writing in support of a law change did so for reasons of individual freedom and laws enabling personal choice to be made. The majority of those writing to oppose a law change did so on the basis that human life has an innate value that should be upheld in law. Ultimately, the HSC concluded that it could not make any recommendations about whether or not New Zealand should introduce assisted dying legislation, and understanding that decisions are generally a conscience vote.

Having been re-elected for the Act party in the 2017 New Zealand General Election, MP David Seymour's *End-Of-Life Choice Bill* was drawn from the ballot. This meant that it was able to progress to be read for the first time by the House of Representatives on 13 December 2017. A conscience vote followed this reading, meaning that individual MPs were not bound by their party's specific stance on the Bill and were instead able to vote following their own beliefs. The Bill will now proceed to another select committee (SC). Once formed the SC will gather information before preparing a report regarding the Bill and recommending changes to it. Following this will be a second reading where the House will debate the report from the SC and vote once again on the Bill, and whether it should continue to proceed.

Prior to the election then Attorney-General, Chris Finlayson, presented to the House of Representatives a report under the *New Zealand Bill of Rights Act (1990)* on the *End-of-life Choice Bill*. This report dated 4 August 2017, was done to consider whether the Bill proposed

by Seymour is consistent with the rights and freedoms affirmed in the *Bill of Rights Act*. Finlayson concluded that the Bill appeared to be inconsistent with section 19 *Freedom from discrimination*, in respect that age cannot be justified under section 5 of the Act. In considering the Bill's consistency with section 8 *Right not to be deprived of life*, 13 *Freedom from conscience*, and 14 *Freedom from expression*, he ruled that it was consistent with those rights and freedoms. This is perhaps significant for two reasons. The first is that it aligns with Collins J's ruling in the Seales case on the right not to be deprived of life, and also agreed that the "social and moral considerations raised by the Bill are matters for Parliament" (Attorney-General, 2017). Secondly, *Brown's Bill* in 2003 had failed its consistency test in sections 8 and 14 owing to the provision of the use of advance directives. The Hon. Margaret Wilson decided that this provision did not have the appropriate safeguards and was therefore inconsistent with section 8. As Maryan Street's Bill also allowed for this provision it could be presumed that it would have also failed in its consistency with the *Bill of Rights Act*. This means that Seymour's *End-of-life Choice Bill* is the first of its kind to be found as being consistent with the right to not be deprived of life.

While the aforementioned report has been in a step in the right direction for advocates of a law change, it is important to consider the social and cultural climate within which change would occur. New Zealand is struggling under the weight of socioeconomic inequalities that increase poor outcomes in health and wellbeing. While these issues *can* be addressed, it remains to be seen whether they will be addressed in an effective enough manner and to an extensive enough degree to ensure that any legislative change protects the most vulnerable in society. Current practices in place highlight that New Zealand is able to provide high quality health care, although standards need to extend to the entire population. Cultural change that has occurred and continues to occur in New Zealand owing to its ethnically diverse population means that the medical system needs to develop to integrate and celebrate the diversity in these cultures and their end-of-life practices.

Concluding Remarks

New Zealand is going to face an increased strain on its social welfare and medical system as more resources will be required by the ageing population who will also necessitate increased aged care provisions even beyond their medical needs. Furthermore, as it attempts to actualise into policy the principles of the Treaty of Waitangi, it will likely see a need to

diversify away from the Anglo-American approach to health care that premises itself on a rational agent who is in complete control of their decision-making, beyond competency and as it relates to their being within social life. Service provision for end-of-life care is already increasing, especially as the benefits of palliative care are realised more widely in the community. Further institutionalisation following the desire for life-extending treatment will also likely increase the numbers of those who are dying within hospitals, hospices or residential care homes. While this paints a somewhat bleak future for the New Zealand population policy, changes and diversity among medical approaches can help to bring medical care in line with the needs of its citizens.

These changes will help to ensure that health care keeps pace with other changing social values and institutions. They can also attempt to avoid the situations and circumstances of the above discussed cases by ensuring the provision of appropriate and effective care. The case of Lecretia Seales in particular captured the discussion around end-of-life choices in New Zealand, and with its widespread coverage meant that communities engaged in their own conversations regarding assisted dying and where they stood on the matter. These opinions are inherent within the communal body of New Zealanders, influenced by the social and cultural forces that affect their individual lives through everyday social interaction. The country is poised to make a decision, with the potential chance of a public referendum that would allow its citizens to vote individually regarding their views on the matter. This can only occur following the final report of the select committee to be established in 2018. The following chapter looks towards the sociological literature on death and dying to understand how it is institutionalised within society and to highlight the social nature of the process which occurs as one dies. Ultimately, the next chapter will show why the context of the New Zealand discussion on assisted dying is important in understanding the debate within this country. The social world in which each individual plays a part helps to define and maintain rituals around death and to ensure its social nature. It also structures the lives of individuals as they enter the medical institution to subsequently become a patient.

Chapter three: Sociological Literature on Death and Dying in Contemporary Societies

Introduction

The sociological study of death and dying has been advanced through a number of different perspectives. A lot of these views highlight the socially embedded nature of death (see for example Aries, 1974; Blauner, 1966; Charmaz, 1980; Kellehear, 2007; 2008; Sudnow, 1967), along with the effect that the dying process has on the community within which it takes place (See also Field, 1996; Finch & Wallis, 1992; Small, 1992). Others (see for example Howarth & Jefferys, 1996) have focused more specifically on the sociological perspectives on euthanasia while highlighting the absence of any overly generous contributions to the relationship. This chapter focuses on the sociological literature that has been dedicated to death and dying within western society. This literature is vast and the contributions made by various sociologists have allowed for thoughtful and insightful study into an inherently natural and social process. Ritualistic behaviour that traditionally surrounded death still maintains the social structures around the end-of-life even amongst the ever-changing nature of medical care itself. This chapter considers a selection of sociological research to inform the reader of the theoretical background from which the social nature of assisted dying can be discussed.

Historically, the sociological literature related to death and dying research has followed the Durkheimian tradition by looking at the religious and social rites surrounding dying as a form of functional behaviour. Research highlights the ritualised ceremonies surrounding death which were reflected in the social life of the communities that performed them. Durkheim (1995) contended that the rituals surrounding death were a conciliatory act that provided mourners a place to express grief at the loss of an individual without disrupting the social order. His work on primitive societies in *The Elementary Forms of Religious Life* (Durkheim, 1995, p. 5), highlighted the collective conscience of these traditional societies that held strong beliefs, values and understandings that were akin to all other members of the society. These comparable beliefs and experiences manifested themselves in the religions that structured the social order with ritualistic behaviours without which death? could have otherwise disrupted the routine experiences of everyday life.

These rituals also provided a form of moral cohesion and integration that was experienced through expectations that were structured by categories of the sacred and profane (Durkheim, 1995). The demarcation between the two structured the moral life of individuals as it evoked the distinction between objects that were to be protected and isolated, and those that were prohibited. The sacred and profane thus evolved to help distinguish the activities that were expected by members of the moral community. These common acts of faith and belief in the two realms of spiritual life were thus translated into acts of ritualistic behaviour that were seen to express the proper nature of the object in question (Durkheim, 1995). Thus, we can see that the conception of the first death rites allowed the moral community to formally dispose of the deceased and ensure that the divide between the sacred and profane was maintained. Functioning as a cohesive act for the survivors, the rites surrounding death in primitive societies were also identified as securing a decent future for the deceased. They ensured that the survivors were to be protected from the actions of ancestors' spirits who may not perceive themselves as having had an appropriate send off. Ritual ceremonies were unlike modern funerals, as historically they were viewed as celebrations of the life lived by the deceased and were accompanied by a belief that they had travelled to another realm to rest with their ancestors (Durkheim, 1995).

Modern death rituals, while not intended to provide the same demarcation between the sacred and profane, can to this day still be seen as a conciliatory act for the communal body in which the deceased once resided. The communal body refers to the community of individuals who share meaningful life experiences and are tied together through these by social bonds. Modern day funerals largely act as memorialisations of the deceased and provide mourners with what is a seemingly appropriate place to make sense of the loss and to say goodbye. Funerals also mark a point of transition before the deceased is moved to the cemetery where it joins a new community (Collier, 2003). Modern funerals are thus meant to mark the end of the grieving process. It is not just the aftermath of dying that has experienced a marked change. With the move into a more modern and technologically reliant society, so too has the experience of death and end-of-life care been altered.

Margaret Gibson (2007), for example, examines the expansion of death and grief into the public sphere as technology mediates the cultural images between personal and public death experiences. Sometimes it is international celebrities who elicit public displays of grief and mourning, which is itself turned into media imagery allowing memorialisation of the deceased. This was notably the case in the death of Princess Diana, the gruesome details of

which were published in front page articles all across the globe. In New Zealand this was also the case when former All Black Jerry Collins was killed in a car accident in France. These deaths, occurring in a relative “prime of life”, are viewed as being tragic representations of the power of death to strike at any moment. While death may remain sequestered within everyday life it is prevalent across our media dependent cultures that rely on image systems to inform, shock and entertain (Gibson, 2007).

As Gibson discusses, not all deaths have the same value in terms of their economic and symbolic representations and this can once again be evidenced in the deaths of Princess Diana and Collins. Gibson (2007, p. 416) holds that, “first world nations, and the lives of elite individuals and groups have greater market and media value”. This idea has of course already been identified in the previous chapter where deaths can be seen to hold a value as “infotainment”, although removing the more subtle complexities of death and dying as they afflict some people. This reliance has had a profound effect on all aspects of life, but perhaps none more so than within the practice of medicine and health care. Although the media may appear to represent death in the service of public information they also mediate the cultural images that are provided to the public and in this way socially construct popular death imagery. With this has come not only the expectation that life and death matters can be mitigated by technological aid, but also a growing medicalisation of many things life and death.

Institutionalised Medicine and the Fight Against Death

Many social scientists have written about the medicalisation of life events and experiences from a range of different perspectives (see for example Ballard & Elston, 2005; Broom & Woodward, 1996; Davis, 2006; Evans, 2016; Szasz, 2007). Medicalisation is perceived as the process by which a greater range of everyday experiences and problems are brought under the ambit of medicine (Conrad, 2008). Throughout this process certain aspects of life have begun to come under the supervision of medical practice and thereby become diseases with a range of symptoms that can be fixed and solved by the medical profession. This dominance enables control as treatments are developed to ensure solutions to the now medically defined problems. The shifting of childbirth into the realm of health care has seen pregnancy come to fall under the watchful eye of doctors who monitor the progress of what was once seen as an entirely natural process. The same has occurred too for the opposite end-of-life, as end-of-life

care has also progressively come to fall under the direction of medicine and health care professionals. In turn, this impacts the actions and experiences that go into caring for those with terminal illnesses, especially as institutionalised care becomes something of an expectation. Ivan Illich (1976, p. 3) claimed in 1976 that, “the medical establishment has become a major threat to health”. It has been a further 40 years since he penned these words and it has become clear that he was not being entirely irrational about the threat of medical domination and the authority of the medical profession over everyday life. It was Illich’s contention that medical practice has come too far, and that its expansion into all parts of society has restricted the authority we have over our own bodies.

Further, Illich (1976) claimed that a medicalised society had the effect of categorising and subdividing those who were experiencing medical care, thus providing the patient with a special status. This status, he believed, gave others the right to encroach upon the freedom of the patient to aid in their recovery, in some cases to the point of institutionalisation. This status is particularly important for the discussion in *Chapter eight* surrounding the construction of self and identity among patients of terminal illness. It is the institutionalisation of medicine and the prolongation of dying that are perhaps most meaningful with regards to death and dying within society, and especially when it comes to the assisted dying debate. The growth of technologies that are able to support life are regarded as having had an overwhelming influence on the way death is constructed and experienced in contemporary society. The purpose of this chapter is to inform the reader of the modern context within which dying occurs, and to highlight the overwhelmingly social nature of death along with the rise in technologically dependent end-of-life practices. The character of death has changed throughout the centuries. Shifts in approaches to its process are important for understanding how the idea of a ‘good death’ is conceptualised in modern society. This helps to situate assisted dying within the context of contemporary death practices by highlighting the importance conceived in the notions of a good death. This chapter will provide a prelude for understanding the attention that has been given to the concept of social death and suffering along with the performance of the dying role in the contemporary dying process, to be discussed in the following chapter.

The literature that deals with the denial, sequestration and fear of death has become particularly prevalent within the second half of the 20th century (see, for example Blauner, 1966; Kellehear, 1984; Mellor & Shilling, 1993; Walter, 1996). The historically religious medicine man has become the modern day physician and has taken over the role as the

‘healer’ within contemporary society. Doctors are now expected to cure and to fix any afflictions that may be presented before them. Discussed by Kathy Charmaz (1980), physicians who practise contemporary medicine have a history of viewing death as the enemy. This mentality, she believes, is characterised by aggressive medical practice to ward off disease and can lead to doctors believing they have a personal and moral responsibility to keep their patients alive at all costs. When doctors do not manage to achieve this goal and death takes over it comes to be viewed as a failure, a lacking of medical knowledge, or an inadequacy of medical technology (Price & Cheek, 2007).

Ideas about the failure of medicine when it comes to dying have led not only to a battle against disease within medical practice, but also to a fight for life extension, often at all costs. This has led to what is widely regarded as *life extension* and not only seeks to avoid death, but to extend the human life span by intervening in the aging process. Although the extensions to life that are envisioned within this project are still some way off, as Alex Dumas and Bryan Turner (2007) discuss, the project will still have immediate repercussions within society, especially in light of current end-of-life debates and decision-making. Even a short extension of life across the wider population, by just a couple of years, let alone decades, will result in demographic shifts that will have larger implications for social institutions and the allocation of resources.

The life extension project sees control of medical decision-making being wrested back to the patient, with often heroic measures being taken in order to maintain a person’s quantity of life while foregoing the quality (for studies on the nature of life extension see Kaufman, Shim, Russ, 2006; Olshansky, Rudberg, Carnes, Cassell, Brody, 1991). Francis Fukuyama (2002) has critiqued the culture of modern medicine stating that the medical profession is committed to the belief that any form of life extension is an undoubtedly good thing. Atul Gawande notes in his book *Being Mortal* that, “In the United States, 25 percent of all Medicare spending is for the 5 percent of patients who are in their final year of life, and most of that money goes for care in their last couple of months that is of little apparent benefit” (2014, p. 153).²⁶ Thus, the extension of life can be seen as a reflection on the modern individual’s persistent desire to accomplish the “good life” (Howarth & Jerrerys, 1996), and of our general rejection of the abject, whether in the form of disability or disease.

²⁶ International comparisons have also shown up similar results for other jurisdictions. For more information see (Shugarman, Decker, Bercovitz, 2009).

The maintenance and preservation of the patient's life as the goal of medicine is the injunction to do no harm. Since the Ancient Greeks death was something to be fought against. Those who died young were seen as martyrs and upheld in society as the heroes of sacrifice. Assisted dying calls into question how far the doctor's responsibility goes in maintaining and prolonging a patient's life and at what point the pain of mental suffering becomes the primary agent in the end of that life. Doctors were traditionally seen as the healers of society. However, due to the advancements in medical knowledge which have seen doctors less likely to "cure" or "heal", their role within society has changed even though evidence shows societies' perception of them has not to the same extent (Gawande, 2014).

Intimately bound up within the life extension literature is a point in the progression of both life and disease that forms an expectation surrounding what can and cannot be considered an 'appropriate death', or perhaps more specifically, an appropriate time to die. A timely death is seen to be consistent with a particular and reasonable life plan that gets fulfilled. Daniel Callahan (2000, p. 180) draws on four suggested criteria that enable an appropriate death. He defines these as ensuring that: one's life work is accomplished; one's moral obligations to those whom one has a responsibility have been fulfilled; the death should not seem to others "an offence to sense or sensibility" nor should it raise existential questions in the survivors; and, finally, the dying process should not be marked by unbearable pain or degrading suffering. This final criteria is to an extent how one would traditionally classify what is at stake in assisted dying debates. The previous three criteria show how social expectations are constructed to form what is viewed as acceptable or timely. Moreover, they create an expectation of the dying process that when tied together with medicine's fight against death and the life extension project can raise unrealistic expectations surrounding the end-of-life.

These expectations can be found in studies pertaining to end-of-life preferences amongst New Zealanders that uncover the importance of a natural and peaceful death, which is found to be preferred by many (Hsin & Macer, 2006). As will be discussed shortly, such are the goals of palliative care, but in the period 2000-2013 from which the most recent data comes it was found that only 6.2% of all deaths occurred within a hospice inpatient setting, while a further 33.9% occurred within the hospital. Just 22.3% of New Zealanders during this time died at a private residence (Ministry of Health, 2013). What can be found is that the institutionalisation of medicine and the end-of-life options for those close to death resign a patient and those surrounding them to death within the bounds of an institution. This can be seen as a shift away from the death and dying of history, which within western societies was

largely relegated to the home (Aries, 1974). During the pastoral age, death was a daily occurrence and one that happened in order for the family to sustain itself, both physically and within social life. However, with the growth of industrialisation and a move towards urbanisation, the everyday worker, surviving not off the land but instead in a factory, became isolated from what had been a common condition of daily life (Kellehear, 2007). Like many of the changes that arose with a shift into modernity there also became a compelling need around this time for the institution of the hospital.

Hospitals traditionally existed as religious institutions that housed the destitute and the poor. They remained places which primarily dealt with pain relief rather than cure, and so care for the infirm was dealt with in the privacy of the home (Aries, 1974; Cassell, 1974; Howarth, 2007). Death was expected to be overseen by a priest who would ensure that the spirit of the deceased passed peacefully into the next life (McManus, 2012). Disease was a prevalent aspect of daily life as poverty and poor hygiene led to bacterial and viral infections, such as tuberculosis, polio and pneumonia, long before their origins were discovered. During the 17th century hospitals began to become associated with a growing medical discipline that paralleled the rise in medical research and teaching. It was at this point that medicine turned the corner as death became something that needed to be fought against and to be controlled (Price & Cheek, 2007). A greater understanding of both the human anatomy and of the pathology of disease allowed for significant developments, whereby this challenge became a reality as it became clearer how the inner most workings of the body functioned (Cassell, 1974; Howarth, 2007). With greater medical knowledge, the power to correctly identify, diagnose and therefore cure a disease became infinitely more possible and so even those illnesses that continued to plague societies became repressed.

It was then during the 18th century that the hospital became a place for caring for a wider section of the population as the birth of the military organisation came to provide a number of patients. The unabated continuance of war over this time contributed to the growth of hospitals as they came to care for the sick and those injured in war. Thus, by the 19th century hospitals had proven themselves to cater to the infirm and, more importantly, to isolate the sick from the general population. It became expected that the rise in medicine would combat the spread of disease to allow the working masses to carry on with daily life. While this led to the wider expansion of hospitals as a social institution they were still held to be places that should be avoided, especially in the face of death. Care, until the middle of the 20th century,

was thus left to women within the extended family who were expected to tend to the sick and injured throughout their life and prepare the body once it was over (Howarth, 2007).

It was at that point that the hospital as an institution of care became an accepted part of the social experience as a number of changes occurred within the structure of many western societies (Aries, 1974). One essential aspect was the development of sound medical knowledge that contributed not only to greater infection control within the walls of the hospital, but also led to greater pain relief and therefore provided a wider motive to seek treatment. The more expansive range of disease and illness that began to afflict the population meant that patients could expect to seek care for any range of conditions across their life, and everything from birth to death presented themselves as challenges toward the forces of medicine. As women too began to leave the domestic sphere and find work their ability to care for invalids at home lessened and the hospital evolved into the institution of care as it is understood today. Where the females in the household were once instrumental in the dying process, there came a shift which resulted in the majority of deaths now occurring within the hospital (Howarth, 2007). The culmination of the above factors has had an incredibly perceptible impact on the way we die within the 21st century.

Technology and the Institutionalisation of Death

The fears brought up by Illich (1976) are perhaps the best evidence of the impact that changes in medicine have had over the way we die. His concern was largely with the dehumanising and disempowering conditions of modern medicine and it is this crisis that modern health care faces today. Like many aspects of modern society, this occurred through the rapid emergence and growth of technology and entailed providing the physical body a greater ability to fight against disease and illness. Certainly, increasing living, sanitation and hygiene standards within modern society can take some of the credit for the rapid decrease of disease over time. Public health initiatives globally have seen a fall in deaths among younger sectors of the population, leading Eric Cassell (1974, p. 31) to state that “the death of infants is unusual, the death of children rare, and the death of young adults so improbable that it must be removed from the realistic possibilities of everyday life”. Not only does this affect the make-up of society causing New Zealand’s steadily increasing aging population, but also has flow-on effects for wider social and public policy, encouraging debates such as those around assisted dying. On the whole, the effort put in by the medical researchers has had a

phenomenal influence on the way 21st century individuals conduct their lives and, more importantly, how dying trajectories are lived out.

The growth of medical knowledge also paralleled the advancement of medical technologies that were able to sustain otherwise failed and lifeless bodies. Pushed from the moral order, death entered the medicalised and technologically dependent wards of the hospital as humans began to view natural forces as something to be harnessed by the profession and held as a separate domain to social life (Cassell, 1974; Giddens, 1991, p. 165). It was here that doctors engaged with technology to ensure that patients did not die on their watch. The overall effect of the growth of medical technologies cannot be understated. It is this point that has had the most pertinent impact on end-of-life care as it became possible for physicians to put patients onto life support when parts of bodies were no longer viable. Ethically it is here that most issues have been raised, and in the early advent it was the problems associated with bodies attached to machines that advanced the most divisive bioethical issues regarding when, and if, it was appropriate to disconnect patients from machines thereby terminating life.

Many authors have provided debates about the rise of medical ethics following technological advancements in health care, as well as the diverse range of ethical dilemmas that they have brought up (Emanuel, 1994; Macklin, 1987). This work has typically defined the debate on assisted dying and provided impetus for the discussion on medical ethics. As discussed by Alastair Campbell, Grant Gillett and Gareth Jones (2001), humans tend to have a strong belief that the way in which a person dies is significant for the overall totality of their lives. David Shaw (2009) furthers this idea in his discussion in his article ‘Euthanasia and eudaimonia’, where he considers the argument by those opposed to assisted dying who want to “leave things to nature”. Shaw proposes that nothing else in life is essentially left up to nature any more, especially in the sense that we go so far as to clothe ourselves, and expect warmth and security, to avoid death.

Beyond this, individuals also tend towards seeking medical care when they are ill and leave very little up to nature in modern society. Shaw (2009, p. 531) therefore proposes a new conceptualisation of assisted dying that moves away from the construct of euthanasia to the more applicable *eudaimonia*. This term, although without direct equivalence in English, can be translated as, “life-long happiness or flourishing across one’s whole life. Eudaimonia is an objective rather than subjective conception of happiness; the eudaimon will have lived a virtuous life and will also want to leave the stage in a manner befitting the time spent on it”

(Shaw, 2009, p. 531). It is, in the truest sense, what most individuals seek in a good death; one that reflects their life and can provide the memories from which family and friends remember one by. As Shaw believes, for a person to achieve eudaimonia they must also achieve the virtue of happiness across the entire lives and not just parts of it, such as death. Shaw argues that by not allowing active assisted death at the end-of-life it halts an individual's achievement of eudaimonia since it allows a slow and insufferable death. It is, of course, the community around the deceased that is to recall the memories and to place onto them their subjective symbolic value.

As identified at the beginning of this chapter, death and the rituals surrounding it were historically deeply embedded within the community. While post-mortem rites like funerals are still held as important processes for the grieving of friends and family, the nature of the dying process itself has changed dramatically as it has moved from the privacy of the home to the sequestered hospital environment (Giddens, 1991). Increasing faith in the medical profession over time soon combined with further state emphasis on the importance of public health. This was along with the management of both health care and death, which shifted from religious control to that of the medical profession. With increasing medicalisation applied to various aspects of individual social life there came the ability of physicians to more pervasively control the symptoms and behaviours that afflicted their patients. Health care professionals thus also came to determine what could be considered healthy and normal within a population and then seek to 'fix' those who did not fit into these categories.

As Irving Zola (1975, p. 86) discusses, once an illness is defined as an undesirable state it turns into a problem not of *whether* to deal with it but *when* and, more importantly, *how*. This fight towards normality is also perceived as a fight against death as abject bodies become cured and doctors fight to ensure that disease does not triumph over their knowledge of the body. Thus doctors impart onto bodies a range of treatments that seek to extend life beyond what would otherwise be seen as natural. Illich (1976, p. 207) identified modern dying as a technical death, one that was only possible when it was deemed by the medical system, acting as proxy for society, when and after what "indignities and mutilations" a patient should be allowed to die. Inherently tied into the doctor's knowledge of the disease is a power over the patient's body to determine when death has been staved off for long enough and when the patient should succumb to the fight.

Before death occurs, however, an individual is likely to spend time on the wards of a hospital where they will make the transformation from person to patient. David Moller (1990) discusses this idea in his study into the human impact of technological dying, drawing on Goffman's work in *Asylums* (1968) and describing the hospital as a *total institution*. He believes this type of social institution is able to optimally dominate the time, interests and activities of the people that inhabit it. A total institution is characterised by its ability to physically separate itself from the outside world and therefore diminish the interaction with society. While not entirely devoid of contact with the wider community, hospitals have been found (Glaser & Strauss, 1966; Moller, 1990; Sudnow, 1967) to isolate their patients through a rigid approach towards organisation that emphasises the qualities of bureaucratic rationalisation to encourage the control and management of patients, workers and visitors within its space.

Two important changes occur when a patient crosses the boundary of the hospital that ultimately both lead to the technologically dependent deaths of contemporary society. The first of these occurs when on entering the institution, as the person admits themselves to become a patient. They thereby submit themselves to what is best put by David Moller (1990, p. 53), as they move from being Mr Smith to 'Mr Smith – the cancer patient in 402'. This stripping of identity should perhaps be defined instead as an overriding of the patient's previous personality and transforming them into a physical body barely resembling their former self. Giddens (1991, p. 61) echoes this idea in his discussion on the rise of the hospital, noting that while they were once locations to deal with poverty as the forerunners to prisons and asylums, hospitals later emerged to focus on patients with distinct physical problems. It is here that medicine encounters the confusion surrounding the mechanical death of the body and the social death of the individual. Without a doubt the disease can take much of the credit for this, but the social organisation and management of the admitting institution also plays its part in the depersonalisation of care that occurs.

This depersonalisation within the institution of the hospital can be seen to reflect the medical discipline's understanding of the body. Cassell's (1974) research shows that as physicians' knowledge of the body increased they were able to further develop their understanding of how each specific part of the body functioned and could be manipulated. The result of this was a specialisation of medical professionals who came to focus on the curative process of certain organs. This argument is also furthered by Moller (1990) who claims that instead of examining the whole patient, the modern physician applies their knowledge not to the person

but to the body part in question. This has led to the view within health care that the needs of patients can be reducible to technically manageable components. The patient and their body become the vehicle that delivers the disease to the physician. The patient, however, is abstract from the body and is viewed as wholly superfluous to the application of medical knowledge (Cassell, 1974). What this means is that the role of identity and personhood is unnecessary, or perhaps better described as ignored, within the contemporary hospital institution.

This brings us to the second change that occurs when a person crosses the boundary to become a patient. Highlighted by the isolation that transpires between patient and community, this has an overwhelming impact on how the terminal patient interacts with and is viewed by society. For this discussion a digression is first needed to understand how death was historically faced by society. Drawing on Aries, and then Kellehear, it can be shown that dying was once a communal matter, but as the deathbed moved from home to hospital the alienation of the patient occurred. Both authors, along with many others (Elias, 1985; Gorer, 1955; Mellor, 1992), provide an explanation surrounding how the culmination of a number of social forces has changed modern dying.

Historically, what death entailed was for the patient to be prepared. This included concluding business and relationships in this life and equipping themselves for whatever was to come in the next. This approach to death was discussed by Aries (1974, p. 7) as a “tamed death” that could be characterised by an awareness of the oncoming of death and appropriate preparation for its occurrence. What differed primarily between historic and modern deaths is that while still an emotional event, death was not fought against. Instead, when people passed, often surrounded by family and mourners, it was accepted as being the right time and the will of god. As recognised by Aries (1974, p. 28), much of this attitude came from an acknowledgement that death was an acceptable part of the order of nature. Alongside this, both the dying and the members of the surrounding community knew the roles that were customary, the gestures that were expected and the actions they would perform.

This is partly because death was so inherently built into the lives of these communities (Fenwick & Fenwick, 2008). It was a common feature within the household and, as noted by Aries (1974, p. 12), it was a public ceremony with the dying individual’s bed chamber as one that was to be entered into freely. There was also a security in knowing that a person would be looked after once they had died because of the preparations in life that had been made to ensure other worldly comforts. This is in comparison to the deaths that occur in modern

society, which are characterised by the social isolation that a patient will likely encounter and the knowledge that there is nothing waiting for them bar their own extinction. Contrary also to how life is now viewed by the modern individual in the 21st century and, in stark contrast, to the values that are illustrated by the life extension project, Aries identified that the man of the late Middle Ages was well aware of the morality of life and was therefore very aware of the extra time he had been given even if that time was brief.

Death, Aries (1974, p. 44) believed, always hung over a person “shattering his ambitions and poisoning his pleasures”. Again, terminal individuals who were faced with a tame death would likely be perturbed by the contemporary dying individual’s dependence on life-supporting and life-sustaining technologies that ultimately delay the inevitable and upset the natural order. As Aries (1974) discusses, the tame death of medieval societies underwent a slow but effective transformation, which followed into contemporary societies and was exacerbated by the growth of medicalisation and institutionalised medicine. A particularly notable change that Aries identified as occurring over the course of the centuries was an increase in the emotionality of the dying event and subsequent mourning period.

Prior to the 19th century, death was seen as an inevitable and somewhat banal event that was marked by specific customary rites and rituals. While these aspects of death and dying did not change, what came to accompany them was emotion, prayer and the outward gesticulation of grief (Aries, 1974, p. 59). No longer was death viewed with a routine complacency and everyday inevitability, but instead it came to mark the loss of *an individual*. A number of social and thanatological changes occurred over the period that Aries (1974) discusses, but most importantly for the present work it is his recognition of a shift into what he called “forbidden death”. Death in this time became shocking and hidden and is in line with the conception of dying proposed by Kellehear (2007), which he refers to as a “shameful death”. Kellehear and Aries both argue that death has become a hidden and stigmatised experience.

These claims were first put forth by anthropologist Geoffrey Gorer (1955) claiming that in modern societies death has overtaken sex as the greatest taboo. He believed that natural death had become increasingly “smothered in prudery” (Gorer, 1955, p. 51), while the natural processes of decay have become disgusting. Commonly-held beliefs are also echoed by a number of other authors who have variously argued that the sequestration of sickness and death has resulted in the denial of death in modern society. These ideas are further emphasised and exacerbated by the shift of dying from the private to the public institution.

Giddens (1991, p. 156) believes that institutional sequestration can be identified as the removal of certain basic aspects of life from individuals' everyday life. These can be evidenced by elements like the hiding of deceased in hospital morgues that are more often than not held below ground and away from the general population of the hospital. Instances occur largely when deviant bodies and behaviours are pushed from the everyday conscience of the community and concealed away from the social activities of the day-to-day. Importantly for Giddens though, one of the greatest (if unintended) consequences of the rise in modern institutions has been the repression of basic moral and existential aspects of social life, opening the way for feelings of shame when faced with deviant bodies.

Giddens (1991) was particularly interested in the influence of society's shift into high modernity and the impact this had on the cultural tools that were available to an individual in the face of death, whether their own or others. As identified by both Durkheim (1995) and Aries (1974), the cultural rituals within a community provided a functional purpose of ensuring social cohesion and allowing the deceased to move comfortably from this life to the next. This was based in faith, in a supreme being who dictated the journey into the after-life and ensured a vital role for communities in structuring the ritual ceremonies carried out following death. With the shift away from religiosity in most societies, there has been a reduction in what is described by Moller (1990) as the culturally shared and defined meanings to the experience of dying. This has left modern societies with an inability to face the existential dread that accompanies death, as well as a lack of social rituals or tools to cope with the loss (Mellor & Shilling, 1993). The combination of both the technologised dying process and the lack of a cultural script for death has ensured that modern death is a very stigmatising and isolating phenomenon.

Beyond the lack of cultural tools available to the modern individual, Kellehear (2008) also identifies a number of technological advances that have created difficulties for the determination of death and that, for the moral realm of decision-making, has created considerable problems. It is important to note that the increased dependence on medical technologies, while instrumental in the prolongation of life, has also inherently complicated many of the deaths that occur within the walls of a hospital. As is highlighted by Glaser and Straus (1968), a critical issue in the process of dying is the ability, or lack thereof, for medical professionals to identify a patient as "dying" or not. They discuss that no matter how certain a patient's trajectory may appear on admission to the hospital, staff must continuously reformulate and redefine their care expectations as the illness progresses (Glaser & Strauss,

1968). While for many patients staff are unable to categorically determine the moment of death, other patients (and their family of proxy decision-makers) are likely to cause distinctly opposite problems. These have been raised by the dependence on life-sustaining machines that have increased uncertainty and controversy surrounding the point at which a patient can be determined as dead.

The Determination of Death

To fully understand this debate and the critiques of it we must first understand the history of death determination to more fully conceptualise the important changes that have occurred. Traditionally, that is until the around the middle of the 20th century, determining the moment of death was a rather simple matter. It occurred when the individual collapsed, their brain ceased to function and thus there followed a permanent cessation of any clinical functions of the body. Although not physiologically observable, such a death was at least somewhat physically evidenced and confirmed once *rigor mortis* and discoloration of the body had taken hold (Bernat, 2009). Developments in medical knowledge soon meant that the detection, or lack thereof, of a heart beat or respiration was soon the easiest and most efficient way to establish a person's passing. However, what occurred in medical knowledge following this turned the page on dying as life-supporting, or more specifically organ-supporting, machines became tools that were able to sustain a body beyond the boundaries of what had previously been able. Jane Seymour (2001, p. 10) views the rise in intensive care units as a symbolic representation of the "modern preoccupation with the mastery of disease, the eradication of 'untimely death' and the prolongation of life". Seymour goes on to discuss, drawing on the work of Peter Singer, that the use of high technology treatments in this setting creates a situation in which multiple interpretations of the moment of death become possible, highlighting the complexity regarding the transition between life and death.

It was the introduction of these new processes through which to sustain life that the issue arose surrounding who was alive and who was dead. In 1968, it also led to an *ad hoc* committee of the Harvard Faculty to define death as "brain death" (Giacomini, 1997). Such a death was identifiable by a non-functioning brain as opposed to the cessation of a beating heart or respiration as it had previously been conceived. Partly, this was owed to the fact that death needed to be reconceived, which as mentioned came about with the rise in medical technologies. Lungs, for example, could be artificially replicated to allow a patient to keep

breathing, while the heart could be duplicated to ensure the continual pumping of blood around the body. While there can be no doubt that technologies have had overwhelming impacts on the way individuals live, it has also modified the way death is viewed and experienced.

The brain could once determine the end-of-life because it meant the cessation of all other vital bodily functions, but this was no longer the case once they could be artificially sustained. The power of technologies and the controversy they caused was also exacerbated by the experience of a permanent vegetative state. In this situation, a patient's brain stem is still intact and so they can experience a range of autonomic functions allowing the heart and lungs to continue unaided. This is in contrast to the "whole-brain" deaths described above that rely on persistent mechanical support to sustain life. A change in the application of technologies ushered in the way for organ donation and transplantation, as well as a far wider use of intensive care units within hospitals. A simple change in the title of death dramatically changed the way it was understood and conceived in the world. As we will see in *Chapter eight*, it also had a wider influence on how death is understood socially. Definitively, the issue remains with an ever larger question mark over it. For some, death remains dependent on the theological underpinnings of life, and rests instead on the realisation that there can be no overall distinction between x and x?.

Allowing a patient to stay on a machine (or machines) after their brain would have otherwise been defined as dead meant that the machine could indefinitely sustain the body, raising many ethical questions as to the withdrawal of life-sustaining technologies. It was these dilemmas that became prevalent following the Nancy Cruzan and Terry Schiavo cases in the United States and which highlight the difficulty in modern medicine of determining just what constitutes life and living. It is on this point that the issues surrounding assisted dying emerge as the redefinitions of death call for questions regarding the role of personhood and identity in the determination of life. For the assisted dying debate, it is these issues that raise questions of the importance surrounding quality of life that have become the most substantive regarding life-sustaining technologies and the dehumanising effect they can have at the end-of-life. This can be evidenced by the debates that surround the provision of a good death as will be shown in the following section. What the rise in medical technologies changed was not only the boundaries of health care, but also how people have come to understand and approach the role of identity when it comes to the mind and the body.

The Many Ways to Die

As discussed elsewhere in this thesis the literal translation of euthanasia is ‘good death’. While many people would not want to deny a person a good death, it is the request to control and predict the exact moment a patient’s life ends that many people find contention with. As discussed by Emanuel and Emanuel (1998), an important point to remember about assisted death is that as an intervention into end-of-life care, it is not aimed at modifying the experience of dying itself, but is instead seen as a means to an end. The term ‘good death’ is often used synonymously with ‘death with dignity’, but for reasons that will become clear in *Chapter six* this term will be avoided. Instead, the subjective conceptualisations of what it means to die well in the face of life-prolonging technologies will be emphasised, drawing particularly on how ideals determine decision-making and social practice at the end-of-life. This section, along with the rest of this thesis, therefore presumes that every individual has an intrinsic and unconditional human worth, although the circumstances surrounding their death might challenge their subjective experience of the dying process. The primary feature of assisted dying legislation in a number of jurisdictions is the relief of suffering.²⁷ It is this point that much of the literature surrounding end-of-life and the good death stems from. Putting an end to suffering, however, was not initially isolated to the domain of euthanasia proponents. These ideas were also the founding goals of the palliative care movement, which seeks to provide holistic care that goes beyond attending to just the purely medical needs of the patient.

While the palliative care movement and hospice care providers have characteristic goals in mind that help to determine how they view a good death, as is discussed by Mary Bradbury (1996), it is difficult to identify amongst the literature a single and all-embracing definition of what constitutes a good (or bad) death. Bradbury, in her work on the representation of good and bad deaths, identifies three categories that she felt could broadly typify good and bad deaths. For Bradbury (1996, p. 87), these were the *sacred good death*, the *natural good death* and the *medical good death*. For many, the idea of a sacred good death is that which was proposed by Aries (1974) as a tame death, in which affairs are set straight while the family, friends and clergy of the patient surround the deathbed. The natural good death is arguably one that is seen least frequently in western societies with the aforementioned medicalised deaths. Although Bradbury (1996) questions the deaths that are represented as “natural”, she identifies being pain-free as being of importance for a passing. She also concludes that death

²⁷ For example, see legislation as outlined in *Chapter two*.

being sudden and free from medical intervention is also of concern for many patients. Walter (1994) extends this description by stating that a death can be achieved by removing the patient from the “artificial” setting of the hospital, allowing them to die at home without heroic measures keeping the body alive.

I would also argue that timing is of utmost importance in a natural death, as those that occur too early or ‘before a person’s time’, such as being too young or at the peak of a career, are considered more devastating than those that take place at the perceived end of a well-lived life. Bradbury’s conception of a medical good death is perhaps the most common within the institutional walls of the hospital. The epitome of a good death lies in the ability of health professionals to ensure that it is as pain-free as possible. In this way, they are expected to manage, or in Bradbury’s words, “manipulate the process of dying” (Bradbury, 1996, p. 88). Emphasis on a medical good death also paradoxically moves away from it being institutionalised and instead is placed on being able to control the place of death, whether that be hospital, hospice or home. Beyond this, ensuring that both the patient and the people close to them have an awareness of the impending death to practically and psychologically put things in order is also heralded as being of consequence for ensuring a good death.

Part of the difficulty of ensuring a good death for patients lies in individual differences that determine what people perceive a good death to be. Another perhaps more overarching difficulty also lies in the idea that dying, rather than being an exact moment in time, has come to describe a complex set of moments and events. While this may be definitively marked by the end of a person’s life, it differs between patients and diagnoses and therefore may end up representing a protracted period of time. It was this idea that was first raised in Glaser and Strauss’ works *Awareness of Dying* (1966) and *Time for Dying* (1968), in which they define the notion of a “dying trajectory” as an individual patient’s course of dying. By identifying the process as such, Glaser and Strauss (1968) believe that health care professionals caring for dying patients are able to continually revise the organisational management of the ward, reformulate their feelings and emotions towards the patient, and influence decisions and interactions regarding care for the patient and family. This enables not only a structural process along which dying proceeds, although with many varying contingencies, but also ensures that they can maintain responsibility and control over the patient.

Within each person’s dying trajectory lies a number of unknowns that help to ensure that no two deaths are the same. As Glaser and Strauss (1968) identify, the nature of medicine and

the human body means that people may endure multiple trips to the hospital and back home again with each expected to be their last. Time and mode of death are therefore very uncertain, and although patients are often faced with a terminal illness, more often than not it is a secondary condition that results as a consequence of the primary illness, which will often serve as the final cause of death. While predictable to an extent, death has still retained its uniquely spontaneous characteristic, which ultimately ensures that planning for or trying to control it is fruitless. This does not stop people from trying, however, and so people have come to anticipate, or perhaps pine, for death to occur in a socially acceptable way. It is from the construction of a socially acceptable death that we can identify the foundations of a good death and what it involves and includes for different people.

A number of studies have been conducted across a range of disciplines looking into the experiences of terminal patients, their support networks, health care professionals and caregivers (See, for example Granda-Cameron & Houldin, 2012; McNamara, 1994; Olthuis & Dekkers, 2005; Steinhäuser, Clipp, McNeilly, Christakis, McIntyre, Tulsky, 2000; Taylor, 1993). Many of these studies have provided their own definition of what it involves to ensure a good death for a patient. A literature review conducted in 2015 (Meier, 2016) that looked into these varying definitions within 36 articles identified 11 core themes that were consistently raised as perceived characteristics of a good death. Most notably within these results was the identification of a number of discrepancies between the perspectives of patients, family members and health care professionals. The qualities of ensuring a pain-free status and enabling a patient's specific preferences for dying were again recognised amongst all three groups as being of particular importance. However, other preferences like an enduring quality of life and the fulfilment of religious and spiritual practices differed in importance among the groups. These results make it difficult to determine how it might be possible to best provide and deliver the end-of-life that patients and their families desire. More importantly though, it highlights the importance that should be placed on ensuring and affirming that end-of-life discussions are taking place between all involved parties.

As has been noted about many of the qualitative studies that have been conducted surrounding euthanasia is the emphasis that has traditionally been placed on patients with either cancer or AIDS.²⁸ These 'high-profile' diseases have meant the exclusion of neurodegenerative diseases such as motor neuron disease, multiple sclerosis, Parkinson's disease and Huntington's disease from much of the research. As part of the symptomology of

²⁸ David Field (1996) also notes that in modern societies cancer has come to epitomise the "feared death".

these diseases, the patient experiences a slow deterioration of bodily control and functions. However, in many cases they remain relatively mentally capable, conscious and alert. A patient suffering from one of the above neurodegenerative diseases, among many others, will experience the deterioration of the internal and external parts of the body. Their symptoms may range in degree, but they will all experience a severe decay in what was seen to be their 'normal', corporeal, lived body.

The treatment and medication used by many of the disease sufferers is palliative as opposed to curative. While relatively successful in controlling many of the physical symptoms in the earlier stages, medication may have side effects from prolonged use that further emphasises motor problems, while also affecting the integrity of the internal organs such as the kidneys and liver through toxicity. What many sufferers thus find is that they experience years of drawn-out medical treatment only to be faced with more constant and terminal decline. Their care is placed upon either family members or institutional care facilities, both of which can place a large burden on the family of the patient as well as on the patient themselves.²⁹

Sociologists looking at death and dying have thus come to deal with the idea of the 'good death', a death that many people who suffer these and other chronic diseases do not get to experience. Instead, what many sufferers face is years of both mental and physical suffering which places a strain on their relationships with others, and their own existential wellbeing and community involvement. These debates see questions raised regarding the boundaries of a good death or perhaps, more importantly, how to both quantify and qualify a person's quality of life. They also raise questions as to the inherent sanctions and expectations placed on the medical community, and more specifically doctors, which see them tied to the historical Hippocratic Oath pledging their adherence to the respect and maintenance of the medical profession at large by keeping their patients free from harm and injustice while in their hands.

Reliant on technology to sustain their life, the quality of a patient's everyday experience is often far from how they had previously lived. Notions of the good death involve the protection of not only the physical, but also the social wellbeing of patients. With the drawn-out deaths that are characteristic of living in a technology-intensive society it is often the socially embedded nature of the patient that comes under threat, especially so when dependent on machines that confine the possibility of activity and experience. This will be

²⁹ Huntington's disease sufferers, for instance, can be expected to live for up to 25 years after the onset of symptoms (Gray, 1995), but will need close to full-time care from quite an early stage.

discussed in regard to the social death of a patient in the following chapter. For now though, it is important to consider who the good death is good for. As identified above, and in much of the literature, the perspective of what can be considered a good death varies between patient, family and practitioner along with the wider community within which they are located. Differences in approaches may make it hard to ensure that a good death is achieved for all, especially when control of the dying process has been given over to the institutional workers.

This idea is also furthered by Kellehear (1990) who identifies five key features of a “good death model”, believing them to be inherently bound up within the social life of the terminally ill individuals. These he considers to be: the social life of the dying person, identifying awareness of dying, social adjustments and personal preparations, public preparations, and arrangements relating to work and farewells. Important to note here is that these features also contain a throwback to Aries’ “tamed death”, as Kellehear places an emphasis on ensuring that the social adjustments and personal preparations being made are important feature of a good death. Peter and Elizabeth Fenwick (2008) identify that the technical equipment around a deathbed is sometimes more concerned with ensuring the relatives and medical professionals are at ease knowing they have done all they can than it is with ensuring that the death is as peaceful and comfortable as possible for the dying.

Concluding Remarks

As the only inevitable outcome of life, the death of an individual within a community can have unsettling and troublesome effects for social organisation. What becomes clear in understanding death and dying over time is the significance of ritualised processes that highlight the social nature of the event itself. Inherently bound up within rituals and social expectations is a reflection of communal values that are enacted and thus aid in the promotion of social cohesion. These rituals attempted to downplay the otherwise disruptive occurrences following the death of a member that plagued moral communities. These traditional death ceremony rites and rituals are reflected in the modern funeral, which also attempts to provide a shared space for memorialising, grieving and reconciling the loss of an individual.

The actions of the community once held great importance for the dying as they typically spent their final days surrounded by friends and family within the bed chamber of their private residence. Unlike modern death and dying, such events were a reflection of the

organic life-cycle of the natural world and were largely accepted, if not unfortunate, happenings within the community. It was not until the 18th century that medical knowledge developed to a point, and the social nature of communities had shifted, that ushered in new, modern dying practices. These practices still reflected the social organisation of both life and death, but where once rites took place in public they soon become relegated to within the walls of an institution, namely the hospital.

The developments that took place reflect not only the social circumstances of communities, but also the growth of knowledge and the authority that the medical profession was increasingly able to claim over those whom they treated. These claims to truth were seen in the development of the term 'medicalisation' from around the 1950s as everyday disorders increasingly came to fall under the guise of medicine and treatments were developed to counteract the symptoms of dysfunction. A number of these illness and treatments would not have been possible if it were not for a simultaneous greater understanding of the body that was advanced alongside the technological innovations of the 20th century. Now able to understand and better control the body and its disorders, health care professionals became ever popular as an ever-increasing degree of faith to cure and heal was placed upon them.

While indeed extremely beneficial to society, these developments in medical care have also had unintended consequences for the ways that illness, death and dying are approached within and by the community. Instead of being confronted with death and dying in the everyday, modern individuals are instead left to deal with losses without the cultural frameworks that were traditionally in place. Gorer (1955) first claimed that death was the new taboo in 1955 and since then a number of authors have put forth claims that death is now marked by its sequestration, denial and avoidance in contemporary life. Added to this are the variations regarding differing determinations of death that can raise difficulties for patients, family and friends, as well as medical professionals when it comes to end-of-life decision-making. What becomes clear is that, in contrast to deaths of the past that encouraged social integration and held expectations for social action and experience, modern deaths do not hold the same cohesive quality. Instead, it is up to individual communities to traverse the cultural tools available and to try and fulfil end-of-life wishes to the best possible degree.

Desires are not always realistic or possible and so often it comes down to the institutional frameworks and tools of social organisation that are in place. The growing emphasis on sustaining criteria for the 'good death' and enabling its actualisation has become increasingly

popular with many proponents of the assisted dying debate. The palliative care movement is viewed as a reaction to the institutionalised care that has become increasingly regular. Palliative care, with its goals of providing comfort and support, is the closest that institutional support comes to providing patients, friends and family with the good death they spent their lives hoping for. The lack of common understanding regarding what the good death could or should entail makes its application in medical practice difficult as it provides varying expectations amongst different people. This difficulty, as will be shown in the following chapter, has profound effects on the way that people spend their final months, weeks and days and is vitally important for the construction of an appropriate end to a person's life. As will be shown in the next chapter, more often than not the terminally ill and elderly do not have access to a good death, as they personally understand it, and instead they are relegated to the role that society places onto them.

Chapter four: Framing the Assisted Dying Arguments – Can These Ever Be Morally Justified?

Introduction

This chapter begins from the question of, “On what basis can, or is, assisted dying legislation morally justified?” In answering this question I explore four formative frames of discussion on which claims of advocacy or opposition for legislation are constructed. The first of these is suicide and this chapter considers the discussion on the ethics and politics of the act of taking one’s own life. For many people, premised in this idea is the inherent wrongness of carrying out the act, along with a belief that ending a life under any circumstance should be viewed as altogether mistaken. As is discussed in-depth by a multiplicity of authors elsewhere, history has taken suicide and suicidal behaviour as deviant and therefore traditionally condemned those that attempted the act. There are many reasons for this, and while the social and cultural contexts within which suicides occur may have changed, the stigma surrounding such deaths has remained. Condemnation from the state with regards to suicide has been a common reaction, and it is in the upholding of life at all costs that sovereign powers are able to retain control and power over their human subjects. Suicide diminishes this power by wresting control back with the suicidal individual, as they are willing to take their lives into their own hands. This plays a vital role in the expectations that are placed around death and the way that cultural rituals are played out in the everyday.

As previously considered in discussions on the good death, the concept of euthanasia denotes the idea of a gentle and easy death. It is a relief from the pain and suffering by the individual who commits it. Suicide, on the other hand, is the act of taking one’s own life, or self-murder. The difference between the two concepts is separated by a thin line, but this is maintained in part by the causation of intention of the individual. While in both instances the intended outcome is death, the causation differs in that a person committing suicide looks to end their life because assisted dying is viewed not as the act of hastening death but as the act of killing oneself to bring an end to terminal pain and suffering. As the term *euthanasia* suggests, it is committed to relieve a person from the agony of a slow and painful death through physical and mental deterioration. Suicide is the act of killing oneself out of despair. As described by Kellehear (2007, p. 94), it is often used as an example of a ‘bad death’ and one that brings with it stigma and shame; despair however would not otherwise naturally lead to death.

Regarding the assisted dying debate, the slippery slope argument is perhaps the most cited reason for limiting the power of doctors to end the life of their patients. In saying this, however, it is not an argument that is only restricted to assisted death and it is prevalent in many other ethical and legal-political debates. The slippery slope argument is defined by Stephen Smith (2005, p. 17) as, “one where it is argued that the acceptance of one standard, while not perhaps undesirable in itself, leads to the acceptance of another standard of the same type which is undesirable. Therefore, it is argued that the first standard should not be accepted because it leads to the second, even if that is the only thing wrong with the first standard”. The fear among many is that once assisted dying is legislated it will lead to an abuse of the practice, whereby vulnerable patients may be coerced into dying by their families, physicians or both.

As Smith (2005) discusses, there is much confusion surrounding the slippery slope argument, how it operates and how best to evaluate it. Part of this difficulty comes from the fact that the arguments looks to *potential* events that may occur and are therefore speculative in nature. The result of introducing legislation for assisted dying and the impact on patient abuse that it may have can never really be known which, of course, is where lies part of the inherent difficulty. The evidence from studies conducted in jurisdictions with legalised forms of assisted dying is often not sufficient to establish trends in behaviour. On the whole, once assisted dying is legalised the evidence does not provide a sufficient basis to draw any definitive conclusions (see Norwood, Kimsma, Battin, 2009). This, however, does not exclude it from being a significant marker of opposition against the legislation of assisted dying. Smith provides a good discussion of the slippery slope argument and, like many other authors, draws on John Keown’s (1997; 2002) comprehensive breakdown of the potential for a ‘slippery slope’ in assisted dying practice.

In this chapter I also present some of the approaches to the definition of dignity along with some critiques against, and arguments in support of, its use within philosophical literature more widely. In presenting these definitions I want to acknowledge the wealth of literature related to differently perceived approaches to dignity. What this leads to is an over-proliferation of authors who believe they have surmised dignity in the most adept way, and others who believe that their categorisation of dignity into its different forms is the most agreeable. However, this has not necessarily resulted in an easy application of the term in everyday life or health care. Those scholars who speak of death with dignity often overlook a

somewhat crucial point in their arguments as is raised by Peter Allmark (2002). In this article, Allmark discusses the approaches to understanding the idea of death with dignity through a discussion, following Leon Kass (1991), of the different ways in which death can be understood. Allmark here highlights an interesting point in the death with dignity debate by noting that often, when speaking of death with dignity, people are referring not to the indignity of death itself, but the undignified way that the dying process takes hold of a person, and concludes that it is thus more apt to term this idea *dying with dignity*.

The death with dignity movement rests itself on a belief in the inherent or, more accurately, undeniable quality of life argument by claiming that a life which lacks a degree of positive qualities is not worth living. The flipside to this argument is made by people who have a belief in the sanctity of life. This group hold a belief that life, and its very being, provides an inherent sanctity that cannot be denied. The sanctity of life claims rest on a belief that the taking of somebody's life *for any reason* is intrinsically wrong. Historically, as is discussed in a number of theologically-based bioethics arguments, this debate was centred on a person's religious beliefs and the idea that God was the one to grant life and should also be the only one to take it away. Having shifted towards more secular societies, and although this belief is still prevalent, it is no longer the primary argument that the sanctity of life debate focuses on. While God may not be seen as the giver and taker of life many people still believe that any act that ends a person's life on earth is immoral. First, however, this chapter considers how suicide is conceptualised in relation to assisted dying.

Suicide

Sociological research into death and dying, containing a section on suicide, would appear negligent to not refer to Durkheim and his foundational functionalist approaches to its study. While taking note of the significance of this literature, this thesis will not dwell on Durkheim's traditional approaches to suicide beyond noting that they are valuable for endeavouring to understand how modern societies and the social structure they promulgate may bring forth changing patterns in suicide. Recognising that this thesis is on the communal body and its place within the assisted dying argument, the structural impacts of suicide owing to a perceived lessening of social cohesion do not have strong implications for the motivation behind assisted dying as do the physical pain and suffering of terminal illness. Further detail

on Durkheim's approaches can be found in *On Suicide* (2006). For the moment, however, I would like to consider some of the continuing issues regarding suicide in society.

As stated by Thomas Szasz (2002, p. 1), "the act of causing of deliberately causing one's own death is treated as spooky, defying understanding and something 'abnormal' or better not spoken or thought about". This aversion to speak of suicide could be seen to be reflected in the media prohibition on reporting on suicides that is borne from an idea of a suicide contagion. As Szasz argues, there is an absence of a wide vocabulary for killing oneself, limited to 'suicide'. This differs from the array of terms that can be applied to the circumstances of killing another. This lack of linguistic opportunity means that there has become a perceived contradiction between public anti-suicide initiatives and the legislation of assisted dying. It is of course apparent in the use of the term 'assisted suicide' that links can be drawn between the two actions which are, after all, the intentional ending of one's own life. However, the want of distinction forgoes the moral boundaries that could otherwise be drawn. The conflation of motivations does not, however, begin to express the range of human experience that is going to dictate the intention behind the termination of life.

In October 2017, the American Association of Suicidology (AAS) released a statement distinguishing between the acts of suicide and assisted dying and stated they recognise that:

... the practice of physician aid in dying, also called physician assisted suicide, Death with Dignity, and medical aid in dying, is distinct from the behavior that has been traditionally and ordinarily described as 'suicide', the tragic event our organization works so hard to prevent. Although there may be overlap between the two categories, legal physician assisted deaths should not be considered to be cases of suicide.

The act of suicide, or self-killing, has had a complex history within western society. I would like to provide a brief overview of historic attitudes towards suicide to fully situate the act of assisted dying. Suicide in western cultures has for a long while now been a taboo act, not only as one which stigmatises the suicide victim, but also the survivors. Suicide, in the view of Cicero, Seneca and other early Stoic philosophers, was deemed under certain circumstances to be a permissible act. It was with the later beliefs of Thomas Aquinas that these perspectives became null as beliefs in the primacy of God giving life made their way into the popular psyche of western societies (Tierney, 2010). Punishment in early societies

saw the confiscation of property and wealth from the family following both successful and unsuccessful attempts at suicide.

Those who were successful in their attempts were also denied a proper Christian burial. These early punishments are not surprising given the social contexts within which they took place, especially given that they were labelled as ‘self-murderers’. From this came the construction of suicide as a deviant act and it became criminalised and the victim punished.³⁰ A label was placed onto those who defied God’s wishes and took their own life, thereby severing both their relationship with him and, more importantly, with society as a whole. In 21st century society there is a distinction drawn between the traumatic death of a suicide or accident and that of an old person who is deemed to have made it to the end-of-life. It is from the conception of the suicide victim as bad, or as a criminal, that the stigma surrounding suicidal deaths has risen, a common understanding that is still often placed onto those who attempt and commit suicide.

It is the perceived irrationality of taking one’s own life that saw the link between mental health and suicide commonly considered. Following its labelling as a criminal act, suicide victims were determined to be guilty of *felo de se* or a felony against oneself. They could, however, also be judged as being *non compos mentis* or not of sound mind. It is this judgement that became particularly popular towards the end of the 18th century as European governments began to view suicide as a symptom of mental illness as opposed to an horrific crime against society. Moving into the 20th century, it was this verdict of the suicide victim as mentally unhinged that has become a popular way of conceiving of suicide. It is only the expansion of discussion surrounding aid-in-dying that has attempted to remove this label from the suicide victim and create a space where rational suicide becomes a possibility devoid of stigma.

The stigma surrounding what is conceived of as a bad or traumatic death is often levelled not at the dead, but at the survivors such as the close friends and family of the deceased. Stigma has been identified by authors such as Kjell Rudestam (1992), who have noted the reluctance of some family members to talk about suicides in the family, let alone even acknowledge that they have occurred. Alison Wertheimer (2013) has found that non-disclosure can have a detrimental impact on the way that the bereaved are able to share and talk about their

³⁰ Recognising that it is difficult to punish a non-living person this was historically done by confiscating property from the family of the deceased.

feelings. In their article on the taboo regarding certain deaths and the perceptions of those bereaved by suicide, Alison Chapple, Sue Ziebland and Keith Hawton (2015) suggest that the manner of death in a suicide contradicts what people view as rational behaviour. Those who were close to someone who has suicided can often become isolated from those around them who are unable to comprehend the emotions that were raised in them following a suicide. These deaths, Chapple et al. (2015) believe, are therefore viewed by some as being disruptive to their own personal ambition and achievement as they are confronted by their own mortality and have their ontological security challenged.

A good death, in common understanding, occurs in old age and is not sudden nor violent. More importantly, it presumes and expects a degree of openness and communication that is otherwise forced to be absent in a suicidal death. While there has been a vast amount of literature dedicated to the sociology of death, dying and suicide, the potential legislation and legitimisation of death by the state changes the landscape for the future of moribund research. The shift in traditional approaches to suicide have tended to emphasise the importance of life-sustaining practice within medicine to a praxis that encourages the premature severing of life, thereby dramatically changing the foundations upon which the social understanding and experience of death is based. It is in this sense that assisted death and suicide can be seen as a third ideological transformation following Ira Byock's (2003, p. S40) claim that, "The act of suicide by an ill person (successful or not) represents not only a rejection of care but an attempt to unilaterally sever the social contract". Byock continues on to say that this social covenant is based on trust and a connection with the community that cannot be severed. Under this approach, the patient is cared for by people who are tied together with them in social life and experience and therefore acknowledge that decisions affect the wider community.

Identified by Margaret Battin (2008) in her work looking at cultural change surrounding physician-assisted suicide, she considers that with greater self-determination given to the patient, as regards the timing and location of their death, there comes a change in which "dying is no longer *something that happens to you* but *something you do*" (2008, p. 52). This form of cultural change is perhaps more directly impressionable on society as it relates directly to the ways that we conceive of death and the nature of the act itself. Battin goes on to argue that changes in social practice relating to the new ways individuals will come to anticipate death will have a wider effect on the way end-of-life choices are made. She

believes that these changes will come to be seen as positive reasons for why some people may want to prematurely end their lives when facing terminal illness. Battin (2008) highlights examples such as the possibility for pre-death funerals, which she believes will be viewed as expressions of both the celebration at the completion of life as well as grief at the loss of said life.

Suicide too, a traditionally solo act, which as we have seen has historically provided an aspect of surprise owing to its secretive nature, also faces a potential transformation in the wake of assisted dying legislation. Under these circumstances a suicide victim is openly able to express their will surrounding end-of-life care with the additional input and support of those close to them. For years, the concept of rational suicide has been debated as it is questioned whether anyone willing to end their own lives is able to deliberate and act rationally. It is claimed that in the face of terminal illness those contemplating suicide will do so because they suffer from depression or other mental illness. In an article on rational suicide among the terminally ill, Valente and Trainor (1998) argue that health care professionals often lack education and training when it comes to evaluating a patient's suicide risk or whether or not they are able to form a rational decision about ending their own life.

A further contention that is often held around suicide – and one of the benefits provided by assisted dying – is the violent means by which patients often take their lives. Without access to medical aid in dying, patients are left to their own devices when it comes to selecting the way in which they die. This therefore often falls to violent or otherwise unpleasant ways as they rely on what is most readily available. These deaths are often more likely to be premature than had assisted dying been available. Assumptions are made on the belief that a person with a terminal illness will suicide while they are still physically able to do so of their own accord and in privacy. This is in contrast to situations in which aid-in-dying is legal where it is believed that patients will delay ending their lives until the suffering is truly unbearable.

Slippery Slope Arguments

As the findings from the select committee report from Quebec titled *Dying With Dignity* (Bergeron, Boucher, Jolicoeur, Simard, 2012) reveal, while there have been many studies undertaken to look at potential abuses in Belgium and Netherlands since they legalised

assisted dying, many of the statistics have been interpreted differently and in opposition to each other depending on the researchers' views on assisted dying. Margaret Batten (1992, p. 142) also concludes that considerations of studies must be taken into account when considering the risks of abuse. She believes that, "the Dutch experience can provide tentative expectations about what our own experience might be were assisted dying accepted ... though of course this is a highly conjectural strategy, examining the practices in the Netherlands can at least initially provide very rough, informal guidelines for scrutinising our own practice". I have drawn primarily on John Keown's popular and comprehensive treatment of the slippery slope argument from his book *Assisted Dying, Ethics and Public Policy* (2002) for the following account, but I would like to acknowledge the overwhelming amount of literature that surrounds slippery slope arguments (see for example, Huxtable, 2007; Lewis, 2007; Smith, 2005; Van der Burg, 1991). While Keown states clearly his [negative] feelings towards assisted dying, he nonetheless manages to provide one of the more critical analyses of the slippery slope argument.

Keown's chapter starts with a reminder regarding the slippery slope argument that many people who are opposed to legislating assisted dying are not necessarily opposed to the practice itself. That is, they believe it is in fact morally justifiable provided that the patient's request to end their life is free and informed and that they are suffering from unbearable and terminal pain and suffering which only ending their life can relieve. The issue for many lies not in the practice but in the potential relaxing of regulations once it becomes legal. That is to say, if *voluntary* assisted dying became legal, it would result in the slide towards *non-voluntary* assisted dying and, potentially even further, towards *involuntary* assisted dying.³¹ The second fear in this slippery slope argument is that voluntary assisted dying that is legislated as a last resort type of practice will soon become a premature alternative to other forms of palliative and end-of-life care, whereby patients and their families will not consider other alternatives if they see voluntary death as a simple solution to suffering.

This is a contentious argument for assisted dying critics to make, and if anything highlights what is lacking from the current assisted dying literature. Assumptions fail to recognise that individuals are social beings and part of this sociality requires reciprocal relationships with those around them. Many people are tormented by the loss of their family members and it is naïve to assume that people will not exhaust other alternatives before ending a loved one's

³¹ For a discussion surrounding these semantic differences see *Introduction*.

life. It is in this slippery slope argument, however, that many of the difficulties of legalising assisted dying are raised as it is not the practice itself that is the problem but the potential for morally objectionable practices to occur in the future.

Many of the fears around assisted dying, and increases in morally objectionable practices occurring, stem from deep-seated historical issues relating to the practice of eugenics. Fears of sliding towards what would be seen as ‘acceptable eugenics practice’ also abound when it comes to the assisted dying literature. The arguments for slippery slopes do not pertain just to doctors or families and the potential actions that they may subsequently take, but also to the future of policy and the relaxing of social values and the protection of vulnerable citizens. Many of the arguments surrounding the slippery slope, especially when using The Netherlands and Belgium as case studies, concern the slide towards the implementation and acceptance of non-voluntary assisted dying. Keown furthers his argument against assisted dying with the belief that “acceptance of [voluntary active euthanasia] leads to acceptance of [nonvoluntary active euthanasia] because the former rests on the judgement that some patients would be better off dead, which judgment can logically be made even if the patient is incapable of making a request” (2002, p. 79). These instances are widely debated in the assisted dying and disability literature with many decisions standing on quality of life judgements that are made by those who are abled-bodied, as will be discussed shortly.

Death with dignity is sometimes also understood as ‘mercy killing’, or the killing of somebody out of compassion, and is heavily tied into beliefs on human suffering and to what extent a person should have to suffer. Mercy killing is thus viewed by some as a beneficent act. The flipside to the death with dignity argument though, is made by people who have a belief in the sanctity of life. This rests on an often even stronger belief that the taking of somebody’s life, for any reason, is wrong. Historically, this debate was centred on a person’s religious beliefs and the idea (already mentioned) that God was the one to grant life and should also be the only one to take it away. Having shifted into a more secular society, while this belief is still prevalent, it is no longer the primary argument that the sanctity of life debate focuses on. Jonathan Glover’s 1990 book chapter ‘The sanctity of life’ provides a good analysis of the different arguments pertaining to the sanctity of life argument and it is to these discussions to which I would now like to turn.

Other authors such as Arthur Dyck (2002), who have moved away from religious arguments relating to the sanctity of life, believe that it is not life itself that is of importance but the

rights that a person has in preserving that life. These pro-life advocates believe that the right-to-life is one that trumps all other rights and stands in somewhat stark contrast to the right to complete autonomy. As Richard Doerflinger states, “Life, a human being’s very earthly existence, is the most fundamental right because it is the necessary condition for all other worldly goods, including freedom” (1995, p. 241). Because a person loses all rights when their life ends it is believed that a person’s life must be upheld against all other reason to ensure and secure all other rights. By upholding a person’s basic right-to-life then we are building the foundations upon which all other rights, and all aspects of life, can be built. Dyck (2002) writes at length about the inalienable human right-to-life and believes that that even in cases of terminal illness this most basic right must be upheld. In stark contrast to pro-assisted dying advocates’ claims of a right-to-die, [missing word?] is the most basic claim of a person’s right-to-life.

Why though must we not take another person’s life? This is an idea that is repeated by many pro-life and pro-choice supporters alike. The maintaining of always upholding life can be evidenced in restrictions on state power more generally. Norman Cantor provides as the first reason for a belief in the sanctity of life the statement that, “The state has an indisputable interest in the preservation of life” (1978, p. 205), carrying on in relation to criminal law and Police power to say the, “... use of governmental authority is grounded on the assumption that citizens invariably want to enjoy bodily safety and uninterrupted life” (1978, p. 205). Any negation of this, such as assisted dying, would result in the potential breakdown of the entire system, owing to wavering on a prohibition that requires absolution by principle. Along the same lines as making an example of a person, Cantor believes that any exception to sanctity of life laws degrade the ones already in place. That is, even with strict regulations in place a state that sanctions any premature hastening of death negates the *universal* sanctity of life. The very universality of such a decree meaning that it applies to all, equally and always.

Many of the fears surrounding the slippery slope address not just the issue of the sanctity of life, or the making of quality of life judgements about another person’s life, but also problems surrounding the use of substitute decision-making in end-of-life care. The potential for abuses to occur in end-of-life care where the families of patients are making the decision to end life is no doubt prevalent in society and are greater than in the cases where doctors are making the decision. This is because it is easy to see that the families of patients generally have a lot

more to gain from the death of a patient, especially where duplicitous behaviour from the family may result in financial gain through inheritance. Further, the burdens physically, mentally and emotionally that many families may feel by caring for their loved ones in the end stages of their life may provide incentives for the lives of patients to be cut short, especially in situations where the family sees no alternative to care arrangements and no foreseeable end to the current circumstance. These types of situations have been widely discussed by John Hardwig (1997) in his work on what he deems the “duty to die”.

There is, however, an evident lack of literature relating to changing assisted dying policy that sees the acceptance of assisted death for those who have previously been excluded from this policy. This is perhaps because we have not historically seen a widening of policy in the jurisdictions where assisted death is legal. However, changes to the Belgian legislation have seen the inclusion of children in March 2014 and more recently, in September 2014, the consideration of the euthanasing of a prisoner suffering from psychological anxiety due to uncontrollable sexual deviance. These measures have highlighted a number of slippery slope concerns raising the question of where changes and inclusionary policies will stop. Much of the current discussion surrounding shifting social values draws on the argument that by allowing assisted dying we will fall into Nazi-style policies that place at risk certain groups within society (Burgess, 1993; Keown, 2002; Smith, 2005). While this is a valid argument made by many, the rise of a rights-based discourse surrounding assisted dying that is based on the premise of autonomy and individual choice is more concerning as regards slippery slope arguments. We thus need to look more at how these individually-framed rhetorics may provide slippery slope type situations as regards the broadening of a person’s claim to rights. Rights-based discourse has seen a large rise in recent decades due to an overwhelming belief by some in the “right-to-die”.

The right-to-die is argued by some as a civil right within modern society. While the right-to-life and the protection from ending a life is the most fundamental right within modern societies, a right that forms the basis for all other rights the state provides, the right-to-die appears, at first, as the antithesis of this. The right-to-die is not diametrically opposed to the fundamental right-to-life, but instead it takes the ideas of autonomy and self-determination to its full extent, and argues that if a physically competent agent has the right to take their own life, in practice, then it should be up to the state to provide that same right to those who are physically unable to do so themselves. As David Benatar (2010) discusses, the right-to-die and the right-to-life are in fact two aspects of the same right. In saying this, Benatar

understands the right-to-life to be a decision or whether one will or will not continue living. The right-to-die, he believes, is a decision about whether one will die when they could continue living.

Dying with Dignity and the Sanctity of Life

Another primary argument in the assisted dying debate is that which is made by those who believe that every individual has the right-to-die with dignity. This debate centres on the belief that every human has the right to choose the point at which their lives end (within obvious reason), especially when suffering from terminal illness which, as discussed above, often strips a person of dignity in their final weeks and months. Many previously self-sufficient and independent people find that in the late stages of their disease, due to lack of motor ability, they are left completely dependent on others to ensure that they retain some of the basic necessities of life like eating, bathing and defecating. The title of the Bill making physician-assisted suicide legal in Oregon, the *Oregon Death with Dignity Act* (1998), points to the importance that many people place on being able to die with dignity. Death with dignity also rests on the idea that for many people they do not want to be remembered with pity. That is, they wish for their family and friends to remember them at the peak of their lives and not as decrepit beings unable to look after themselves. In essence, those who call for death with dignity want to be remembered by the social narrative they developed throughout their healthy lives, as opposed to being remembered as their illness narrative dictates.

Dignity as a buzzword

A main argument both for and against assisted dying surrounds a preoccupation with dignity and whether or not those with terminal illnesses can retain it throughout the latter stages of their lives. While I present to the reader a number of approaches to dignity here, this is by no means the entirety of approaches towards the term ‘dignity’. Here I have selected authors whose works I believe form an overview of the approaches to this topic. However, it can also be noted that while the terms used by authors may be different, they largely paint the same picture in characterising dignity. This content will preface a discussion about how human dignity is approached within the context of both health care and assisted dying. What is important to remember throughout this discussion is that the issue in using this term is not that we *lack* a definition for it, but that we have *too many* workable ones, which only work to cloud meaningful and altogether accurate uses of the term. For wider ethical and moral

discussion this abundance of definitions poses complex dilemmas for the regulation and legislation of health care practices, and for the recognition of care and concepts of justice, a result of which is a sizeable impact on how the assisted dying debate is conceived. Moreover, and increasingly, there are deeper and more widely reaching contentions over how these issues are reflected in patient care and how we understand (and determine) the end-of-life. In summary, this chapter informs our discussion of assisted dying by highlighting the nuances of dignity and the resulting array of applications, both for and against, the legislation of assisted dying.

The concept of dignity has perhaps never been as contentious as it is in the 21st century as philosophers, medical professionals, legal academics and ethicists try and grapple with its myriad uses across a range of subjects. Despite its contested status as a subject, or maybe because of it, dignity has become a highly studied topic and is now often used in human rights and health care discourses. David Badcott and Carlo Leget (2013) question though whether or not any of these writings significantly advance our understanding of the concept of dignity or have any influence on its practical application. I would have to agree with Badcott and Leget when they say that there is no overwhelming consensus about the concept itself, or what it really means. To the political philosopher dignity has become an “essentially contested concept” from a term that was first coined by Walter Bryce Gallie in 1956. Gallie (1956, p. 169) defined essentially contested concepts as those that, “inevitably involve endless disputes about their proper uses on the part of their users”. To the more general audience, a disbelief in our understanding of dignity may seem strange as people are readily able to identify when they believe they have witnessed a breach of dignity. One might say that there is a generally taken-for-granted-attitude towards an implicit acceptance that individuals understand and know what it means. Thus, it does not provide much guidance for how dignity is used as a tool within bioethics rhetoric and health care practices.

Even as a generally confused and ambiguous concept, the word dignity has become one of the forefront terms in the assisted dying and right-to-die debate. Perhaps as an example of its ambiguity, it can be used by those on both sides of the argument, those who are advocating either for or against the legislation of assisted dying. Human dignity is an illustrious term that is used widely in relation to the general esteem of individuals. Its use largely grew in prominence owing to the Nuremburg Trials following the Nazi genocide in 1945. Following the end of the Nazi regime and a near universal recognition of the atrocities that had occurred, the United Nations worked to establish an international bill of rights that would

ensure the security and wellbeing of the global population. Thus, they conceived the United Nations Universal Declaration of Human Rights (UDHR) and, in December of 1948, members of the General Assembly adopted and proclaimed the 30 article document.

Significant in this discussion is the prominent use of the term ‘dignity’, which appears initially in the first sentence of the preamble, highlighting it as one of the foundational ideas within this international treaty. It then appears again in Article 1 in which it states:

All human beings are born free and equal in dignity and rights.
They are endowed with reason and conscience and should act
towards one another in a spirit of brotherhood.

Twice more human dignity is referred to within the UDHR and in a similar vein in other international instruments which also employ it. However, at no point within these documents is the term ‘dignity’ ever fully elucidated. Instead, it is used in the way mentioned above, assuming that the reader not only knows what dignity is, but they also understand how it differently manifests itself.

The shift towards increasingly secular societies can be argued to have impressed upon us a new significance in how we understand and apply the concept of dignity. This break can be seen as a symptom of modernity concentrated on society’s central existential claim, in which individual autonomy is tied into the capacity of people to be lord of their own fate, and be shapers of their own future (Arieli, 2002). Furthermore, the rise of biotechnologies and the scientific revolutions have begun to reshape our understanding of what it is to be human and to be alive. Along with this there has been a large question mark also placed over what it is for a human to have dignity. What is still unsure is how one gains dignity, or perhaps loses it, or whether one just always has it. In everyday parlance, the term ‘dignity’ is widely understood with reference to the perceived standing and esteem of a person. The *Oxford English Dictionary* (OED), like some of the authors who are about to be discussed, list four varying definitions for dignity. These reflect the positions held by authors and highlight why dignity can be an enigmatic term, especially when it is used within bioethics and its practice. The OED categorises *dignity* as follows:

- 1a. The quality of being worthy or honourable; worthiness, worth, nobleness, excellence.
- 2a. Honourable or high estate, position, or estimation; honour; degree of estimation, rank.
- 3a. An honourable office, rank, or title; a high official or titular position.

4a. Nobility or befitting elevation of aspect, manner, or style; becoming or fit stateliness, gravity.

As can be seen in the above, the terminology used surrounding dignity, while similar, has in its differences some crucial distinctions. In reference to international human rights law the term follows the ambiguity of the above definitions, with no neatly demarcated approach that can apply in all cases of its use. A large part of the issue comes down to debates which surround whether or not a person is *born with* dignity, if they *develop* it through some sort of rank or profile, whether it is something *one has* until it is lost, or whether it is something that others *impart* and *bestow* on us.

Historical approaches and use of the term dignity

The term ‘human dignity’ is primarily, and somewhat controversially, linked to both the Old and New Testaments (Cancik, 2002).³² Like the previously discussed international treaties, neither of these biblical texts use the term ‘dignity’ itself. It is still firmly believed though that the basis of human dignity stems from a belief that all humans are created in the image of God. Writing on the notion of human dignity in medical ethics, Martin Hailer and Dietrich Ritschl (1996) believe that the biblical texts do not conceive of human dignity as being inherent within an individual, instead dignity is imparted by God to a human being. Where once God was the omnipotent and omniscient creator it was thought that every human-held inherent dignity owing to their creation by the Heavenly Father and were therefore to be treated with decency and respect. Modern understandings of human creation and evolution paint a different picture.

Historically, it is thought to have been the Stoics who were the earliest users of human dignity within their writing, in particular Panaetius of Rhodes and Marcus Tullius Cicero who first made mention of human dignity by reference to the ‘dignity of man’ (Cancik, 2002). In his work on Stoic anthropology, Hubert Cancik (2002, p. 19) determines the root of the phrase human dignity to be the original Latin term *dignitas hominis*, which he believes denotes “worthiness, the outer aspect of a person’s social role which evokes respect, and embodies the charisma and the esteem presiding in office, rank or personality”. Much like God would do in the future, this form of dignity is concrete and inherent in the rational persona which is given by Nature. In this sense, it is more like the notions of dignity that we

³² Hubert Cancik states that he could not find a single piece of evidence of the ‘dignity of man’ in the Bible.

see in contemporary society in the declarations and constitutions mentioned earlier. That is, while it may no longer be believed that dignity is imparted by Nature, today we can still understand it as being something that each human being is born with.

With philosophical beliefs heavily bound up in the teachings of Christian theology, Kant's (2012) notion of dignity was also tied into this ideology. His approach to dignity, like many of his other theories, are grounded within his second formulation of the categorical imperative, which holds that all persons must, "So act that you use humanity, in your own person as well as in the person of any other, always at the same time as an end, never merely as a means" (Kant, 2012, p. 41/4:429). With this imperative Kant believed that dignity is something inviolable within all human beings, by way of being grounded in a person's autonomy of will and stemming from the rational nature in human beings. This idea grows from the proper valuing of humanity and the humanity of each individual. This entails the acceptance of persons as more than commodities with market value which can be traded, and instead views them as agents who have an intrinsic worth and value irreducible to price. From this, we gain the above premise that people should never be treated as a means to an end, while also recognising that the value of dignity is unconditional and without equivalent.

Ideas set forth by this categorical imperative establish the basis for many of Kant's deeply held truths and also help establish the foundations for his views on suicide or 'self-murder'. His perspective towards such phenomena was that it violated the imperative of humanity and led to a person treating themselves as an ends and not a means, for "[i]f to escape from a troublesome condition [he] destroys himself, [he] makes use of a person, merely as *a means*, to preserving a bearable condition up to the end-of-life Thus the human being in my own person is not at my disposal, to maim, to corrupt, or to kill him" (Kant, 2012, p. 41/4:429). Viewed as violations of dignity, such acts, including suicide and murder, are seen as expressions of disrespect. This can be levelled against our own self or as an assault on others. When a person is believed to be in violation of dignity or the second formulation of the categorical imperative itself, Kant believed that they were not altogether overlooking a person's dignity, but instead considering their own, or that worth of another object, superior to another's.

While Kant's approach to dignity has held its own within debates surrounding the term, it becomes clear at this point that historical approaches towards understanding dignity were largely based in the belief of universal human dignity that was entirely perpetual. What is

also clear is the problematic nature of this approach to dignity when it comes to bioethics as it undermines the claims of those who feel their dignity has been stripped. Numerous examples abound of how this could occur, but the most obvious in this discussion are those who believe that the symptoms and circumstance of disease can divest a person of their dignity. That is, if dignity is inherent in all humans, it follows that even in times of humiliation, shame and suffering all of humanity retains a minimum level of consistent dignity. This, however, is not often expressed as being the case by those who have perhaps lost control of their bodily functions and rely on constant care or live in constant pain. As is about to be shown, these ideas have not stood the test of time and many of the controversies and criticisms surrounding the term now are rooted in this divergence from what could be seen as its original meaning.

Contemporary usage

Severe criticism has been levelled at the term ‘dignity’ in the most recent past, as its critics highlight the growing dissonance between its various uses. Part of this criticism can also be directed at the fact that within contemporary parlance and rhetoric the word is thrown around somewhat loosely. Mirko Bagaric and James Allan’s 2006 article ‘*The vacuous concept of dignity*’ is perhaps one of the most well-known critiques of the concept of dignity. It begins with an analysis of the foundations of rights and its purported overuse within rights-based discourse. They conceive of disputes between how to rank competing rights, based on the judgements of which human interests warrant the protection of rights based on a level of importance. Bagaric and Allan (2006, p. 259) highlight the contention over which rights should be pre-eminent, “... be it the one to autonomy, to equal concern and respect, to choose progressively how one should live, to dignity, to property, to justice, to participate in political decision-making, or to some other option”. Here they draw on the multiplicity of other rights-based terms that besiege the word dignity to back up the existence of other rights on a philosophical and legal level.

Bagaric and Allan (2006, p. 260) claim that the right-to-die, among many other rights for example that of the right to privacy, or the right not to give evidence implicating oneself, have all grounded themselves within the concept of dignity. Bagaric and Allan (2006) deduce from this that dignity is therefore a *vacuous concept*, and believe that it is without bounds and so incapable of explaining or justifying any narrower interests. There are numerous other claims of opposition to the use of the term ‘dignity’ that highlight the growing dissonance surrounding its impact as an ethical principle and doctrine. Bagaric and Allan (2006) are

particularly concerned about the proliferation of the rights-based discourse that surrounds the term ‘dignity’, holding it in higher regard than other principles. While they are concerned about the conflict between and general abundance of these new rights they do not believe that it follows from this that all such claims should be abandoned. Instead, they believe in an idea in which rights talk can be effective in advancing human interests.

Bagaric and Allen also go so far as to claim that the concept of dignity is a notion used by academics, judges and legislators when rational justifications have been exhausted. This argument is used by other authors in a slightly different way, whereby they argue that the word dignity is used in a way that it overrides all other arguments through its very use (2006, p. 260). Arguably, this is due to the nature of rights and dignity-based arguments which, in the uncertainty of their application, assume a general pre-eminence over other claims that are made. As the authors argue, claims that use the language of rights carry a far more emotive punch than others, especially those related to duties. While this may be so, Bagaric and Allen believe that the notion of dignity needs to be retired as a foundation for rights claims until the point where its source, nature, relevance and meaning are determined. Judging by the bountiful array of definitions for and arguments about dignity it is not hard to see why they would argue for this. It is not only these two authors who claim that dignity is a vacuous concept; it has also been critiqued on a number of different fronts.

Dignity as empowerment

Deryck Beyleveld and Roger Brownsword (1993, p. 29) propose two ways of looking at dignity; the first approach is as empowerment, and the second is as constraint. Their approach towards these two different understandings of dignity can be looked upon in much the same way as Isaiah Berlin (1958) approached positive and negative concepts of liberty. As is the case with negative approaches to liberty, in which a person’s individual choice can be restricted either paternalistically for the sake of the individual or defensively for the sake of the collective, dignity as constraint seeks to place limits on biomedicine. This constraint is made, Beyleveld and Brownsword argue, to reflect a 21st century belief that the concept of human dignity must reach beyond the individual and therefore has a focus towards human *duties* as opposed to human *rights*. Dignity as constraint is held by Beyleveld and Brownsword as constraining actions and can be viewed as compromising human dignity, whether it be the active person’s own dignity or the dignity of another individual or wider community.

On the other hand, dignity when viewed as empowerment seeks to prioritise the autonomous action of an individual and is backed up by the belief that every individual has an inherent human dignity. As is seen in Berlin's (1958) discussion of positive liberty, an individual's choice can flourish with greater freedom and an absence of internal limits, which enables dignity the ability to grow. Writing on dignity as empowerment in a discussion of intentional human rights instruments, such as those mentioned earlier, Beyleveld and Brownsword consider this approach to dignity as being the foundation stone on which human rights are built. Under this conception they believe that dignity is inherent in each and every human being. This inherent dignity is the ground for the possession of human rights, and it is because all humans have dignity that they all in turn have equal rights. To them, this understanding of dignity as empowerment is viewed as integral to how we prioritise autonomy, for example, within biomedical decision-making, the arguments for which can therefore be formed in much the same way. (For a discussion on this see *Chapter seven*.) Human dignity, understood thus, becomes the rock on which all human rights are built (Beyleveld & Brownsword, 1993, p. 13). Beyleveld and Brownsword also highlight that within primary practical and political discourse, the use of the term is based on human rights as opposed to human dignity. Therefore, where one might view human dignity as the deeper foundation or justification for human rights, in practicality when human choices or interests come into contest, it is in fact human rights and not dignity upon which claims are made.

The presumption of inherent dignity though is not the issue that Beyleveld and Brownsword have with this approach to the term. Instead, they raise a problem that they believe is at the very heart of human dignity, lying in its grounding of human rights, and questioning how the justifying link between human dignity and human rights can be presented. Beyleveld and Brownsword refer to this as contingency, which owes itself to the linking premise held in this grounding. We can understand that in order for it to be recognised that all humans have intrinsic worth there is a requirement for human rights, which owes itself to the fact that although individuals may recognise their own value they are not so inclined to recognise that same value in others. The issue as Beyleveld and Brownsword see it, is that human rights under this conception becomes redundant within an idealised understanding of the notion. Universal acceptance of a belief that all humans deserve a right to protection rests entirely on contingent acceptance, as it also depends entirely on all other humans having the "right attitude", or as they identify it "a human rights attitude". It is an approach that also screams

out the problematic issue of scepticism and our moral status as bearers of human rights that it never solves or clarifies.

Beyleveld and Brownsword instead believe that there is a different way to look at dignity that empowers individuals through the simple idea that they are at least capable of valuing their own existence, or more problematically as possessing a distinctive capacity that essentially makes them worthy. Within bioethics especially, it is the assumption that this essential feature is autonomy, which itself throws many more proverbial spanners into the works. Not only does having the capacity for autonomy not rid itself of the contingency that was identified previously, but it also discriminates in favour of only those individuals who have the capacity for autonomy. It is in this secondary contingency that Ruth Macklin (2003) bases her belief that the term ‘dignity’ is too often equated with the idea of autonomy.

Macklin (2003, p. 1420) believes this inextricable bind means that dignity has become an altogether useless concept that can be eliminated from medical ethics without any loss of content. Macklin contends that previous attempts to define dignity have resulted in notions which have become recapitulations of each other and have consequently added nothing to our understanding of the term. Referring to the Council of Europe’s *Convention for the Protection of Human Rights and Dignity of the Human Being With Regard to the Application of Biology and Medicine*, Macklin (2003, p. 1420) shows how within this document, dignity appears to have little to no meaning, beyond what is meant by “respect for persons” as understood within medical ethics, and relating to requirements of voluntarily provided informed consent, privacy and the avoidance of harm. Commenting on the United States President’s Council on Bioethics report from 2002 titled *Human Cloning and Human Dignity*, Macklin (2003, p. 1420) highlights how, although it refers numerously to dignity, at no point does it contain an analysis of the term or how it relates to other ethical principles, thereby leaving it uncertain as to when violations to a person’s dignity have occurred.

A further document that Macklin (2003, p. 1420) makes reference to is that of the Nuffield Council on Bioethics report *Genetics and Human Behaviour*, which she concedes at least attempts to specify a meaning of dignity. However, as this report considers (2002, p. 121), in a chapter on genetics, freedom and human dignity:

... an essential ingredient in the conception of human dignity, [is] in the presumption that one is a person whose

actions, thoughts and concerns are worthy of intrinsic respect, because they have been chosen, organised and guided in a way which makes sense from a distinctively individual point of view.

In this approach, they are drawing on a definition that has an uncanny likeness to many popular definitions of autonomy with its similar references to the capacity for rational thought and action. It is therefore not hard to see why Macklin might own the belief that the repeated and often abundantly unclear ways that dignity is used merely convey another interpretation of the principle of autonomy. Requiring the same contingency as a belief in autonomy, as Beyleveld and Brownsword (1993, p. 25) so succinctly put it, it is right to think of human dignity as empowerment only so long as we think it right to do so. This contingency highlights a further dispute that arises from attempts to define dignity, and leads Beyleveld and Brownsword to also identify the ways in which human dignity in the same way can also be seen as a constraint on human action.

Dignity as constraint

Where dignity as empowerment has looked backwards at historical human rights documents, it is in looking at dignity as constraint that we can perhaps see how more contemporary variations of the word have developed in line with international human rights instruments without having clarified its historical application. Beyond this lack of clarification, Beyleveld and Brownsword (1993, p. 29) believe that there has been a turn in the way that dignity is characterised in more recent international instruments of peace. Drawing on the example of the Council of Europe's *Convention on Human Rights and Biomedicine* (1997), Beyleveld and Brownsword (1993, p. 30) hold that when viewed as a constraint, the application of dignity should not be driven on the whim of human choice, but instead with an understanding of respecting human dignity as a collective virtue. That is, by approaching dignity as one of the foundational values in society, it follows that those individual choices that breach a social objective understanding of dignified conduct, or do not at least maintain dignity, are entirely prohibited. In this, a social objective understanding of dignity can be approached much like that of relational autonomy, as it views an individual not as a singular entity but within a network of social connections. In order for these connections to remain, the onus of responsibility falls to everyone to maintain the dignity of themselves and others.

An understanding of human dignity that follows from this idea highlights the nature of the constraint that can be enforced, and more than anything clashes with the personal autonomy of individuals in society. Here, dignity represents an objective value that outweighs the autonomy of individuals for the sake of the collective good. We must appreciate here what is understood by autonomy and just who the individuals who hold it are. This issue is raised in the aforementioned Convention in Article 1 which states that parties, “shall protect the dignity and identity of all human beings and guarantee, everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine”. Here we can note the inclusion, alongside dignity, of two similarly problematic terms, that is, “all human beings”, which is identified as being distinct from “everyone”. I do not want to get bogged down in the semantics of these differences which Beyleveld and Brownsword, along with centuries of philosophers, have provided a discussion of, but instead turn to make note of the problems that it raises for our notions of the beginning and the end-of-life (see *Chapter five* for further discussion on the determination of death).

This argument dies at the cross-point at which the “everyone” referenced in the Convention become the “human beings” that require the respect of dignity, and at which point that a human being’s individual choice is permitted to infringe on everyone’s dignity. According to Beyleveld and Brownsword, the use of the term “everyone” in the Convention refers to the potentially contested idea of an individual as a bearer of human rights. “All human beings” is then contrasted with the view that there is a generally accepted principle that a human being is to be respected as soon as their life begins. Restrictions placed on women’s bodies are a prime example of the abstract line that designates a person with or without an option of choice for the sake of another’s dignity. Laws surrounding abortion, the majority of which constrain women and impede their autonomy over their own bodies, are a primary example of the way in which dignity can be seen as constraining. Here, the foetus itself is an “everyone” whose dignity overrides that of the individual “human being”.

With regards to the termination of a pregnancy, there is a literal decision made between one life and a potential other. It is on this point that Beyleveld and Brownsword (1993) demonstrate the greater power of dignity than human rights. Here they argue that human dignity provides a *direct* justification for protection through human life having dignity, rather than an *indirect* justification that relies on the framework of restrictive human rights theory.

This idea rests on the understanding that the moral status and dignity of the foetus has stronger justification for protection than does the moral status and rights a woman has over her body. As Beyleveld and Brownsword surmise, the emergence of human dignity as a constraint does not place a whole new limitation on autonomy, but instead places a limitation in the form of a direct justification where a previously indirect one stood.

Tension surrounding dignity as constraint is also prevalent regarding whether or not one has the legal ability to consent to undignified treatment, which hides an altogether more tenuous problem with autonomy. There are many notable cases that have been taken to the courts internationally, but *R v Brown, Laskey, Jaggard* ([1993] 2 All ER 75) (hereforth *R v Brown*) is one that displays an example of issues in approaching dignity as constraint as well as having judgements that are of consequence for the death with dignity movement. *R v Brown* grew from a case that was initially heard by the British Courts in 1990 before seeing three men put in prison. It transpired after a routine Police investigation in which they happened to stumble upon video films of sado-masochistic acts taking place over a 10-year period from 1978. Three British nationals, Mr. Colin Laskey, Mr. Roland Jaggard and Mr. Anthony Brown, were all charged with a series of offences that included assault and wounding relating to sado-masochistic activities with over 44 other homosexual men. This was regardless that all of the acts engaged in were done by rationally consenting adults.

Beyleveld and Brownsword provide an insight into this ruling through their sense that human dignity here is illustrated as a specific version of the ‘good life’ that is preferred by certain members of society and therefore used to constrain individual autonomy. For the judges who made these successive judgements, they may have seen themselves as empowering the community with human dignity. For the men at the centre of these court hearings, however, the constraint on their dignity saw a resultant restriction on how they could choose to conduct their private lives. This balancing act is a prime example of how dignity creates tension owing to its varying applications. As I began, dignity is a confused term that, while able to be catalogued and employable within a wide range of contexts, can be seen to make assumptions about the intentions of others because of the limitless way it can be applied. Some may argue that this does not make the term ‘dignity’ any less worthy or that there is no longer any reason for its use.

Affirming the use of dignity

Doris Schroeder (2008; 2010) and Suzy Killmister (2010) both advocate in favour of the view that the myriad of approaches to dignity does not have to make the term redundant, with Schroeder arguing that dignity can be a useful term if one accepts that there is no singular meaning. Following this idea, she believes that dignity can be broken up into four discernible definitions which can themselves be further placed into two separate categories.³³ This follows from her belief that in order for principles to be useful within ethical debates they must stick to the conditions of being widely known, specified and attributable (Schroeder, 2010, p. 118). In other words, by expanding the use of dignity through four different approaches, Schroeder believes that ethical debates can be illuminated and some of the vagueness surrounding the concept can be eradicated.

Schroeder's first concept of dignity follows the ideas of Kant as has been previously discussed and is what she refers to as *Kantian dignity*. She believes that the modern Kantian-inspired definition of dignity is as follows: "Dignity is an inviolable property of all human beings, which gives the possessor the right never to be treated simply as a means, but always at the same time as an end" (2010, p. 120). Furthermore, a discernible link can also be made between this dignity that is inherent in everybody and Cicero's first definition of dignity, which we can recall as pointing to the "concrete, visible quality of a person". In Schroeder's second use of the term 'dignity' she refers to it as *aristocratic dignity*, which can again draw inferences to Cicero, but this time to his second approach relating to that of respect and prestige. She defines this type of dignity as, "the outwardly displayed quality of a human being who acts in accordance with her superior rank and position" (2010, p. 120). Those holding this type of dignity are generally believed to hold secular and religious positions of higher rank and behave in a way befitting them of such a position and status. As Schroeder notes, this type of dignity has historically been bestowed on a small minority of people who have held occupations like kings, popes and nobles.

Somewhat in line with aristocratic dignity is *comportment dignity* which can be understood as the active and explicit display of action that is appropriate to a person's rank. Luscious silks and extravagant furs along with an upright posture provide a sense of dignity that in some communities has come to be expected of a person deemed of higher class. Schroeder believes

³³ In later articles, Schroeder refers to five different definitions, the additional one being what she terms "traditional Christian dignity" as outlined briefly above.

comportment dignity to be, “the outwardly displayed quality of a human being who acts in accordance with society’s expectations of well-mannered demeanour and bearing” (2010, p. 120). Comportment dignity is not only seen as an expression of aesthetic value, but also by the employment of outward signs of dignified behaviour. Thus, in most societies there are norms and expectations surrounding how a person acts in public; eating with one’s mouth open or belching loudly after a meal are both actions that could be seen to violate a person’s comportment dignity in certain societies. It is also this type of dignity that we see more routinely referenced in death with dignity debates, as patients believe that certain involuntary actions cause them a loss of dignity.

Schroeder’s final approach towards the definition of dignity can again be brought forward in arguments relating to maintaining death with dignity and follows closely behind the ideas put forward for comportment dignity. Schroeder defines *meritorious dignity* as, “a virtue, which subsumes the four cardinal virtues and one’s sense of self-worth” (2010, p. 120). This approach to dignity can be useful in the context of medical ethics in the way that a person can appear to have dignity without necessarily deserving it. That is, while a chronically ill person may not outwardly show signs of dignity because of circumstance bringing anguish, distress or hurt, so long as they possess the four cardinal virtues of temperance, courage, justice and wisdom they will maintain dignity as an utmost expression.

These cardinal virtues follow the Aristotelian approach to virtues as set out in *Nicomachean Ethics*, according to which he views a virtue as a disposition to behave in a certain way. It follows that those who behave virtuously, and live life as they ought to, will therefore enjoy happiness. These virtues, Aristotle held, could be categorised under the cardinal values listed above. The independence of the virtues of temperance, courage and justice each highlight that they can each be displayed independently of each other. Wisdom, however, was seen by Aristotle as being the utmost virtue as it is a requisite needed to inform the remaining three virtues. In regard to the cardinal virtues, in order for a person to be dignified they must display all four of the cardinal virtues. Meritorious dignity is therefore earned through outward action much like comportment dignity, but meritorious dignity in this case does not rely on what could be understood as an ascribed ranking.

It is this idea of having an ascribed ranking that Schroeder uses to further categorise these four different approaches to dignity. Instead of referring to them as ascribed or achieved ranks as is often discussed within social sciences, Schroeder (2010, p. 122) uses the terms

aspirational and inviolable dignity. As the name suggests, aspirational dignity entails a level of effort on the part of the person who is trying to gain or maintain their dignity – they must meet a standard and fulfil the aspiration of being dignified. Schroeder believes that aristocratic, comportment and meritorious dignity all fall under this category of aspirational dignity. In this sense dignity can be seen as dynamic and fluid, something that can ebb and flow accordingly. In contrast to this, Schroeder also outlines the idea of inviolable dignity, which she believes is best seen in Kantian and traditional Christian dignity. That is, in these approaches to dignity there is no conscious effort made on the part of a person to sustain this dignity. Instead, and as discussed above, it is something that is endowed on all of those with the *ability* for autonomous action and rational thought, but not the *capability*.

Thus, even those who are going through the dying process and maintain little to no bodily control retain a level of inviolable dignity by virtue of being in a human body. It is these two categories that Schroeder shows are taken up by both sides of the assisted dying debate. Contributions may be beneficial to ethical argument in a number of ways, but whether they provide a valuable contribution to the assisted dying debate and the idea of *death with dignity* more specifically is questionable. As Schroeder herself admits that in order for dignity to be a useful principle within ethical debates it must be “specified”, which she believes can be done if one is prepared to allow for several distinct meanings. While four definitions may provide the ability to more accurately convey what one is trying to say, without universal understanding of the four definitions as separate entities we face the potential for being lost in translation or, even more problematically, being left in the same, largely ambiguous situation that we are now. As Charles Foster (2011, p. 46) somewhat scathingly states, “Schroeder’s defence of dignity consists essentially of saying ‘there are four possible meanings of the word’. One or other of them is bound to be helpful in answering your bioethical conundrum. Choose whichever is most helpful”. As it happens the issue with the bioethical use of the term ‘dignity’ is that it is interchangeably used in these four different ways, and this is where the confusion lies.

Foster’s (2011) is not the only criticism levelled towards Schroeder’s approach(es) to dignity, with Suzy Killmister (2010, p. 161) acknowledging that while her approach may be useful, it stops short of seeing the important relationships *between* the four definitions. Killmister advances that only if one is able to fully appreciate the dynamics of these relationships can we see that dignity is useful, if intricate. Killmister (2010) believes that by reuniting the currently

competing forms of dignity, guidelines can be provided for ethical action towards patients. Of interest to our discussion here, she further notes the difficulty surrounding the use of dignity on both sides of the death with dignity debate. Before delving into this more, I would like to turn to Catherine Dupre (2009) who situates her work as a 21st century approach to dignity and believes that the mainstream legal definition that is used for human dignity still draws back to Kant's original ideas (2012). Dupre's handling of dignity bears a similarity to relational approaches to autonomy and is therefore useful for informing this research.

Dupre believes that the idea of autonomy is particularly crucial as a human attribute to distinguish us from other beings. By not treating other persons as objects Dupre, like others, suggests that our current system of human rights is founded on a belief in the inherent dignity of all rationally autonomous human beings. Dupre believes though that this approach does not allow for an appreciation of the "complex reality of human lives and experiences" (2009, p. 1993), the standard of protection that this abstract philosophical reflection affords human rights, so is not well suited. It is worth quoting Dupre to wholly understand how she feels in relation to the "autonomous subject of rights" (2009, p. 193). Dupre sees human beings as going through their theoretical life "apparently effortlessly", while all the time asserting their political preferences and living a private life (2009, p. 193). We should note that she does not believe this version of an autonomous subject of rights exists in reality. Instead, she states, "Real lives are complex and messy; people are not all born in dignity. Many of them lead a life of abject poverty and indignity" (2009, p. 193). Crucially she follows, "People fall ill and, while some of them recover, others do not. The process of dying, in relation to which the concept of dignity is increasingly being used is not an abstraction and not many of us enjoy some autonomy in dying" (Dupre, 2009, p. 194).

To an extent this is the ultimate crux of the dignity argument. Deep within the debates about the different definitions and applications of dignity there is the underlying tug of war between the inherent dignity of human beings and the reflective view made by certain individuals that they are not living a dignified life, and nor are they being treated with dignity. Dupre (2009) instead proposes a relational, or what she refers to as a holistic, approach to dignity that is opened up in two directions: one relating to the inner emotional world of the individual, and the other to their social and relational identity and being. This allows for an approach towards human dignity that takes into consideration the existence of mental suffering, anguish and stress that some regard as inhumane or degrading treatment. Dupre believes that by

acknowledging these forms of suffering it would not only account for the possible range and diversity of it, but also allow greater means of protection to those vulnerable to abuses of human dignity. She proposes what she refers to as a “time-inclusive concept of dignity” (Dupre, 2009, p. 200), the first step to which she believes is an approach to the term that acknowledges that human life is as much about the instantaneous present as it is about a continual process of becoming (Dupre, 2009, p. 200). This idea follows the belief that an individual’s personality is in a constant state of flux throughout their life, as they continuously evolve and develop mentally and socially.

This is an important observation on Dupre’s part, as she delineates between different phases of life from unborn foetus to elderliness. She notes that dignity is most often relied upon to provide specific protection to human life when it is particularly vulnerable. However, I believe what she crucially overlooks is that oftentimes a person who is in a vulnerable state and perhaps lacks a degree of dignity (whether or not it is in breach of our traditional understandings of human rights) may not always perceive an opportunity for improvement in their situation or condition. That is, what Dupre’s approach seems to overlook is that while a foetus has the potential for further development and a greater attribution of dignity, this is not the case for those whose future presents a continual, largely downward, outlook, which does not allow for any evolution of personality as Dupre would so have it. Individuals, such as the elderly or those suffering from terminal illness, would fall into this category as most would not have any hope for a change in circumstance and therefore a more dignified presence. In doing so, and even though recognising that “the only physical certainty at the end-of-life is death”, she fails to appreciate that some people believe, whether young or elderly, that their terminal condition has led them to a point in life that is so far from what it was, or what it could be, that leading an independent life alongside participating in the social and cultural life of the community is not possible. As discussed above, in relation to Killmister’s work (2010), there can at times be a crucial distinction between capacity and ability.

Concluding Remarks

As has been shown in this discussion, the term ‘dignity’ can be seen to be too deeply embedded in our everyday language, along with its particular nuances to be disregarded entirely as a term. Maybe in the long run dignity will not provide us with a stronger grasp on our approaches and views on larger bioethics debates, but it will play a part in showing us how we are able to show decency and regard for the care and end-of-life for all people. What

is perhaps needed instead is a different toolkit from which to choose and refine the characteristics of care that have come to be expected in the age of the modern hospital. As was discussed in the methodology chapter, it is the beauty of discourse that it both constructs and is constructed by social praxis, discourse and action. Here it is all three of these that need to be employed – not to deter the use of the term ‘dignity’ or to define it as ‘useless’ – instead when discussing terms of an important nature to open up what is meant when it is being used. The word dignity, as we have seen, largely provides a catch-all term that covers the human rights bases. In future it may, however, be a more useful approach to reconfigure the “conceptual toolkit” (Shaw, 2015b) of what it is that people are afraid of losing. This can help to reimagine some of the policies and practices that are in place regarding end-of-life care. Some recommendations for alternative use and a discussion of a toolkit will be considered in *Chapter eight*.

It is the use of discourse surrounding the term ‘suicide’ that also creates confusion regarding its association with assisted dying. While more people are continuing to denounce any relationship, there are others who maintain that on its similarities alone it should not be considered, let alone as something to be sanctioned by the state. Physician-assisted suicide is complicated by the complicity of a doctor in an act that has historically held a number of taboos. If assisted dying is to be legislated these terms must be reconceptualised to provide sufficient attention to the degree of subtlety that each action holds and how the intention behind it is vital for understanding whether it is an act to be hindered or otherwise. Those with mental illness must, of course, be restricted from access to assisted deaths and the reasons for wanting to suicide mitigated against through further public health initiatives. Provisions need not be placed onto those who seek to end their lives for other causes that, while similar in regard to ending one’s life because of the perceived futility of life, and while at times this is a difficult distinction to draw, remain contingent on their unrelenting physical suffering. It is differentiation of experience that maintains the division between suicide as it is commonly understood and the various forms of assisted dying.

Studies have been unable to show any conclusive evidence of abuse within assisted dying policy, nor do rates of deaths in countries with legislation appear to have changed significantly over the years (Battin, Van der Heide, Ganzini, Van der Wal, Onwuteaka-Philipsen, 2007). This is perhaps because there has not so far been a widening of policy or a relaxing of safeguards in the jurisdictions where assisted death is legal. However, changes to

the Belgian legislation by the government of that country, as discussed in *Chapter two*, have highlighted a number of slippery slope concerns, raising the question of where policy changes and inclusionary policies will stop.

Much of the current discussion surrounding the slippery slope draws on the argument that by allowing euthanasia we will fall into Nazi-style policies that place at risk certain groups within society (Bone et al., 2017; Burgess, 1993; Keown, 2002; Smith, 2005) that United Nations declarations have sought to safeguard. While this is a valid argument made by many, The rise of rights-based discourse surrounding euthanasia that is founded on the premise of autonomy and individual choice is more concerning as regards slippery slope arguments. Thus we need to look more at how these individually-framed rhetorics may provide slippery slope type situations as regards the broadening of a person's claim to rights. Rights-based discourse has seen a large rise in recent decades due to an overwhelming belief by some in the 'right-to-die'.

In a 1991 essay, Leon Kass discusses the rise of the phrase right-to-die. He believes that it comes from the developing belief in the supremacy of human choice, stating that, "In the name of choice, people claim the right to choose to cease to be choosing beings" (Kass, 1991, p. 119) The claim of a right-to-die is often grounded in the belief of individual autonomy and the right to self-preservation. It is this sense of self-preservation on which death with dignity, suicide and slippery slope arguments are all premised. That is, they seek the overall survival of the communal body and humanity as a whole. The principle-based bioethics debates that are about to be discussed in the following chapter move away from focusing on the collective towards individual approaches that provide a framework for practising health care. These concepts are primarily held to inform the rights of the patient and, following Kass, highlight the supremacy of rational and autonomous decision-making by individuals.

Chapter five: The Principle-Based Approach to Bioethics

Introduction

A large body of literature currently surrounds the field of bioethics, and with the ever-increasing ability for health care professionals and machines to control matters relating to life and death, there is an even greater need to understand the effects and impacts of this control and associated changes. As noted by Rhonda Shaw in her work in *Ethics, Moral Life and the Body* (2015a, p. 93), since the first named inception of ‘bioethics’ as a definitive field, the term is commonly understood and used in a narrow sense to refer to the “study of ethical dilemmas and issues raised by advances in the biomedical sciences and technologies”. Specifically also this range of dilemmas and ethical problems extends to end-of-life care and decision-making. Here the literature is particularly substantive and is contributed to by authors within the bioethics field such as James Rachels, Daniel Callahan, Ruth Macklin and Sheila McLean. These authors have all provided extensive discussion about the difference between active and passive assisted dying, the ethical issues associated with each practice, and have made generous contributions towards the field.

This chapter sets out the current bioethical debates as they relate to assisted dying. Moving away from the sociological discussion, this chapter positions the principle-based bioethics approach along with the relevant arguments that are features of it. As in much of the principle-based bioethics that have been predominant since Tom Beauchamp and James Childress’ first edition of the *Principles of Biomedical Ethics* in 1979, it has been the principle of autonomy that has trumped the others. Personal autonomy has been at the core of medical decision-making. Its over-emphasis within the biomedical literature, however, often crucially disregards or under-emphasises not only the other fundamental principles of beneficence, non-maleficence and justice, but also the importance of informed consent and competency in autonomous decision-making (Callahan, 1984).

Although Beauchamp and Childress’ approach to autonomy has often been referred to in the bioethics literature, of late there has been a rise in claims arguing for different approaches towards the nature of autonomy within medical decision-making. Bruce Jennings (2007, p. 72) has written extensively on the topic of autonomy claiming that, “No single concept has been more important in the contemporary development of bioethics, and the revival of medical ethics, than the concept of autonomy”. Jennings, in his simply titled *Autonomy*,

points to the numerous approaches to the concept of self-determination that have historically been used in bioethics debates. He is also critical of its over-emphasis in health care and recognises its failure to address the richness of human experience.

Onora O'Neill (2002) contends that by highlighting the disjunction between autonomy and trust within bioethics, the rise in calls for autonomy represents a lack of trust in the doctor-patient relationship. Much of the literature, as noted, has provided a significant contribution to the wider assisted dying debate, but while substantial has failed to address the crux of the issues. It is clear that such arguments have done little to find a balance between those strongly opposed to, and strongly for, assisted dying. The polarising nature of the topic itself certainly raises questions as to whether there is a way to reconcile these two different sides, although it would appear there are new ways to try. The bioethics literature has largely approached assisted dying from the point of view of lawyers, theologians and medical practitioners, without looking at the wider social causes and effects of social changes to current policy and legislation. The question I raise that has been posed by sociologists working in bioethics over the last two decades (for example see Haines, 2002; Shaw, 2015a), and which is pertinent to the current debate in this area, is whether sociologists can add to these debates to enhance our understanding of the topic.

Many arguments and contributions to the assisted dying literature have covered the potentiality of adverse medical practices. However, they have not sociologically examined the biomedical dilemmas that have brought rise to the issues being dealt with. That is, while they have focused on the potentially disastrous effects of abusive assisted dying practices they have failed to regard the society within which legalised assisted dying occurs. While death with dignity and right-to-die arguments have highlighted the subjectivity and impermanence of socially important definitions, they have failed to take into account the social history and importance of such terms. Bioethicists have strongly debated the legal, medical and theological issues of end-of-life care, and especially autonomy, informed consent, beneficence and non-maleficence, but they have similarly overlooked how individuals shape, problematise, use and negotiate such terms. At play on this stage is a patchwork of politics, media, technology and social attitudes towards both life and death. These are the values and opinions that are fuelling the debate around assisted dying and will continue to shape what it becomes after it is brought into law.

It is clear to see in these discussions that assisted dying arguments are often weighed down by people's approaches and personal beliefs in the right-ness or wrong-ness of assisted dying and that these discussions are far from settled. It is also clear from the literature that has been produced over the last 50 years that we are far from coming to any conclusive decision about whether or not medically-assisted death should be legalised. What scholars often fail to acknowledge within this literature is the overwhelming emphasis that is placed on the individual within assisted dying debates. That is, when the literature looks to the pain and suffering experienced by the patient or the quality of the patient's life it fails to acknowledge the community and society within which they are experiencing the illness and the affects that both the illness and subsequent death, hastened or not, has on the wider communal body. Although assisted dying-based literature that looks outward to the community currently focuses on the financial, emotional and physical burden of caring for a terminal patient it stops short of looking beyond to what I would call the *burden of death*. That is, the literature, up to this point, has been distracted from understanding how those in the presence of death justify and comprehend their own moralising.

The following sections of this thesis will address this absence, beginning with a discussion of the ethical principles involved in the assisted dying debate. I aim to show how patients are viewed as being individually centred and rationally autonomous beings within much of the current literature. This chapter works from the presumption that the active and passive distinctions in assisted dying, while critical for overall discussion, are not wholly relevant to this thesis owing to the well-established doctrine within New Zealand medical practice which currently upholds an ethical distinction based on the differentiation between active and passive assistance in death. As will be shown in a later chapter, the rise in the ideas of relational autonomy and a move to provide for the subjective experience of end-of-life can be seen to counteract this idea. Furthermore, I will look toward a sociology in bioethics to highlight how such an approach can aid this current research by emphasising an empirical basis to the study of bioethics through sociological engagement. First, however, a discussion on the wider ethical frameworks through which assisted dying has been defined follows.

A Principle-Based Approach

Following a number of questionable research trials in the United States that came to light in the 1970s a subsequent document, the Belmont Report, was also formed to provide guidelines for the conduct of research on human subjects. The Belmont Report came to be seen as a

highly influential document in the formation of bioethics. However, it was Tom Beauchamp and James Childress in 1979 with their publication of the *Principles of Biomedical Ethics* who solidified the area of bioethics into academic literature. Beauchamp and Childress' (1979) book, and the subsequent seven editions, has become a highly influential and significant account of ethical principles covering both clinical research and medical practice. The book focuses on the four principles of respect for autonomy, beneficence, non-maleficence and justice and has attempted to structure principle-based decision-making within bioethics.

In an article discussing the principlism that is found within much bioethics discourse, Beauchamp (1995) believes that these said concepts contribute a foundational level to bioethics to ensure that it rests on something other than disciplinary bias or subjective judgement.³⁴ These principles allowed for normative standards of conduct to be developed into the more specific rules for health care and research ethics that we see in contemporary medical practice (Beauchamp, 1995). In his article on principlism, Beauchamp states that, "Principles should [therefore] be understood less as norms that are applied, in the model of 'applied ethics', and more as guidelines that are interpreted and made specific for policy and clinical decision-making" (1995, p. 184). In view of this comment, I would now like to turn to a more in-depth look at the principles of biomedical ethics and how they can be interpreted in light of the assisted dying debate and the impact of new medical technologies that have emerged in contemporary society.

Since the publication of *Principles of Biomedical Ethics* there has been a steady increase in bioethical debates. As modern science and technology has progressed they have drawn into the arena new problems that were once inconceivable within orthodox medicine. The opportunities that new technologies have enabled have blurred the boundaries in medical science. Being able to keep patients alive, and augment others, has created new bioethical dilemmas that push the limitations of some of the more traditional accounts of biomedical ethics. In this sense, biomedical ethics has failed to develop at the same rate as the social changes that have been brought about with new technologies.³⁵ Many of the dilemmas that the principles of bioethics sought to solve have therefore largely ignored the wider social contexts within which many of the medical technologies and practices it focuses on are contemporarily situated. Further, bioethics has failed to incorporate the social impacts and

³⁴ For further discussion on this term see Evans (2000).

³⁵ See *Chapter five* for more information.

effects that practices may have, looking instead at narrowly bureaucratic and rationalised institutional practices of medical care.

Autonomy

Debates about autonomy often occur in relation to the primacy that is placed on the term within bioethics discussion. This often results in the overlooking of other principles when it comes to bioethical matters. Further debate occurs regarding the nature of autonomy in organised societies that are under governmental rule and are therefore able to impinge on the rights and liberties of its citizens. Beauchamp and Childress (2013) were among the first contemporary academics to formulate a holistic understanding of respect for autonomy in bioethics presenting a complete and substantive account of the principle. Deriving from the Greek *autos* (“self”) and *nomos* (“rule” or “governance”), autonomy was originally a term that referred to the self-rule or self-governance of city-states in Ancient Greece. Since then, its more common application within biomedical ethics has come to refer to it in the individual sense relating to the rule of individuals. Specifically denoting self-rule that is free from interference by others, autonomy ensures that self-determined choices are being made while also reflecting the individualism that is apparent in many western ways of thinking.

Since the beginning of the post-industrial era there has been a shift in the way individuals have come to view their place in the social order. Modern western thought has largely rejected the notion of meta-narratives that dictate the way that individuals are expected to navigate life and death. These could previously be found in the solidarity that was formed by religious bonds and the mechanical solidarity which Durkheim believed to be a feature of traditional societies. This means that individuals within modern societies no longer identify to the same extent with institutional ideas and expectations of how to live, breaking with the symbolic meaning of many rites and rituals that meta-narratives once provided (Collier, 2003). This has given rise to the more individualised ideal of autonomy and allowed people to make health care decisions that may deviate from commonly dictated models seen in more traditional societies. Autonomy as a concept has risen to the fore of bioethical debates, and for many bioethicists and those practising medicine it is the guiding principle by which people judge ethical decision-making.

In contrast to an autonomous person, Beauchamp and Childress (2013) also make reference to people with diminished autonomous capacity as those who are in some respect controlled by others or incapable of choosing and acting on one's desires. As regards this thesis, cases are normally brought about when a person lacks the mental competence and capacity to make rational decisions about their medical care. This idea follows from their "three-condition theory" of autonomy which states that autonomous action must satisfy the three conditions of intentionality, understanding and non-control (Beauchamp & Childress, 2013). These three conditions are particularly important when understanding autonomy as separate components and highlight some of the complexities of the concept. The condition of *intentionality* ensures that any decisions the patient makes are not accidental outcomes. Instead, any decisions must be in line with the patient's understanding of the choices they have and the potential outcomes and contingencies that may occur.

The second condition of *understanding* ties strongly into the related idea of informed consent which will be discussed shortly. This condition provides that a person must have an adequate level of understanding when it comes to deciding upon any potential action. That is, any condition that limits their level of understanding such as irrationality or incompetence may nullify any autonomous action. Further, any failings on the part of the medical practitioner in communicating the necessary details about the action may also lead to a lack of understanding. The final condition of *non-control* means that in order for a patient to make a fully autonomous decision they must be free from controls that may stop them from exerting self-directedness, whether from external or internal sources. This condition means that any action that is agreed to under coercion or undue pressure is to be regarded as a non-autonomous action.

As touched upon earlier, the idea of autonomy has developed a lot from its original conception in Ancient Greece. Since its use by the Greeks, namely Plato, who came up with the neologism, it also became a subject that was deliberated upon greatly by both Immanuel Kant and John Stuart Mill, who again had different opinions as to what it entailed and how the term was to be understood. An overall history of moral philosophy is not within the scope of this work. Kant (2012) believed in the idea of autonomy as freedom of will and, following the formulations of his Categorical Imperative, argued that people should always be treated as autonomous ends in themselves and never as means to the ends of others. This type of autonomy has been described as a form of positive liberty that is based on rational reflection

around universal rules and principles. In contrast to this, Mill (1974) spoke of autonomy as freedom of action. This position towards autonomy was described by Mirko Garasic (2011) as establishing a system to address autonomy in more practical terms with an emphasis on utility.

Mill believed that there was no universal right way to live and that individuals should accept social and political control over themselves only so long as it was a necessity to prevent harm to other individuals. Mill further held that the promotion of individual autonomy was the way to maximise the utility of the overall community as it followed that it promoted an individual's own values and priorities. He argued for what has since been described as a form of negative liberty, meaning that a patient has the right to refuse treatment as opposed to Kant's above-mentioned positive liberty, which means that a patient cannot in general demand a certain treatment (Tauber, 2003). As discussed by Jennings (2007), the understanding of autonomy that is applied within contemporary biomedical ethics is closer to Mills' notion with its strong emphasis on a patient's individual values.

In *Practical Ethics*, Peter Singer (1993, p. 200) argues that Mill takes his respect for individual freedom and non-interference by the state "too far" as he believed that enhancement of an individual's own good was not a justification for state intervention. Singer (1993, p. 200) claims, however, that it "may occasionally be right to prevent people from making choices that are obviously not rationally based and that we can be sure they will later regret". On this ground, Singer therefore holds that prohibiting voluntary euthanasia on the grounds of paternalism cannot be justified because, he believes, there are times when voluntary euthanasia and its outcome might be the better of a number of other options. Singer's views on assisted dying are nuanced and expansive. These views, along with his vast array of others, follow a utilitarian approach that are not in keeping with this thesis which follows a deontological, or more Kantian, approach to its ethics. In western medical practice the granting of autonomy to the patient places confines on the doctor-patient relationship by restricting possible issues of paternalism by physicians. It is seen as being a particularly valuable principle within bioethics in the way that it extends choice to the patient, as it enables them to express and follow through with decisions that show respect to their particular values. However, this rise in emphasis placed on autonomy can also be seen as a reflection of a loss of trust in medical professionals.

While historically doctor-patient relationships have been based on the ideal of trust which saw authority given to doctors through paternalism, as Onora O'Neill (2002) points out, this institutionalised opportunities for abuse within this relationship and led to doctors making decisions that were not always in the patient's best interests. Placing trust in doctors was seen as the only alternative to the lack of professional knowledge held by patients. The lack of understanding and the 'hands-off' approach physicians maintain in health care decision-making is viewed by Tauber (2003) as an inadequacy of autonomy as it fails to account for what he calls "medicine's moral calling". By this Tauber (2003, p. 486) refers to the idea that common conceptions of autonomy fail to account for the moral responsibility of health care practitioners. He believes that, "The sense of responsibility exhibited by physicians and nurses arises from their commitment to care for others, not primarily from a set of rules designed to protect patient autonomy". It is here that beneficence comes to the fore as will be shown shortly, situated alongside autonomy as another ethical principle within biomedicine. Contemporary biomedical ethics tried to shift this relationship in order for patients to regain some of the power balance. One way of achieving this was through the practice of informed consent, which was set to give patients more knowledge to make informed decisions about their treatment options.

Consent, Competency and Coercion

Consent, competency and coercion are all critical components for the conceptualisation of the principle of autonomy. Informed consent as a principle in biomedical ethics stems directly from the importance and emphasis that is placed on a patient's right to autonomous decision-making in health care. It is argued that informed consent and autonomy are crucially intertwined, with informed consent allowing for the individual choice central to our construct of individual autonomy (Manson & O'Neill, 2007). The idea of informed consent though is not as simple as might first be assumed. For many it is the basis of good medicine, allowing patients to make what are deemed to be informed decisions that are also free from coercion. Providing a selection of decontextualised information in order for a patient to make a 'rational' decision about their health care is often seen as being out of place in end-of-life care. Again, the emphasis on individual autonomy fails to take into account the situatedness of the patient and how their subsequent decision may affect and be affected by their own social situation. Furthermore, implicated through a patient's social world is how the illness affects them and how it is mediated by those who share in their death sequence.

Patients with chronic and terminal illness, along with those who have been institutionalised for a while, also feel a sense of disorientation having been taken away from situations with which they are familiar (Schneider, 1998). Their isolation from their social worlds has a depersonalising effect on their overall sense of individuality, changing who they inherently think they are (see Mulkey & Ernst, 1991 for an extended discussion). Further, and especially in relation to health care decisions pertaining to the complex situations faced at end-of-life, much of the information that is processed by a patient at that time is not able to be processed rationally and instead can often be burdened with the emotions of their current situation. Depending on how the information is framed by the physician, patients will take different information from what they are being told. It is nearly impossible in end-of-life situations for doctors to present information neutrally. Adding even more complication to difficult situations, some patients will consequently find it difficult to interpret the information that is being relayed to them, adding even more uncertainty to the situation (Schneider, 1998). This may result in patients viewing their treatment options with more favourable outcomes than they actually have, as patients tend to understand the information as individual statistics as opposed to population averages.

There are many standards for judging the limits of informed consent and just how ‘informed’ a patient must be based on how specific the information relayed should be. As discussed by Manson and O’Neill (2007, p. 15), there are at least three ways that it is possible to judge the “standards of specificity”. The first is set on the standards of what the “reasonable doctor” would expect to disclose. The second standard is set by what the “reasonable patient” would want to know and the third by what the “individual subject” would want to know. This third standard, while theoretically superior to the other two, is harder to implement in practice as it requires a doctor to have good knowledge of the patient they are dealing with. This is a reasonable assumption to make when it comes to patients with terminal illness, and especially neurodegenerative conditions, as doctors and patients often form a long-lasting relationship. It is not always the case for other patients, however, especially as we see more of a shift towards the bureaucratisation and rationalisation of western medicine which sees more distance placed between the doctor-patient relationship. Further, even when the doctor and patient may have a relatively strong relationship it can be hard for a doctor to gauge what may be important for an individual patient and what they will infer from a particular piece of information based on their “varying beliefs, varying inferential commitments and varying vocabularies” (Manson & O’Neill, 2007, p. 16).

Many doctors practising contemporary western medicine who are overtly aware of individual patient autonomy and fear the risk of paternalism may remove their input from decision-making out of respect for the self-determination for the patient. Deborah Lupton (1997, p. 379) discusses, for example, the idea that within the “privileged representation of the patient as the reflexive, autonomous consumer” it fails to account for the “unarticulated dependence” that patients may have on their physicians, owing to the patient’s emotionally and physically fragile state. What this means is that patients are left to make decisions about their medical care without the support and guidance of trained medical professionals. As Fra Ingelfinger (1972) believes, while a patient may be offered *informed* consent, this is a far cry from *educated* consent. Unfamiliar with, or at least untrained in, medical practice, the lay patient is required to make a decision information presented to them in language and with terms that they are unversed in and unaccustomed to in everyday life. As Carl Schneider (1998) discusses, physicians speak the language of medicine which a patient does not. Translations between doctor and patient can thus be difficult, while important concerns may be lost in translation. It is here that the further effects of the institutionalisation of health care can be seen, as they appear devoid of understanding to those without expert knowledge.

As previously mentioned, Beauchamp and Childress (2013, p. 104) believe that a crucial element of autonomous action is *understanding*, which they state can be hampered by deficiencies in the communication process. Like many other aspects of the informed consent debate, the standard of understanding required by a patient is going to be difficult to measure and relative to respective patients. Further, and as is discussed in *Chapter five*, there has developed a culture within contemporary western medicine that perceives a doctor as having ‘failed’ when death occurs even if it was inevitable within the foreseeable future. This can be seen to stem largely from the goal of medicine to heal. By disengaging themselves from the decision-making process a doctor can thereby dislocate themselves to some extent if a death in fact occurs. As Alfred Tauber (2003) believes, by incorporating informed consent into medical practice the physician can shift the responsibility onto the patient. While Tauber discusses this in relation to a way of avoiding malpractice suits, an issue that does not plague New Zealand’s no-fault health care system (see *Chapter two* for more detail), in this context it is still applicable to New Zealand medical practice as it is a way for doctors to avoid the ‘failure’ of their decision when the patient dies. Instead, all decisions are accountable to the patient and therefore so too are the outcomes.

Informed consent is further muddled by issues surrounding competency and the ability of patients to make decisions pertaining to their health care. Discussion about the competency of patients is rife within bioethics, especially within end-of-life care where patients are perceived as being particularly vulnerable, and it raises new issues that have not been discussed in the bioethics literature. Issues surrounding assisted death and a patient's ability to make competent decisions become highly questionable, especially when it comes to the vulnerability of patients. Faced with terminal illness it is doubtful as to whether a patient is ever truly coherent enough to make a decision which could bring about their own death. As Sheila Mclean and Laura Williamson (2007, p. 106) discuss in their book *Impairment and Disability* "... we are all vulnerable to proxy decisions about our death, irrespective of whether or not we had previously been described as impaired or disabled, because we all become impaired or disabled when we are in the kind of condition that triggers such decisions". What we see here is the difficulty faced by many health care practitioners in deeming a patient competent enough to make a decision.

This view is again repeated by Ingelfinger (1972, p. 466) when he says "Incapacitated and hospitalised because of illness, frightened by strange and impersonal routines, and fearful for his health and perhaps life, he is far from exercising a free power of choice". While for some decisions certain levels of incompetency are accepted it is widely held that the more life-changing the decision the more stringent the standard of competency must be. This means that for patients who are making decisions about when to end their life, a decision which is irreversible and life-changing in the truest sense of the word, the standard of competency needs to be extremely high, potentially at a level that is arguably not achievable by those in the position to be making the said decision.

Ideas of competency and capacity surrounding end-of-life decision-making also give weight to the idea of rational suicide that is often used in association with assisted dying. The notion of rational suicide aims to breakdown some of the stigma associated with normal conceptions of suicide by instead viewing it as an act based on rational decision-making. To believe that a suicide can be rational is to believe that the person committing suicide had good reasons for ending their life and that, with consideration of the circumstances, it made good sense (Mayo, 1986). Following a Senecan approach, proponents of rational suicide believe that in certain situations in which a person's inescapable circumstances, for example due to terminal illness, may be so at odds with their fundamental interests that their life may no longer be worth

living, suicide can be an appropriate option (Mayo, 1986). This attitude goes against many modern psychiatric approaches to suicide, which tend to view suicidal ideations as symptoms of a mental disorder.

Having developed from traditional theological approaches that view life as a gift from God, psychiatry medicalised the subject of suicide which was attributed wholly to mental illness (Mayo, 1986). For some, their decision to end their life can be seen as such, but for others their decision can also come about through altruistic motives. Often people at the end-of-life, or even just at the onset of terminal illness, are overtly aware of the burden that they do (or may come to) place on their families who are likely to end up caring for them. This can result in consenting to procedures they otherwise would not consent to, or in instances where assisted dying is legal, it could mean consenting to assisted death. This burden is often financial, emotional and mental and can result in the patient making decisions to end their lives prematurely for the benefit of the family and not themselves. Drawing on the assisted dying discourse, this is referred to as a *duty to die* and it is often seen as a strong motive not to legislate for assisted dying.

The duty to die is where a person feels that they are going to place such a heavy burden on their carers that it would be easier on everybody for them to end their lives. Different motives are often discussed as regards the duty but within terminal illness, especially neurodegenerative diseases that extend a person's life when they are incapacitated, this duty becomes particularly problematic. When a person is to be cared for at home there is the risk that the carer will be forced to quit their work to provide full-time care. Alternatively, where outside care is brought in this can place an overwhelming financial burden on the family to maintain the services. Where people are placed into institutional care which may incur high costs, as is the case in residential care facilities, patients may believe that it is money that is not being well spent. Given the opportunity to end their lives prematurely in these cases the patient may opt for this to ensure that money is left for their families when they are deceased.

Some decisions are not always accountable to the patient, such as those which occur under the duress of a coercive act. The vulnerability of patients becomes a particular problem when it comes to coercion. Coercive acts are a major concern within biomedical ethics as they seriously challenge the autonomy of patients. Following Beauchamp and Childress' conditions of autonomous action, coercive acts can be seen to impinge on and undermine the condition of non-control. Within end-of-life care they are also of particular concern as they

can be targeted at already vulnerable patients. Coercion occurs when an “intended and credible threat displaces a person’s self-directed course of action, thereby rendering even intentional and well-informed behaviour nonautonomous” (Beauchamp & Childress, 2013, p. 138). Part of the difficulty surrounding coercion is that it can often be confused with persuasion and manipulation, that is, not all instances of an individual infringing on another’s autonomy are acts of coercion. Coercive acts occur when undue pressure is placed on an individual to make a decision that fulfils another person’s desire. They can be unjust and deceptive and entirely undermine informed consent (O’Neill, 2002). What must be present in a coercive act is an intention to coerce, or a coercive will. However, as identified by Beauchamp and Childress (Beauchamp & Childress, 2013), this coercive will can at times be justified such as in the case of public health.

Coercion can, however, result in the exploitation of an individual. In end-of-life care it is particularly concerning as often the coercer will have something to gain from the ending of a person’s life, such as gaining an inheritance from a will or otherwise freeing themselves from the burden of having to care for the patient. Vulnerable individuals, specifically those with terminal illness, are often at greater risk of coercion resulting from the aforementioned issues pertaining to informed consent. Often a person who is suffering from a terminal illness and who has been in institutionalised care for an extended period of time may be more open to the powers of persuasion resulting in a decision being made that would have negative consequences in the future. End-of-life decision-making must be particularly free of coercion as the negative result is *particularly* life-threatening to the person involved. The *End-of-life Choice Bill* seeks to safeguard patients from coercive acts by not specifying that a person must consult with family to be assisted in their death. This, however, does not safeguard all acts of coercion which can also be carried out by medical practitioners and may also occur in instances where the patient does in fact decide to consult their families.

Justice

Justice, when applied within a bioethical framework, concerns the allocation of finite resources and, as Charles Foster (2009, p. 2) states, it reminds us, “that there is more than one patient in a hospital”. Further, justice takes into consideration the fact that where finite resources are concerned one patient’s access to treatment may result in another patient’s denial of treatment. A continual problem in the application of justice to health care is related

to ongoing questions surrounding which values and principles should be upheld and to what ends. These questions and their subsequent answers determine the allocation of resources as a reflection of what, if anything, justice requires of society (Beauchamp & Childress, 2013). Granted, it is also not only health that must compete in the marketplace of resources, and along with education, welfare and infrastructure, it must fight for a just portion of tax redistribution.

The concern for proponents of disability rights is that in environments with finite resources it becomes the vulnerable, such as the disabled, who are put most at risk. As will be discussed in the following section, the marginalisation by society of those with impairments occurs through the prescription of an ableist format onto the social world resulting in the disabling of many who are impaired. For now, suffice to say that disability rights activists are concerned about inequalities of access and opportunity that are faced by those living with disabilities and how, with further tightening on access to health care owing to limited resources, they may become more vulnerable to coercion by family and physicians to seek assisted dying.

The other side of the principle towards justice as it relates to assisted dying can also be applied to the wider community of vulnerable people within our societies. As was discussed in *Chapter two*, socioeconomic, geographical location and age also play a part in the system of distributive health care justice. All three factors play an integral part when it comes to lower socioeconomic groups, an isolated geographical location, and increased age in decreasing an individual's access to and quality of care. As is discussed by Alistair Campbell, Grant Gillett, and Gareth Jones (2002, p. 254), this unequal distribution of resources has a disproportionate impact on particularly vulnerable groups such as they provide, "the intellectually handicapped, the very young or the elderly, who require a higher provision of health care resources". They go on to argue that what is required is a "need theory" of distributive justice, which uses need as the criterion for successfully achieving equality of outcome as the final goal.

Norman Daniels (1996, p. 10) argued for a social conversation about the goals of medicine. He believed that should this occur there was a requirement for managed care organisations to, "adopt publicly accountable procedures for deciding when to cover new technologies and when to impose limits on others' treatments". Daniels provides a discussion of the ways in which he believes that current principle-based approaches to distributive justice remain inconclusive for solving key questions around health care rationing. Therefore, he goes on to

say, we do not yet know how, in a principled way, to balance the promotion of best outcomes with the promotion of fair opportunity. Without principled solutions, we must subsequently look either for more “fine-grained principles” or apply fair procedures, thus treating their outcomes also as fair. In a later chapter, Daniels (2001) furthered and refined his position on justice in health care, which I would now like to briefly discuss.

Daniels bases his theory of justice in health care around three questions that he seeks to answer in his chapter *Justice, Health, and Healthcare*. The first of these questions begins with Daniels (2001, p. 17) identifying what the central moral importance of health is, before moving on to understand when health inequalities can be viewed as unjust, and leading him to answer how competing health needs can be met fairly under reasonable resource constraints. Daniels’ approach to the moral importance of health is arguably even more exaggerated owing to the increase of neoliberal sensibilities in society, as he argues that its importance derives from the way that protecting “normal functioning” contributes to protecting opportunities for individuals. In this way, by meeting health needs to ensure that people are “close to normal functioning”, doing so also ensures their ability to participate within the political, social and economic spheres of society.

Daniels argues that to the extent that health care is able to protect, promote and compensate for losses of normal function, it protects an individual’s fair share of the normal range of opportunities. This “normal range of opportunities” to be considered as an individual’s fair share is construed by Daniels (2001, p. 18) to be:

... the plans of life it would be reasonable for them to choose (given their talents and skills) were they not ill or disabled and were their talents and skills suitably protected against mis- or underdevelopment as a result of unfair social practices and the consequences of socioeconomic inequalities.

This approach, it is claimed, would protect an individual’s opportunities that they could reasonably choose to exercise. This leads Daniels (2001, p. 18) to conclude that “*if* we have social obligations to protect opportunity, we have a framework for protecting health”. As will be highlighted in the following section the common perception surrounding disability is that it presupposes unhappiness in the person living with an impairment. As Daniels points out, however, illness and disability need not always lead to unhappiness even if they do restrict the range of opportunities that are available to people.

Commonly it is now thought that many people with impairments may be more satisfied with their lives than is perceived by those living able-bodied lives. While this may be the case, it does not account for the fact that some will still face an objective level of loss in the range of capabilities and opportunities that are available to them. This loss, Daniels argues, is able to be covered by appealing to a fair share of an opportunity range. Further, he believes that it is our social obligation to provide institutions that protect opportunity and not, as in fact may be the case in many instances, to maximise aggregate welfare or achieve efficiency. This approach to the principle of justice Daniels identifies as moving away from utilitarian goals. He believes that there is something intuitively beneficial about locating the moral importance of meeting health care needs on an objective basis of opportunity, rather than on an inherently more subjective basis that judges its impact on happiness.

Criticism can be levelled against this approach identified by Daniels, as the elderly may fear that owing to their lack of future opportunities they will be taken as having no objective basis for many further opportunities. However, he also argues that owing to the universality of ageing, the allocation of resources can be made to ensure consideration of an age-relative opportunity range. Thus, by treating individuals differently at different stages of life, health care resources could be saved from one stage of life for use at another, all of which can be achieved by designing a system that provides a “prudent allocation over a lifespan” (Daniels, 2001, p. 5) The universal impact of ageing means that a system of allocation would not produce inequalities across persons the way that gender or ethnicity does as we all age, but we remain one race or gender throughout this process. This approach to allocation within health care is also beneficial in that it does not isolate health care from basic necessities such as food, shelter and rest, which are also crucial for ensuring and preserving normal functioning. The opportunities approach put forward by Daniels views the prevention and treatment of disease and disability as the primary rationale for deciding assistance and resource provision within health care.

Another advantage to approaching the allocation in this way is that it achieves a more widespread coverage of other determinants of health. Thus, for assisted dying it becomes applicable in a couple of instances. First, such an approach to the allocation of health care that ensures an equality of opportunity for all means that social barriers that restrict individuals’ ability to function in society would be removed. This would be owed to a more holistic approach to resource allocation, which identifies hurdles and obstacles for those with impairments, while simultaneously also appreciating the social conditions affecting the able-

bodied which are also likely to have detrimental impacts on health. Secondly, and perhaps more importantly for the wider topic of this thesis, taking this approach to health care would mean that the wider communal body, many of whom are themselves implicated in patients' health care decisions, would also be considered when it comes to resource allocation. That is, such an approach to the principle of justice would ensure a greater sense of relationality by also taking into account the opportunities often foregone by those surrounding the patient and instead ensuring their provision. Most importantly, for end-of-life care it would ensure a relief from feeling like a burden to their families, which some patients feel, by enabling normal functioning and protecting equality of opportunity.

Beneficence and Non-maleficence

In bioethics the concepts of beneficence and non-maleficence refer largely to the practice of doctors and the duty that they have towards their patients. As the name suggests, beneficence requires physicians to act only for the benefit of their patients when making medical decisions. Non-maleficence on the other hand requires, much like the Hippocratic Oath, that doctors do no harm. The practice of beneficence and non-maleficence is greatly complicated by assisted dying debates as it raises questions as to just what the concepts of benefit and harm entail. Like many other aspects of the assisted dying debate one's approach and attitude to death, and all that it entails, greatly affects the way that beneficence and non-maleficence are viewed.

The bioethical principle of non-maleficence can typically override the principle of beneficence, and at times autonomy in medical practice, because of the weight it holds as regards the moral obligation of doctors. At first light non-maleficence appears in strong opposition to assisted dying as the ending of a person's life is seen to go against the sanctity of human life, with the ending of it being seen as the greatest harm that can come to a person. Many assisted dying advocates though do not believe that this is always the case, because when it comes to terminally ill patients it is believed that the trauma and pain of keeping a patient alive, especially against their will, can cause more harm than assisting them to die. It is with this understanding that it becomes evident how a person's approach to death and dignity may greatly determine their views on the principle of non-maleficence.

It is in the realms of non-maleficence that difficulties in one's approach to the concept of dignity complicate how the principle can be applied within the everyday experiences of patients. Those who believe that humans hold inalienable dignity, and therefore life is

something to be upheld at all costs, believe that the obligation towards non-maleficence would see a physician doing all that they can to keep a patient alive, while also attempting to keep the pain at bay. Death with dignity supporters, on the other hand, believe that the harm inflicted by keeping a person alive against their will, and the subsequent loss of dignity through such action as well as the continual bodily deterioration, would view the continuation of life-sustaining treatment as a malevolent act.

Part of the complication of the non-maleficence principle is that it does not necessarily just require a doctor to do no harm, as harm may be a consequence of a beneficial action. Following Beauchamp and Childress (2013), the duty of non-maleficence holds instead that harmful actions must be justified. Beauchamp and Childress use the example of leg amputation, which is oftentimes beneficial to the patient, to highlight this point. In her article on the boundaries of non-maleficence, Sandra Woien (2008, p. 31) holds that a counterfactual account of harm maintains that “an event harms a person if and only if it makes the person worse off than she would otherwise have been”. She claims that to assess what a person understands as harm, we first need to know what is considered “good” or “bad” for and by the patient. In the case of assisted dying arguments what dictates a bigger harm often comes down to quality of life judgements on behalf of the patient, and they are therefore difficult to substantively and objectively judge. If anything, difficulties surrounding what exactly can be viewed as harm play the largest role in determining the influence non-maleficence should have in medical practice.

It is also in the face of quality of life judgements that strong opposition is made against assisted dying owing to the perceived slippery slope that will lead to a wider destruction in the values of those living with impairments. In 2005, The Netherlands introduced the Groningen Protocol, which allows for the termination of life in infant newborns under specific criteria. Criticism was, and still is, levelled against the Protocol by those who believe that it will result in a “Hitleresque type of eugenics programme” (Manninen, 2006, p. 643) and lead to the termination of all infant life deemed to be below a certain standard. Arguments surrounding the Protocol abound (see for example Jotkowitz, Glick, Gesundheit, 2008; Manninen, 2006; Verhagen & Sauer, 2005), and while it is not within the scope of this thesis to discuss termination of the life of infants, the Protocol can be illuminating for end-of-life more generally and the ultimate goals that are embedded both within the medical profession and individual life itself. Particularly, as it relates to non-maleficence and beneficence, struggles regarding the moral evaluation of seemingly similar clinical actions

highlight the perplexities not only of what constitutes harm and/or beneficial care, but also the fine line that becomes evident between the justification of passive over active assisted dying.

While historically taking actions that would benefit or do good to the patient would have included carrying out all life-sustaining measures, as we have seen in contemporary medical practice, this is not always the case. This has largely complicated the concept of beneficence in contemporary medicine as questions have been raised as to whether the premature ending of a terminally ill patient's life would be more benevolent than keeping them alive. According to Beauchamp and Childress (2013, p. 203), the principle of beneficence "refers to a statement of moral obligation to act for the benefit of others". As with non-maleficence, beneficence is also based on quality of life and subjective judgements. For some people suffering from terminal illnesses it has been conceded that death may indeed be more beneficial, with continued living creating more harm.

The subjectivity of arguments is often tied directly into legislation when it comes to assisted dying. Seymour's *End-of-life Choice Bill*, for example, like many from other jurisdictions, stands on the grounds that it is up to the patient to decide when their life is no longer worth living so long as the patient appears to be within a certain timeframe away from death. In the New Zealand case it is proposed to be six months, as it is in many other jurisdictions. Patients with a terminal illness are expected to judge for themselves as to whether or not their disease renders their life unbearable. In making this judgement the patient is therefore deciding that death would be the more beneficial option for their future and that staying alive would in fact do more harm to them than good. Often the question in end-of-life care is not whether further treatment will be of benefit to the patient but whether or not the patient's life is beneficial to them. The subjectivity of making such judgements can be contentious within end-of-life care as what some patients are willing to bear can differ greatly to others. Further, what is viewed as a harm being done to a patient also differs widely as some believe that being kept alive is a greater harm than death itself.

As Adam Cureton (2016, p. 76) writes in an article on 'Offensive beneficence', beneficent actions can "go awry" when they were intended to benefit the patient but in fact do not. However, if they are successful they will advance the good of somebody else, as was intended for their own sake. The question in bioethics largely centres on what it is that constitutes a harm. In the assisted dying debate it relates specifically to a number of

discussions. It draws on moral frameworks like the sanctity of life argument to claim importance for public over private emphasis on good. It alternatively draws on rights-based frameworks that claim the harm of suffering, borne by a specific few in the face of death, is evidence of a right-to-die. Further, it questions who should get to decide not only what constitutes a benefit or a harm, who is recipient of which benefits and harms, but also what is beneficial and harmful enough.

Christopher Riddle draws on Anita Silvers (1998) who makes “the point forcefully” that “characterizing people with disabilities as incompetent, easily coerced, and inclined to end their lives places them in the roles to which they have been confined by disability discrimination” (Silvers, 1998 from Riddle, 2017). I cannot disagree with such a statement that has been otherwise referred to as a “paternalistic overemphasis of the vulnerability of persons with disabilities” (Bickenbach, 1998). However, and this remains a pertinent point, this attitude also risks overlooking those who do find themselves in vulnerable situations owing to their conditions. It seems counterintuitive to not provide a strong voice for those in these positions, which can only be done by first understanding the risks when individuals are in fact incompetent or in situations of coerced decision-making. This understanding cannot be gained if we fear offending those who fortunately do not find themselves in such situations. An open dialogue accounting the risks and harms of different communities is therefore vital. It is the principle of autonomy, however, that Riddle (2017) ultimately returns to. He argues contrary to the suggestion that legalising assisted dying would devalue the lives of those with disabilities. Instead, he believes that respect, “both generally and for the autonomy of the disabled”, requires that we allow the provision of assisted dying to everyone.

Anita Silvers (1998) provides a somewhat more meaningful treatment than the argument posed by Riddle regarding the perceived state of vulnerability applied to *all* of those living with disabilities. She agrees with Bickenbach (1998) who claims that by assuming vulnerability it overrides the self-determination of those living with disabilities and places the state in a paternalistic role of providing protection. Silvers’ article, from a collected edition looking to expand the physician-assisted suicide debate, considers whether the view that assisted dying poses a danger to vulnerable groups, especially to disabled people, is paternalistic. It is useful to look at her argument to understand how the application of Daniels’ (2001) principle approach to justice can be used in a way to remove, or at least counter, the prevailing view that assisted dying would threaten the safety of vulnerable communities. Pertinent in Silvers’ argument is highlighting the current lack of data that

shows that people with disabilities are in fact more inclined to end their lives than other people. Quoting the American Suicide Foundation, she states that problems associated with physical illness play a role in only one in four suicides. Silvers goes on to discuss the wider able-bodied public belief that impairment, “must be experienced as irrevocable loss”. This works together with the idea that individuals with disabilities have a higher likelihood of being despondent or depressed. Whether this is true or not, she argues it does not follow that individuals whose experience is pervaded by hopelessness are suicidal.

It is at this stage that Daniels’ (2001) approach to justice in health care can be understood within assisted dying. Silvers (1998, p. 140) states that, “Depression is the absence of that hopefulness that initiates functioning”. While taking this to be an overly simplistic approach to depression, we can presume that if a person was lacking the hopefulness needed to initiate functioning they would also be lacking the equality of opportunity needed to undertake “normal functioning” as understood by Daniels. Applying the principle of justice in health care, as he encourages, which allocates resources based on the need to attain a “normal functioning” to receive equal opportunity, it would follow that those individuals with depression would receive a just ration of health resources to do so. *If* this were the case, it could be presumed that those who find themselves in vulnerable situations, whether depressed and easily suggestible, or experiencing a perception of burdening loved ones, would receive the health care required to eliminate such circumstances and feelings and that could lead to premature assisted death.

Certainly, if one believes in the prospect of rational suicide, then it also becomes vital to emphasise the rational decision-making capabilities that many with physical disabilities retain. As described by Bickenbach, even in a society where ill health and disability are held to lower quality of life, and where this is reflected in social attitudes, policies and law, it is still possible to imagine that a rational individual may make the self-determined decision to commit suicide. This does not of course mean that all those with impairments can, or should, access assisted dying, but that they do possess the will to make decisions. It is on this point that both Bickenbach and Riddle make different but equally compelling points. Bickenbach here highlights the issue of coercion in assisted dying practices for disabled people, and points out that attitudes and practices that devalue the lives of those living with disability create more than just psychological pressure. Bickenbach argues that such attitudes and practices themselves lower quality of life and, drawing on work by psychologist Carol Gill, he identifies that for some death may be the only escape from substandard institutional care

or as a means to spare family the emotional and financial burden of what may be a lingering illness.

Bickenbach also identifies another form of coercion that may be produced by an artificial absence of viable alternatives. Choice may be constrained for those with disabilities owing to social attitudes and practices, which he deems to be the “moral sense of ‘coercion’”. It is worth quoting Bickenbach (1998, p. 128) at length to highlight his position:

What is salient to the moral conception of coercion is that the range of options has been unfairly, arbitrarily, or unjustifiably limited, not by hard facts and physical law, but by human beliefs, decisions, actions and policies If, because of mental or physical disability, one individual is confronted by a more limited range of options concerning his or her remaining life than another, then the decision setting is discriminatory. Straightforwardly, one person has a different set of opportunities than another, and that difference is neither immutable nor morally justifiable.

It is in the sense of moral coercion that we perhaps have to be most aware of the inequalities of access and opportunity that exist across present day New Zealand society. While arguably more progressive than other nations as regards the standard of everyday experience that can be expected to be lived by all members of its society, New Zealand still faces a number of both infrastructure and social policy problems that impinge on the lives of those living with disability and may subsequently lead them to make decisions they otherwise would not.³⁶

It is in light of the difficulties of understanding the subjective experience of individuals, and how this is exacerbated by a principled approach to bioethics, that the social sciences and sociology in particular are able to aid the dilemmas and contentious issues surrounding assisted dying. In the following chapter I propose an alternative approach to these issues that signals the importance of the incorporation of a sociology of bioethics, to a sociology in bioethics. As will be shown, literature that deals with the relationship between sociology and bioethics has shifted perspectives in the past couple of decades to allow for new treatment of the bioethical debate within sociological literature. Changes have ushered in ways for sociologists to aid in solving bioethical dilemmas, solutions which seem to have stagnated

³⁶ See, for example, the recent social housing crisis faced by those with physical impairments as reported by *Radio New Zealand National* in ‘Disabled tenants shut out of market’ available at: www.radionz.co.nz/national/programmes/ninetoon/audio/2018622554/disabled-tenants-shut-out-of-market

owing to the repetitive nature of a principle-based approach. These principles are often realised to be limited in their clinical and bedside application.

Concluding Remarks

The emergence of the field of bioethics from around the 1970s has developed in line with the burgeoning of new medical technologies. The possibilities of the changes ushered in with the new technologies largely unwittingly changed the relationships between medicine and the communities it provides for. Together with these changes came new approaches for sociologists who looked towards the structural impact of these innovations and how they would forever change the social world. As this chapter has identified, a number of significant principles are critical to the assisted dying debate. Without adherence to the principles of autonomy, justice, beneficence and non-maleficence, health care risks harming those who it seeks to care for. As a number of sociologists (see for example, Evans, 2000) have now identified, however, an overly strict adherence to these said principles can also harm a patient by not taking into account the values and attitudes that are important to them and which provide for a connection to community and society. As was shown in the previous chapter the use of certain rhetoric, such as the term ‘dignity’, has become weighed down by the historical and social contexts within which it was used. It has an unsuitably ambiguous application that can be pulled out, referred to and drawn upon by opposing forces within the assisted dying debate. Alongside terms like ‘dignity’, principle-based bioethical approaches also highlight the incongruence between discourse and its real-life applicability and effectiveness within health care.

Chapter six: Methodology, Research Design and Data Analysis

Introduction

In the following chapter, I discuss two linked data sets that cover the topic of assisted dying in order to answer the research questions outlined in *Chapter one*. While there are diverse perspectives in bioethics and sociology relating to the topic of assisted dying, there has been little work done that combines the two. The aim of my research is therefore to synthesise the bioethics and sociology debates to enhance the other's current contribution and to provide a greater understanding of the topic of euthanasia. Further, by widening my approach to include empirical work, I intend to augment bioethical discussion with empirical analysis. This chapter and the one following should be taken as being in conversation with the rest of this work. While at first glance it may appear as if they are disparate with regards to the literature, this highlights a similar disparity between the conversations being had by academics and other informed stakeholders and those being had by the media and the lay public. Ultimately, these distinct discourses represent the sum of conversations being had by the communal body.

A discursive analysis of media articles provides the data set, thereby strengthening the empirical work being undertaken. Following a similar study by Elke Hausmann (2004) that analysed press discourse in Britain from November 1998 to October 1999, I have conducted a discourse analysis of articles containing the word 'euthanasia' in either the headline or body of text within and across two selected time periods. The aim is to highlight the role of the media in creating discourse around euthanasia and how it is represented in debates to understand the version of reality it constructs, makes possible or excludes (O'Connor & Payne, 2006). A second data set uses 12 face-to-face interviews and provides for a discussion of the similarities and differences between discourse from experts and that which the media is framing. The intention of doing this is to understand how the dominant discourse that surrounds euthanasia has an impact on the legislative process, as well as public engagement with specific cases that make it into the public domain.

Critical discourse analysis (CDA) looks at the relations between language and power (Wodak, 2001). I have decided to use CDA to examine the data because there is a current lack of literature and understanding around language and power in relation to euthanasia. In recent years the mainstream media has developed a relatively supportive stance towards

euthanasia and, in cases such as the recent death of Brittany Maynard at the end of 2014 in the United States, it has created martyrs and heroes out of those who have chosen to take their own lives in the face of terminal illness. Presentations of cases, which from a lay perspective seem relatively straightforward, create a dominant discourse surrounding the public understanding of euthanasia and construct it in such a way as to seem simple and unproblematic. Representation of deaths that are classed by the public and media as mercy killings highlight the disparities within media reporting and can provide evidence as to the construction of moral discourses that are pervasive within the media. I suggest that there is a relationship to be found between the production of a euthanasia discourse by the media and the narrative constructions of terminally ill patients. This discourse supports the idea of the sick or dying role and the expectations of patients to conform to specific identity constructions surrounding their illness, as opposed to creating their own. This part of the project is in line with a sociology *of* bioethics approach (discussed in *Chapter eight*), as De Vries (2003) defines it, and will add an important layer to my analysis.

I interviewed 12 international and New Zealand-based experts who deal with issues surrounding euthanasia. The objective of the interviews was to provide a snapshot of present concerns in the euthanasia debates from a variety of different sources within different fields. These concerns are constantly evolving and there is often a time lag in academically produced literature, in terms of publication, which is not present with the interview method. Interviewing participants provided an insight into the issues as they are being discussed, negotiated and shaped in contemporary society. A TA was done on the interview transcripts to allow for a systematic understanding of the discourse being employed within and around the euthanasia debate. The analysis was based on codes, or themes, that I believe signify the current extent of the moral debate. They were drawn from conceptualised notions and understandings that, while useful in having delivered society to this point, fall short of allowing the polity to engage in a productive debate that solves the current end-of-life dilemmas. That is, there exist discrepancies in the rhetoric engaged in by the media and that of informed stakeholders. This exposition seeks to highlight divergences in the discourse being produced.

The overall aim of this qualitative study was to identify the ways in which dominant discourses were framed within mainstream New Zealand regional print media and how this differed from stakeholder discussions. This was done to understand how the euthanasia

debate is portrayed to the wider public and, in turn, influences how they are produced and reproduced in everyday rhetoric, social action and social change. Through a CDA of this field of media I argue that we can determine the reality of the public's understanding about a change in legislation to allow assisted dying under prescriptive circumstances in New Zealand. This is done alongside identifying the mediated position of the mainstream media over this period to highlight the critical role that it plays in shaping and disseminating information that the public can engage with. I suggest that there will be disparities between discourses used in the media and those discussed and understood by stakeholders. Stakeholders explicitly argued for a particular position along with their own specific construction of morality. Drawing on these same values, the media uses frames to implicitly inform the public with a form of reality. These frames help readers to navigate through the terrain of news and allow them to consume it as prescribed by mainstream media outlets. In doing so they provide a media constructed version of reality that is articulated in a way that is accessible to the wider public, entertaining and, most importantly, able to influence public opinion.

Research Questions and Objectives

The first data set identifies the ways in which the media has produced and reproduced a constantly dynamic form of social commentary relating to euthanasia discourse. In this thesis, I claim that the mainstream New Zealand media has documented the euthanasia and right-to-die debate with a distorted lens to captivate readers with the intrigue of personal losses brought about by terminal illness. The relationship between the vulnerable groups and the key actors in this debate is one of dominance, power and control which can overlook, or more accurately, override the view from those in the disability and aged-care sectors. This further perpetuates the dominant position that is held by the physically and mentally-abled within society. The second data set comprises interview data from discussions I conducted with 12 different stakeholders and experts, both nationally and internationally. Interview participants were either in some way engaged in debate about euthanasia or dealt with end-of-life care and assisted dying in their professional lives. Through the interviews I aimed to understand and engage with the constantly changing and evolving nature of the euthanasia debate, both in New Zealand and in countries that already had forms of assisted dying legislation in place.

Both data sets were collected to address the following research questions:

- On what grounds do stakeholders and interested parties discuss assisted dying?
- How is euthanasia and changing assisted dying legislation framed within the mainstream New Zealand print media?
- What links can be found between media discourse and the informed opinion of stakeholders?
- What does a CDA of the mainstream media identify about the production of dominant discourses relating to assisted dying?

These secondary questions are set in order to aid in answering the research questions as laid out in *Chapter one*. In answering the above questions, it highlights the disparate dialogues that are carried out by the media on the one hand, and informed stakeholders on the other, and how this can seek to inform this thesis by foregrounding the various interacting forces in the assisted dying debate. For example, it emphasises how the dominant discourses identified in the media's analysis could be beneficial when engaging in further discussion regarding relational autonomy or the dying role, or when attempting to understand the relationship between vulnerable groups and other key actors. The qualitative analysis in this research, and the related discussion regarding which dialogues are being produced and reproduced, can be taken as a precursor to the penultimate chapter that highlights further benefits of the sociology in bioethics approach and turns our attention to potential new ways forward.

Methodology

Interpretation and interaction with the social world relies on a form of moral communication. An epistemological framework underlies all sociological research and this study is no exception. This framework provides a set of underlying assumptions about the nature of knowledge upon which the research is based. For the present study, a social constructionist epistemological approach was employed. Social constructionists believe that we are born into a world of meaning which allows us to make sense of and understand the social and cultural world around us. It is because of and through the social and conventional institutions into which we are born that we come to know and understand the social world in which we live. The 'social' in social constructionism relates to where the meaning of the object is generated. That is, while we may interact with social and natural objects in our environment, it is our culture that enables us to understand the object and how we are to interact (or otherwise) with it.

Although still incorporated within the rubric of social constructionism, a critical discourse approach enabled me to question the hegemonic social constructions that are taken as commonplace within New Zealand society. This approach allows for engagement with the issues surrounding euthanasia, especially where they were seen to serve the interests of those within particular power structures. These power structures are particularly important to legislative change that has the potential to affect several vulnerable groups within society. The theoretical perspective of this study, or the philosophical framework that lies behind the methodology, is one of interpretivism. This interpretivist approach is based on an interpretation of the world as culturally derived and historically situated (Crotty, 1998). Interpretivism was discussed by Max Weber by contrasting *erkalen*, or explaining, and instead with *verstehen*, or understanding. In this contrast we are able to see the underlying ideas in interpretivism as based in the social life of an individual actor and how they envisage the world around them (Crotty, 1998). This approach is particularly noteworthy when it comes to data from interviews as stakeholder perspectives can be viewed as an interpretation of the world around them.

The relationship between morality and communication is often discussed within sociology owing to the intrinsic morality that is imbued into everyday social interactions. Communicative actions, whether explicit or implied, are premised on a complex social process that is constantly being negotiated and maintained by the polity. Following Thomas Luckmann (2002, p. 19), this chapter takes morality to be a “reasonably coherent set of notions of what is right and what it wrong”. These notions provide a framework for individual conceptualisation of the ‘good life’ and help to guide human action within the collective. These notions of morality have developed over time; stemming from institutional edicts and historical tradition that determine what is viewed as right and what is viewed as wrong. The binary nature of these notions define the norms of any given society at any given time. They compel a collective sensibility, which articulates a desire towards the good life, and provides the boundaries for the organisation of the communal body.

As is about to be discussed in relation to discourse, the process of legitimation that is displayed in the media works to rationalise certain actions and to morally evaluate them through the use of certain discursive forms. Berger and Luckmann (1991, p. 111) define legitimation as providing the “explanations” and justifications of the salient elements of the institutional tradition. This is done by way of explaining “the institutional order by ascribing

cognitive validity to its objectivated meanings” and in doing so justifying the “institutional order by giving a normative dignity to its practical imperatives”. Theo Van Leeuwen (2007) discusses that moral legitimation is based on moral values as opposed to them being authorised or imposed by an outside authority without further reason. In this sense, they can simply be asserted by the use of certain rhetoric such as the words “good” or “bad” that can be used and applied to a range of scenarios, situations, objects and actions.

In most cases, however, Van Leeuwen (2007, p. 97) suggests that moral evaluation is linked to “specific discourses of moral value”, that while not explicitly stated can be identified within adjectives such as “normal”, “natural” and “useful”. He describes these adjectives as forming the “tip of a submerged iceberg of moral values” in the sense that they trigger a moral concept but all the while remain separated from the interpretation from which they hold value. Van Leeuwen (2007, p. 98) does, however, caution that as a result of the interpretative process through which discourse is conveyed, it is not possible to find explicit methods for identifying moral evaluations. Instead, he suggests, one can “recognise” them on the basis of common sense cultural and social knowledge. Beyond this, he concedes, the usefulness of linguistic discourse stops.

Signs and symbols provide the communicative features of social life and enable interaction within this socially constructed system. They make possible the continued traditions of a particular society, and legitimise the moral order by way of customs and rituals, transmitted and received, through an individual’s constant negotiation with the social world. Morals set attitudes towards life and provide an internal reality, an “inner voice”, defining when the rules of the moral order have been violated. As discussed by Jörg Bergmann (1998, p. 282), while, “In principle an actor’s consciousness and moral attitudes are not directly accessible to others”, it does become possible to observe and assess a limited form of another’s moral character. This is done by way of a normative standard through such things as appearance and outward qualities, which allow inferences to be made regarding an individual’s moral qualities. Processes become a taken-for-granted element of values and opinions, as the ascription of quality and character rely upon being able to draw on internally referential systems and principles.

These systems and principles are themselves founded within the communities and institutions that provide the external organisation of social life. Historically, it is the institution of religious orders that provided a sense of community and helped to shape everyday social

interactions through a series of universally understood norms and values. Social expectation was an integral part of the ritualistic system that structured the social, and therefore moral, order. Religiosity in the western world has diminished, but many of the moral attitudes and values that form the “proto-morality” (Bergmann, 1998) of societies have remained. As rational systems of social organisation have begun to more deeply permeate social and political institutions, singular religious knowledge systems have had to make way for multiple sources of morality to be a persuasive influence on individual decision-making. It is from this point, and the belief that discourse and morality are constituted within social life, that the following analyses begin from.

Critical Discourse Analysis (CDA)

There are many different iterations and ways of undertaking CDA. In general, discourse analysis seeks to analyse discourse as a form of social interaction. This is done to identify the ways people use language within social interactions and to accomplish social acts, such as through constructing meanings, roles and identities (Van Dijk, 1997). The choice of methods for an analysis being undertaken depend on the topic of investigation. This allows for a flexible approach that, as Norman Fairclough, Jane Mulderrig and Ruth Wodak (2011) claim, does not weigh itself down with a fixed theoretical and methodological stance. Through this process I was able to approach the articles knowing that they all related to *euthanasia*, but being unaware about what they would provide in terms of analysis. Fairclough et al. (2011, p. 359) go on to argue that the “increased importance of language in social life has led to a greater level of conscious intervention to control and shape language practices in accordance with ... institutional objectives”. It is these institutional objectives of the media, by means of their power, dominance and perceived reliability and trustworthiness, which this analysis seeks to identify.

For the following study, I will be following Fairclough’s (2003, p. 2) approach which is “based upon the assumption that language is an irreducible part of social life, dialectically interconnected with other elements of social life, so that social analysis and research always has to take account of language”. Drawing upon Michael Halliday as a main point of reference, Fairclough employs Systemic Functional Linguistics (SFL) as a linguistic theory and analytical method. SFL approaches the linguistic analysis of text through the social character of those texts. It concerns itself with the ongoing relationship between language and the variable other elements of social life (Fairclough, 2003). SFL begins from the idea that

language is a tool for social interaction which has evolved to meet the communicative needs of any given society. Instead of existing as an autonomous system, SFL holds that language is a meaning-making resource that is not only used to represent the world but to actively construct it (Herriman, 2012).

The discourse analysis that follows uses Fairclough's (1995) analysis techniques from *Media Discourse* as a starting point. Fairclough holds that there are three dimensions of an event within the construction of a discourse; (1) discourse practice; (2) the process of text production and consumption; and (3) sociocultural practice, the social and cultural goings-on which the communicative event is part of. The following analysis engages with all three of these dimensions to understand how the moral order, and with it relations of power and identity, are constructed within a dialectical relationship between the authors of these articles as producers, and the New Zealand public that consume them. It is the discourse practice element of the communicative event that is of most significance for the media analysis that follows, as it is what mediates between the text itself and the sociocultural practice. In this way, properties of the sociocultural practice constitute and are constituted by the discourse practices that are evident within the text, and they themselves rely on these constructions to be understood by the readership.

In his work *Analysing Discourse*, Fairclough (2003) draws on Theo Van Leeuwen (2007) to provide four main strategies through which texts can provide legitimation for certain actions and morally situate and evaluate the positions and decisions people make. As discussed by Van Leeuwen (2007, p. 91), this is useful for "analysing the way discourses construct legitimation for social practices in public communication as well as in everyday interaction".

He sets out the four strategies for legitimation as follows:

- Authorisation: legitimation by reference to the authority of tradition, custom, law, and of persons in whom some kind of institutional authority is vested.
- Rationalisation: legitimisation by reference to the utility of institutionalised action, and to the knowledge society has constructed to endow it with cognitive validity.
- Moral evaluation: legitimation by reference to value systems,
- Mythopoesis: legitimation conveyed through narrative.

Using the example of antenatal procedures, Fairclough considers how they can be viewed as an instance of *rationalisation* with their strong emphasis on the utility of specialised systems. Following Jürgen Habermas (1984), he views these systems as being set apart from the rest of social life in the ways that they prescribe processes based upon “instrumental” or “means-ends” rationality. Fairclough claims that the state provision of health care is one system and it assumes certain agreed ends, legitimising actions, procedures and structures to maximise the utility in achieving these ends. He therefore holds that *rationalisation* overlaps also with the strategy of *moral evaluation* in so far as the motivations given for carrying out certain actions are done on the assumption of a generalised value system. As is about to be shown in the case of euthanasia, this is largely done on the basis of an implicit bias *towards* assisted dying legislation.

Van Leeuwen (2007, p. 98) suggests that there are three ways in which moral evaluation can be identified within discourses, and holds this to be achieved through the use of *evaluation*, *abstraction* and *analogies*. Adjectives used within media texts are thus able to modify sentences to portray certain reactions as legitimate and specific behaviours as “normal” or “natural”. This is done by constructing an idea of the social world as being natural. Van Leeuwen (2007) presents the idea of abstraction and the ways in which practices, actions or reactions are referred to in abstract terms to moralise them while at the same time sanitising the rhetoric from moral discourse itself. This ensures and allows for portrayals of characters who are defined by their actions and by the labels that are placed upon them which become the only qualities by which the readership comes to know of their lives. In the final idea of legitimated discourse construction, as discussed by Van Leeuwen (2007, p. 99), he discusses *analogies* that largely provide comparisons which he explains as having a legitimacy or de-legitimacy function. He describes this as occurring by applying a description of an activity belonging to one social practice onto another activity that belongs to a completely other social practice. The positive and negative values that are inherently embedded within the description therefore work to ensure that a comparative value is applied onto what is being discussed. These tools for the legitimisation of discourse have all been employed in the following analysis.

The social research themes of the following analysis are based on overarching concepts that have been identified within the media texts: *identity*, *agency* and *injustice*. I found that these three elements highlight the ongoing dynamics of the relationship between media production

and consumption. More significantly, they also highlight the order of discourse that is present within the texts and how these are able to situate actors within the social context and provide a moral element to their actions. The media draw on forms of membership categorisation to understand the morality imbued within the construction and reproduction of characters within the articles. It also draws on sociological ideas of deviance to understand and identify the constant manipulation and negotiation of deviant behaviours when it comes to those who have been cast into the euthanasia spotlight.

Originally taken from Williams Gamson's (1995) work on collective action frames, these themes represent the characterisation of persons inherent within print media, but are not themes in the sense that they are constitutive of the euthanasia debate. Instead, they can be taken as ways of moralising about the specific events and personalities within these stories. By attributing onto them qualities, circumstances and characteristics, and drawing on their social relationships, reporters construct moral beings who may invoke sympathy or disdain among the readership. In this way, they construct a version of reality that is accessible and easily understood by the lay public.

The *identity* theme is evidenced in the ways that identities are constructed within the selected media reports. The characters drawn on by the media ensure that the readers are able to piece together the 'personalities' of those they read about. While not explicitly vilifying or sympathising with these actors, reporters implicitly detail feelings towards them through the use of language and by drawing on particular, often seemingly irrelevant, details from their lives. Journalists writing on specific cases in New Zealand situate actors in relationships with certain institutions or as being authoritative voices when discussing euthanasia matters. Reporters draw on contextually relevant discourses that allow a moral permissibility of certain actions and actors, but not others. This is often done by way of membership categorisations through which identities are constructed by an individual's professional and personal life, as the media conveys images that draw on the experiential knowledge of the reader. By enabling emotions towards and against certain parts of an actor's identity the media is able to ensure that the readership are provided with a sense of collective action which frames them within a "we", and defines them in opposition to a perceived "them" (Gamson, 1995).

Elements of *agency* are drawn on from within the scope of *identity* as people's relationships with others are situated by the social context. It is in constructing an individual's identity that

observations can be drawn as to the agency that they held over their actions or, more specifically, the actions of others. Through this, the readership is able to garner ‘truths’ about an individual and through their reported affiliations construct actors as being (dis)empowered by virtue of these associations. As Gamson (1995) notes, the media spotlight that the actors are given by the media validates them as being important characters in this “morality play” (Tileagă, 2012). Individual agency is also given and taken on the basis of passive and active actions by those depicted in the articles. As will be shown, within certain cases agency is stripped from particular individuals to justify their actions by way of decision-making articulated as being out of their hands. The *injustice* theme is bound up within the euthanasia issue itself. While it can be directed towards certain individuals or groups, it is an anger towards those deemed to have wronged that enables the inherent sense of injustice within these articles. Referred to as a righteous anger by Gamson (1995), there comes from this a moral judgement being made towards acts or conditions that have led to the hardship or loss depicted in the stories.

As Gamson (1995) discusses, particularly where the reader is able to attribute undeserved suffering or malicious and selfish acts onto specific groups or people, there will be a definite element of emotional response required for an injustice. Importantly, these individuals do not have to claim autonomy over their actions and so *injustice* intertwines with the *agency* theme to highlight and play on the emotional elements of the story for readers. Following Gamson (1995), actors do have to hold some of the onus in bringing about the harm and suffering depicted and evidence of this can be found in the analysed articles. An important consideration is that while the reader may be strong in their conviction of right and wrong or good and bad, the perceived injustice that they have observed from the report may still be mis-informed or under-informed. It is on this point that the membership categorisation can be linked to CDA. As considered by Fairclough (2003) and Van Leeuwen (2007), this is achieved by reference to “persons in whom some kind of institutional authority is vested”. The characterisation of actors in specific ways, as will be discussed, provides them with an authority that allows them a right to speak.

The construction of identity, agency and injustice that emerges into the overall morality of these articles is based on ways of framing individuals. In a 1997 article on how media frames can shift public opinion, Nayda Terkildsen and Frauke Schnell argue that by deciding which issues to cover the media sets the public agenda, and in turn influences how the public

respond to certain issues. They argue that by framing and elevating certain issues over others the media is able to influence the public's evaluation of actors by altering the criteria by which they are judged. Frames are able to provide a sort of road map for the readers; they deliver a structure for the public debate and influence the information disseminated on particular issues (Terkildsen & Schnell, 1997). That is, stories play into the social construction of deviance, owing in large part to the frames upon which the actor's identity relies. The actor's associations and friendships ensure that they can be characterised by already culturally available concepts.

Deviance is defined by Anthony Giddens (1993, p. 116) as "non-conformity to a given norm, or set of norms, which are accepted by a significant number of people in a community or a society". Those who feature within the body of these stories are defined in large part by their refusal to abide by the norms and values that have typically been accepted within end-of-life care. The first glimpse that the readership is given into these actors is on the basis of this deviance. It is from this point that characterisations are made and qualities imposed upon them within the news, leading to the public believing this construction of the reality of other people's lives. Some people do not remain deviant for long; instead, their actions are justified by the language used to take the burden of guilt away. Others have their deviant behaviours confirmed by affiliation with voluntary euthanasia societies. Some are further regarded by the quality of their professional lives and therefore those they rub shoulders with.

The Articles – Characteristics and Collection

The first data set is used to present a CDA of New Zealand print news media surrounding the topic of euthanasia across two time periods. The first period chosen was between January 2002 to December 2005 and the second was January 2012 to December 2015. These two time periods mark important eras, which saw a number of so-called 'mercy killings' occur while they also marked significant periods for the discussion of assisted dying legislation in New Zealand. The first time period, between January 2002 and December 2005 (henceforth period one), covers the publication of Martin's book *To Die Like a Dog* in 2002, an event which sparked the author's subsequent arrest, charge, trial and later imprisonment. Just a year earlier New Zealanders had seen the arrest and jailing of a 77-year-old Thames man, Rex Law, who had killed his wife in a supposed suicide pact. This case attracted media attention in the years ahead owing largely to a perceived injustice in sentencing. During this time period there was also the death of Victoria Vincent in Nelson in September of 2002 that saw her husband,

Ralph Vincent, come under suspicion for aiding in her death. Just months following this there was another death, this time on the Kāpiti Coast, which saw a terminally ill man charged with his wife's murder following a suicide pact between the two of them.³⁷ In this case the couple were found together in her rest home unit. Elizabeth Green was deceased, having been killed by suffocation, while her husband Mark was found unconscious beside her in an attempt at murder-suicide. Green and Vincent died not long following the deaths of their wives, Vincent by his own hand. Perhaps most notably, period two covers the lead up to, vote on and period following the last Parliamentary vote on assisted dying with the introduction of Peter Brown's *Death with Dignity Bill*, which was voted down 60-58 by Parliament on its first reading.

The second period, from January 2012 to December 2015 (henceforth period two), covers the lead up to and then announcement of Lecretia Seales' High Court trial, the verdict and her death. This period also covers the handing of Maryan Street's cross-party petition to Parliament calling for an enquiry into assisted dying and the announcement of the Health Select Committee (HSC) to do so. During this period, there are again a number of notable deaths that made the headlines. The first of these is of Edna Gluyas who was found by the Chief Coroner, Ian Smith, to have committed "euthanasia by suffocation" and that led to his subsequent, and quite unprecedented, calls for Parliament to investigate the matter. In December 2011 there was also the death of Rosemary Mott whose husband, Evans Mott, pleaded guilty and was later discharged without conviction for aiding in her death. Again, notably during this period was the publication of a book by Sean Davison that, in a bizarre repetition of events like Martin's, saw him being charged for his mother's death in 2006 following his admittance in the publication. Thus, throughout both time periods the mainstream New Zealand news media provided relatively constant sources of articles relating to euthanasia with 'real-life' situations and stories for readers to reflect on.

The articles were collected using the Australia New Zealand Reference Centre (ANZRC) database, which allowed the use of filters to refine the search periods to New Zealand newspaper articles between the specific dates. Using the keyword 'euthanasia', a search was made in both the titles and bodies of the texts. Other methods were attempted before this process was selected as providing the most reliable representation of print media at this time. These methods included using the publication's own web search function, but this was to no

³⁷ Owing to name suppression by order of the courts, this couple have been given pseudonyms to protect their identity, so they are referred to here as Mark and Elizabeth Green.

avail. This search collected 792 articles for period one and 1,096 for period two. Each article was then read and those that referred to animal euthanasia, that were Letters to the Editor, or not primarily on the topic, were excluded. This turned about to be a significant number of articles but also prevented against data saturation. Letters to the Editor were eliminated because I wanted to focus primarily on the views espoused by the media and not necessarily those who consumed it. Articles also had to be written by New Zealand press outlets which omitted sources such as Reuters or Associated Press. All in all, this resulted in 269 articles for period one and 235 articles for period two.³⁸

After becoming familiar with the chosen articles, the decision was then made to eliminate editorials and feature articles from the selection. While a valuable gauge of morality, to identify implied moral discourse from which readers draw their ‘knowledge’ it was decided that these articles did not serve that purpose. Feature articles were written, for example, by Sean Davison. His inclusion for understanding the objective trustworthiness and reliability of the media, as portrayed by its neutrality, was not seen in cases which expressed an outward opinion. This culling meant the article count was also a manageable 269 articles for period one and 235 articles for period two. These represented a spread of articles from 10 regional newspapers, all bar one of which was published daily. The exception to this was the *Sunday Star Times*, a weekly broadsheet published by Fairfax Media on a Sunday and distributed around the country. The daily papers were also primarily published by Fairfax, with only the *New Zealand Herald* being published by New Zealand Media and Entertainment (NZME). Fairfax publications made up the rest of them are as follows: *Manawatu Standard*, *Taranaki Daily News*, *Dominion Post*, *Nelson Mail*, *The Press* [Christchurch], *Southland Times*, *Timaru Herald* and *Waikato Times*.

These publications make up half of the overall print media in New Zealand, and were taken to cover a good spread of the country. This provided the typical three main centres (Wellington, Auckland and Christchurch) along with the larger of the small town centres. Owing to the mainly Fairfax distribution, there was a significant amount of replication of articles, with editors swapping out the headlines instead of having reporters produce a novel article. It was noted that this became a more prominent practice in period two, presumably owing to a depletion in resources across print media as the readership turns toward digital

³⁸ This aggregate decrease in articles for period two is largely a reflection of a significant increase in Letters to the Editor being published. While eliminated for this study, reviewing these articles would make for interesting research.

formats. This can have a potentially significant effect on media transparency as it decreases the provision of values, news and opinions that is realistically disseminated.

Articles were then reread and catalogued depending on the cases that were referred to. These cases represent a cross-section reflecting some of the difficulties involved with end-of-life care as well as the current nature of the euthanasia debate in New Zealand. They highlight the variation in charges and punishment that are handed down to those involved in aiding in someone's suicide or death. Significantly, they also focus on both those who have taken another's life (Law, Martin, Vincent, Mott, Davison, Green), those who have taken their own (Gluyas and Appleby), and those wanting the right to do so for themselves (Seales). Thus, the collected articles can be taken as a reliable spread of the euthanasia-related issues and events that the public were relayed during these periods. Overall, these nine cases were seen as being particularly significant amongst other euthanasia-related events, such as the establishment of the select committee, when it came to moral communication for the sake of this analysis. A table breaking down the data set by newspaper, year and corresponding article count is as follows:

Table 1:

Newspaper	Year	Article Count	Year	Article Count
<i>Dominion Post</i>	2002	7	2012	8
	2003	18	2013	4
	2004	30	2014	5
	2005	13	2015	15
	Total	68	Total	32
<i>Manawatu Standard</i>	2002	3	2012	1
	2003	3	2013	1
	2004	0	2014	4
	2005	0	2015	5
	Total	6	Total	11
<i>Nelson Mail</i>	2002	3	2012	10
	2003	17	2013	4
	2004	7	2014	5
	2005	4	2015	20
	Total	31	Total	39
<i>New Zealand Herald</i>	2002	8	2012	20
	2003	18	2013	9
	2004	28	2014	8
	2005	8	2015	14
	Total	62	Total	51
<i>The Press</i> (Christchurch)	2002	0	2012	6
	2003	5	2013	1
	2004	0	2014	6
	2005	0	2015	15
	Total	5	Total	28
<i>Southland Times</i>	2002	0	2012	5
	2003	4	2013	3
	2004	2	2014	0
	2005	0	2015	2
	Total	6	Total	10

<i>Sunday Star Times</i>	2002	4	2012	4
	2003	15	2013	2
	2004	10	2014	1
	2005	5	2015	0
	Total	34	Total	7
<i>Taranaki Daily News</i>	2002	2	2012	6
	2003	14	2013	2
	2004	20	2014	5
	2005	4	2015	8
	Total	40	Total	21
<i>Timaru Herald</i>	2002	6	2012	3
	2003	2	2013	0
	2004	3	2014	3
	2005	0	2015	9
	Total	11	Total	15
<i>Waikato Times</i>	2002	0	2012	3
	2003	0	2013	4
	2004	5	2014	3
	2005	1	2015	11
	Total	6	Total	21
Total Article Count		269		235

The Interviews – Recruitment and Participant Overview

To provide weight to the theoretical and philosophical discussion of this research, 12 interviews were conducted with stakeholders and experts in the field of euthanasia. Stakeholders are taken in this study to be those who hold a vested interest in the matter or have been publicly outspoken in their views on assisted dying. Experts, on the other hand, are those who have an expert knowledge within a particular field or discipline that allows them a particular insight into the debate. The designations are not to be taken as exclusive when referring to participants. As highlighted in the objectives above, a large motivation behind interviewing came from wanting to include viewpoints from professional stakeholders who maintain a constantly evolving area of discursive expertise. With the ever-changing nature of a topical and polarising subject, by collecting interview data it meant that these continuous

developments could be used and accessed without the time delay that is often associated with published material. Ethical approval to interview participants was gained on 12 May 2014, after which point the recruitment process began. Ethical approval was sought from the Human Ethics Committee at Victoria University of Wellington, which seeks information about the research involved and potential harm to participants or researchers, and it makes decisions based on ethical practices to mitigate harm to the community. In all, three extensions were applied for and granted which gave approval to conduct interviews. Extensions followed just a year-long permission for contact with human subjects in the first instance as it was initially anticipated to contribute towards a Master's thesis.³⁹ All participants were given a participant information sheet along with a participant consent form, the latter of which was signed by the participant and returned to me prior to the interview. Samples of these forms can be found in *Appendices five and six*.

Invited participants were selected for their relevance to the topic with an aim of providing a broad discussion of euthanasia and the topical points involved in it. Convenience sampling was used to recruit participants who were attending events or in places practical to my location. Further snowball recruitment was later used owing to connections made through interview contacts. Interviews were sought with people from the medical field dealing with issues at the end-of-life, such as palliative care specialists, as well as those in support roles dealing with specific medical conditions and community health organisations. Academics dealing with the theoretical underpinnings of euthanasia and the bioethical debates surrounding the issues were also sought. Further invites were also sent to participants who were in some way involved in the campaign for legislation of euthanasia in New Zealand, either in terms of advocacy or opposition to the policy change.

Both international and national participants were selected and contacted via email in the first instance. A generic email was sent to the invited interviewees that stated the nature and intention of the research and outlined the discussion that their involvement would include, as well as highlighting some of the more general issues that would be focused upon. It also stated that interviews would be kept between 20 minutes and one hour with a location of the interviewee's choice. All but one participant was happy to consent to be identified by their name and occupation. Throughout this thesis a pseudonym is used while also excluding any

³⁹ Reference number 20914. Memorandum of the initial approval and the subsequent amendments and extensions can be found in *Appendices 1-4*.

identifying features of the person's occupation. This highlights the controversial nature of euthanasia within the New Zealand health care context as health care professionals are often reluctant to put their views on the topic forward for public scrutiny. In this instance, it means that only one out of the two New Zealand medical practitioners who participated in this study were willing to be identified alongside their positions, although further research into this would need to be undertaken before suggesting any significant statistics on this matter.

International experts, specifically academics, were chosen through their attendance at the International Conference on End-of-life (ICEL) in 2014 in Brisbane, hosted by the University of Queensland, as this provided an opportunity for contact while attending the conference. This approach for recruitment of the international participants from the ICEL followed a method of convenience sampling which was beneficial in terms of both time and money owing to the geographic isolation of New Zealand. In total, seven participants were contacted, with four of them responding positively and willing to partake in interviews. Due to time constraints at the time of the conference it eventuated that not all willing participants were able to be interviewed and just two participants, Jocelyn Downie and Jennifer Llewelyn (both legal academics of Dalhousie University in Canada), were selected. A multi-participant interview was conducted with Downie and Llewelyn on 15 August 2014 at the ICEL venue in Brisbane. While this thesis is New Zealand-based, interviewing international participants was done to thoroughly understand the nature of the assisted dying debate worldwide to discern how this might have influences on this country's legislative choices.

A further international participant who had not attended the conference was also recruited during his trip to New Zealand in 2015. This participant was Rob Jonquiere, the Communications Director from the World Federation of Right-to-die Societies. A medical doctor from The Netherlands, Jonquiere was also influential in the development and implementation of that country's assisted-dying policy and, in the past, has spoken openly about his experience of euthanasing patients, both before and after it became legal for doctors there to do. Further interviews were also conducted with in The Netherlands with three stakeholders, all of whom were or had been involved with the Euthanasia Review Committee. These individuals were recruited through a process of snowball sampling in-which they were suggested by other interviewees for participation in the study. A final Dutch participant was also contacted from an email address found online. Recruitment of Dutch participants came through an opportunity given by Victoria University when they generously provided a grant enabling me to attend the International Association of Bioethics 13th World Congress in

Edinburgh, Scotland. This international travel grant provided an opportunity to interview further participants that would not have otherwise been possible due to cost international travel from New Zealand. In The Netherlands three interviews were carried out with Jacob Kohnstamm in The Hague, and Suzanne van de Vathorst in Rotterdam on 27 June 2016, and Theo Boer on 28 June 2016 in Utrecht.

Throughout 2000-2006 Kohnstamm was the chairperson of the Dutch Association for Voluntary Living (NVVE) and has been a board member for the World Federation of the Right-to-die Societies since 2002. Since 1 April 2016, he has served as chairperson of the Dutch Euthanasia Review Committee. Boer also held a position (2005-2014) on one of five regional review committees that provide the backbone for euthanasia regulation in The Netherlands. Statements he made to the media in 2014 were taken out of context and he became for a while one of the most outspoken critics of the practice in his country. Currently, Boer chairs the Committee on Bioethics and Biotechnology of the Conference of European Churches, is a board member of the Dutch Research School of Philosophy (Section Ethics and Practical Philosophy), chairs the Dutch and Belgian Research Group in Theological Ethics, and co-chairs the interest group Evangelical Ethics of the (American) Society of Christian Ethics. Van de Vathorst was in 2013 appointed Special Professor of 'Quality of the Final Phases of Life and Dying' at the Erasmus Medical Centre (MC). The chair is set up by the NVVE Association. She currently has the role of ethicist in the North Holland branch of the regional review committee, as well as being the secretary for the Committee of End-of-Life issues at Erasmus MC and is secretary for the ethics committee there also.

In New Zealand a larger selection of participants were approached for interviews, but in many cases there was a lack of response from those who were invited to participate. Some of those invited would not agree to be interviewed due to the organisation that they represented already holding a formal and public stance towards euthanasia. Others did not believe they were the right person to be speaking on these matters. In total, 17 participants were invited to be interviewed with seven participants responding positively. Those who agreed to participate were very willing to discuss the topic, with all of them having relatively strong views either for or against the legalisation of euthanasia. The New Zealand-based participants included: Jeanette Wiggins, advisor for the Wellington region branch of the Huntington's Disease Association; Maryan Straet, a Labour MP and author of the *End-of-life Choice Bill*; Sinead Donnelly, a consultant in palliative medicine for the Capital and Coast District Health Board

and intensive care specialist; Kerry Weaver,⁴⁰ a geriatrician dealing specifically with neurodegenerative disease sufferers at a regional hospital; and John Kleinsman and Susan Buckley of the Nathaniel Centre for Bioethics in Wellington. Following the passing of Lecretia Seales an interview was also conducted with her widower, Matt Vickers.⁴¹ These locally-based participants largely fell into two categories. The first were those who deal with the treatment of patients with terminal illness and who were in a position to make requests for assisted dying or were otherwise experiencing end-of-life care practices within New Zealand. The second category of participants held those stakeholders who have been personally outspoken about the euthanasia movement and those whose associations or actions have made them important players in the euthanasia debate. A table of participants and interviews along with corresponding details is provided in the following pages.

As the format of semi-structured interviews provides, no set plan was followed during the interviews, although the participants were informed that the aim was to keep them semi-structured and conversational. The conducted interviews all maintained their own style, dependent largely on the interviewee(s) that participated. The majority of interviews were one-on-one and in three instances two interviewees participated at once. These group interviews were unplanned and somewhat opportunistic. However, as Denscombe (2010) discusses, this style of interview works to be more illuminating in both instances, allowing participants to interpret questions differently, express support for certain views and supplement similar perspectives with additional points. Four broad themes were chosen around the topic of right-to-die – relationality, health care practitioners, euthanasia and society – with the questions formulated around these areas. These were taken to be very broad themes through which the questions could be structured that by no way tied the discussion into specific topics. The approach towards interviewing was left intentionally broad with open-ended questions that enabled the interviewees to largely dictate the direction the interview went in. Not all questions asked to some participants were asked to others. Instead, questions were deliberately selected and developed relating to the expertise and experience of the interviewee. This allowed for more thoughtful answers to be provided as questions were not directed to participants with little knowledge of certain areas.

⁴⁰ Name has been changed to protect identity.

⁴¹ An interview was initially to be conducted with Lecretia Seales, but the rapid development of her illness following the trial meant this did not happen?.

Table 2. Characteristics of interview participants

	Name	Date of Interview	Country of Residence	Gender	Role	Group affiliation
Interview 1	Jeannette Wiggins	1/07/2014	New Zealand	Female	Advisor	Huntington's Disease Association Wellington Inc.
Interview 2	Maryan Street	3/07/2014	New Zealand	Female	Minister of Parliament - New Zealand Labour Party	President of the End-of-Life Choice National Committee (NZ)
Interview 3	Sinead Donnelly	14/07/2014	New Zealand	Female	Specialist - general and palliative medicine	
Interview 4	Jocelyn Downie	15/08/2014	Canada	Female	Professor of Law, Schulich School of Law at Dalhousie University	
Interview 4	Jennifer Llewellyn	15/08/2014	Canada	Female	Professor of Law, Schulich School of Law at Dalhousie University	
Interview 5	Kerry Weaver*	4/09/2014	New Zealand	Female	Gerontologist at a provincial New Zealand hospital	
Interview 6	John Kleinsman	16/09/2014	New Zealand	Male	Director of the Nathaniel Centre, NZ Catholic Bioethics Centre	
Interview 6	Susan Buckley	16/09/2014	New Zealand	Female	Researcher/Administrator at the Nathaniel Centre, NZ Catholic Bioethics Centre	

Interview 7	Rob Jonquiere	3/03/2015	The Netherlands	Male	Former medical doctor	Communications Director of the World Federation of Right to Die Societies
Interview 8	Carole Sweeney	5/03/2015	New Zealand	Female	National Secretary of End of Life Choice Society (NZ)	Secretary of the World Federation of Right to Die Societies
Interview 9	Matt Vickers	14/07/2015	New Zealand	Male	Widower to Lecretia Seales	
Interview 10	Jacob Kohnstamm	27/06/2016	The Netherlands	Male	Former Dutch politician	Chairperson of the Dutch Euthanasia Review Committee
Interview 11	Suzanne van de Vathorst	27/06/2016	The Netherlands	Female	Associate Professor/Professor by special appointment, Erasmus Medical Centre	Ethicist for North Holland Branch of the Dutch Euthanasia Review Committee
Interview 12	Theo Boer	28/06/2016	The Netherlands	Male	Senior lecturer of ethics at the Protestant Theological University, Groningen	Chair of the Committee on Bioethics and Biotechnology of the Conference of European Churches

The interviewees themselves varied in terms of how stringently they stuck to the line of questioning. In some interviews, the participants were happy to talk largely to their own agenda and questions were not needed to keep the conversation going. In others, answers remained specific to the questions asked and interviewees would stop talking when they felt they had provided a satisfactory answer to the stated question. In both instances, follow-up questions were formulated *ad lib* in reaction to the response of the participants. This formula allowed for a range of non-specific points to be dealt with and participants were able to express their views and, more importantly, points they believed to be pertinent to the euthanasia debate while developing their own ideas and talking widely on the issues raised. This allowed for views on euthanasia to be created by the participants themselves in the hope of allowing this thesis to address end-of-life issues from a wider social perspective.

In some interviews reference was also made to statements that other participants had expressed to gauge different views on specific matters. At the end of the interviews, where time allowed each participant was also asked if there was anything they believed had not been covered that they wished to raise. All interviews were voice recorded and subsequently transcribed by myself as an aid to memory. Notes were also taken as needed throughout the interview and a brief summation was also made following each occasion. After transcription, the interviews were read and reread to ensure familiarity with data. A form of open TA was then conducted on the transcriptions to pinpoint themes and highlight ideas that would contribute to and strengthen the theoretical basis of this research. NVivo software was used to organise and manage the data and to help with the process of coding. Codes were first applied using a broad approach.

A second process of coding was then undertaken to narrow down these broad themes and to highlight more in-depth codes that could be identified and which related to more specific aspects of the texts. As previously mentioned, the interview questions were based around five broad topics and when analysing the data an inductive approach was used for the identification of further themes. This was due to the fact that the style of interviewing undertaken allowed the participants to emphasise new themes, or what might be more appropriately deemed sub-themes, which they believed were particularly important to the topic. This was also beneficial for the data-driven approach of analysis that was mentioned above. This form of analysis meant that new concerns were highlighted by the interviewees

as the data collected was not analysed in a stringent way that was heavily committed to my own ideas, allowing for new understandings to be developed.

Thematic Analysis (TA)

TA is a popular method for analysing qualitative data in the social sciences. By offering insights into patterns of meanings and themes across a data set, this form of analysis enables the researcher to find latent meanings or otherwise innocuous patterns and themes (Braun & Clarke, 2012). Unlike other forms of qualitative data analysis that seek to describe patterns across the data, TA is based instead on understanding people's everyday experiences of reality (Braun & Clarke, 2006). It has been identified as being a useful tool for systematically identifying and describing features of qualitative data which recur across participants (Marks & Yardley, 2004). The benefit of using TA in this research was that it highlighted what experts and stakeholders perceive the issues surrounding euthanasia to be from their everyday understandings at the frontline of end-of-life and academic knowledge. Following Braun and Clarke's (2006; 2012) breakdown of TA, the identification of themes in this instance was theory-driven, in that I employed a deductive approach to analysis which drew on existing ideas that were brought to the data. These were largely informed by the previous theoretical research that had been undertaken and which seemed to provide a way of drawing on moral concepts that are already well developed within euthanasia discourse. If anything, the extent to which these themes run so pervasively through the data also provided evidence of the ways stakeholders engage in the broader euthanasia debate and how this differs from that espoused by the media. This relationship between the rhetoric of the expert stakeholder and the everyday language of the media will be developed further in the discussion.

Using a deductive approach towards the data provided for an understanding of the text drawn from the already established popular discourses present within the euthanasia debates. These themes then became the basis of the analysis that was done on the interview transcriptions. By using a deductive approach to coding through the themes that were raised I was able to analyse how different actors reacted and responded to different points that were raised and could identify how responses reflected other views within society. I began addressing these questions by coding the articles using a line-by-line, deductive framework that recognised the pre-established order of discourse within the data set. The themes drawn upon, which are to be discussed shortly, represent six categories through which moral judgements and attitudes

are produced. Each of these can themselves be used to both advocate for and oppose euthanasia. The overarching discourses that can be identified within these interviews can be seen to argue on the basis of the following four categories: choice, compassion, coercion and criminal.

As David Marks and Lucy Yardley (2004) identify, this second level of coding provides for a hierarchy in coding categories. These four categories make up a higher level that can then be subdivided into the themes below. Marks and Yardley (2004) highlight the idea of splicing, whereby the analyst fuses together a set of codes under an overarching category. This idea requires that the research identify which codes are able to be grouped within the more “powerful” codes. For example, the dangerous discourse theme may be apparent under a coercive code when it is argued that pressure will be put onto vulnerable individuals. Or the choice code might be identified within medical discourse when participants discuss the imperative of making autonomous choices in their own health care decision-making. Following this initial coding the themes were refined further to correspond more specifically to the ideologies and moral discourses evident within the interviews. These six broad categories reflect how the participants framed aspects of the assisted dying argument from within the social and institutional context within which they spoke from.

The frames were drawn from both latent and manifest ideas and conceptualisation in the data and were identified as: a) rights-based discourses; b) the medical profession; c) dangerous discourses; and d) autonomy. I would now like to turn to a breakdown of the characteristics of the frames identified to show how I perceived of them. The frames discussed below were believed by the author to be the most critical and overarching of the arguments that are employed by those fighting for or against euthanasia. The discourses used by both sides, while diametrically opposed, are often similar in how they position themselves in relation to the frames discussed below. Examples can be seen in the death with dignity argument that is used to fight both for and against changing policy around assisted dying. Relatedly, the right-to-life versus right-to-die parties engage in rhetoric that reflects similar values about respect for human life, bodily integrity and the importance surrounding the respect for and rituals of death. Both sides, however, end up with vastly different results in opinion and values depending on the moral emphasis posited.

The first argument frame – rights-based discourse – occurred when participants were shown to present the belief that euthanasia is a human right, or in interviews within which the stories

presented such beliefs to portray the primary characters as using rhetoric that conceived of the euthanasia argument, either positively or negatively, as rights-based. Negative examples were when the right-to-life arguments were employed as a way of disavowing euthanasia. Likewise, the frame of political discourses was identified as occurring when the participant spoke about euthanasia in relation to political parties, political action or political climates. Otherwise reporting on the beliefs of a MP also constituted a political frame. The third argument frame, dangerous discourses, was found when the interviewees expressed views which highlighted euthanasia as being dangerous and/or otherwise bringing to attention a 'slippery slope' position. Death with dignity, the fourth argument frame, engages that position either in defence of or in opposition to euthanasia from the viewpoint of either the author or actors(s). The final two argument frames, medical discourses and merciful claims, followed the same pattern. The focus on medical aspects was framed from the perspective of the medical community, the implications that it might have on the wider community, the practice as a whole, or other medically-related concerns raised. The merciful frame similarly portrayed euthanasia as a compassionate act that brought an end to a patient's suffering. However, stakeholders who believed it was uncompassionate to end a life were also drawn under this frame.

Limitations of the Study

Limitations in this form of data collection can be attributed to factors pertaining to both the participants involved and the nature of the topic. As previously stated, time limitations restricted the international participants who could be involved, which was also enhanced by New Zealand's somewhat isolated geographic location. These participants were limited to those contactable during the International Conference on End-of-life. As regards the national experts and stakeholders who were invited to participate, the controversial and polarising nature of the topic can be seen as one of the main attributions as to why there was a low response rate to the initial email, with many people not willing to be associated with opinions on the topic. The fact that several organisations already have policies relating to their stance on euthanasia can also be seen as another factor in this. These policies were not easy to find and it was not until one association identified itself as having a policy that I became aware of this phenomenon.

The nature of group interviews too can be viewed as a particular limitation within the research conducted. As mentioned, the group interviews were somewhat opportunistic owing

to the participants being available at that time which meant that group dynamics were not something that was able to be taken into consideration before the interviews commenced. While there was nothing obvious to indicate that the participants were swayed in any way by the other interviewee, as can sometimes occur (Frey & Fontana, 1991), it did mean that the power dynamics within the group itself were skewed. As Pile (1991) notes, all fieldwork involves power relations, both socially and intersubjectively, and these can affect how the interview plays out and the information that is shared or stymied between participant and interviewer. This idea of power relations is further backed up by Desmond (2004) in research? looking at the methodological challenges posed in studying an elite in the field.⁴² As Desmond's (2004, p. 265) research shows, that "with elite interviewees the relationship is inevitably asymmetrical regardless of the research strategies deployed. The researcher is dependent on the cooperation of a relatively small number of people with specialized knowledge". This highlights phenomena that can be noted in all interviews conducted, however, even more so with the group interviews which placed two 'elites' in a more knowledgeable and therefore powerful position against a researcher owing to this imbalance. There were no notable power imbalances perceived throughout the interviews conducted in this study.

Another limitation in the interviews was that there was no 'anti-euthanasia' participants, (although Boer's views do waiver slightly) from The Netherlands. This is largely a product of the snowball effect of collecting participants for interviews as it depends on the associations that others have. As was shown by Megan-Jane Johnstone (2016) following the morality salience hypothesis, individuals are more likely to interact and form substantive relationships with those who hold their same moral beliefs and values. Relying on a snowballing method of collection, the result can be an exclusion of negating views unless the different sides are directly contacted.

Concluding Remarks

The two analyses conducted for this research attempt to understand the complexities of the euthanasia argument as it is being discussed by New Zealand stakeholders and the media who are meant to represent their voices. To make progress towards answering the research

⁴² Desmond here notes that, "Social and political scientists have traditionally conceived elites as those individuals 'so placed within the structure that by their decisions they modify the milieu of many other men'" (Mill, 1953, 112).

questions I will provide a consideration of the analysis undertaken that will use the frameworks discussed in these sections, as ways of understanding the influence of the mainstream media on public opinion and the position of power this puts it in. Comparing these results with the themes and arguments that were drawn on by interview participants provides an interesting insight into the construction of discourse.

Chapter seven: Findings and Discussion

Introduction

This chapter focuses on the communication of moral and ethical views in relation to assisted dying in the media and in the discourse of academics and other stakeholders who work in the field. It shows how engagement with, and negotiations around, the communication of assisted dying in the New Zealand print media, when discussing euthanasia, can be taken as evidence of the discordance between media discourse and stakeholder opinions on the topic. In this chapter, I suggest that the portrayal of euthanasia in the media does not sufficiently provide the readership with an informed account of the euthanasia debate, owing to the superficial descriptions of actors and events that have played a significant role in media reporting. That is, while there is a prominent use of moral discourse in the media discussion of euthanasia, this is done in subtle, indirect and passive ways and results in a denial of the complexities of the matter. I aim to show how this is achieved by media reportage. Evident throughout the articles I discuss are threads of information that enable the construction of individual personalities, based on scripts that are used by the media to present morally justifiable behaviours and frameworks for the assessment of moral character. I show how specific phrases and terminology can be identified as persuading and even manipulating the views of readers.

Previous studies have occurred in relation to both discourse analysis and the media's discussion of assisted dying. These highlight the need for further such studies, including the one conducted in this thesis, and especially when these are specific to the New Zealand context. Prominent among this research is a study by Elke Hausmann (2004) that investigated how the press treats the subject of euthanasia in British newspaper articles over a 12-month period. The findings of this research identified that the press discourse frequently endorses a "voluntary euthanasia discourse". In doing so, it creates a form of legitimization for assisted dying surrounding the idea of choice. Such a view, Hausmann proposes, appears to be widely shared in society. Hausmann also identifies what she refers to as a "terminal illness discourse", whereby the presence of an illness in and of itself becomes the standard which justifies euthanasia. The framework for the following study has been informed by the research conducted by Hausmann (2004) and follows a similar methodological approach.

As discussed in the previous chapter, Luckman (2002) believes morality to be a “reasonably coherent set of notions of what is right and what is wrong”. This chapter shows how the media frame the assisted dying debate in terms of a specific morality, and a set of notions about what is right and wrong, which then encourages print media consumers to construct assisted dying arguments by using the frames provided as reference material. Herein an order of discourse is produced by reporters as they situate certain individuals as key actors, sometimes condoning and justifying certain actions while vilifying others. By breaking down some of these effects into specific themes, and through close analysis of the texts, the ways in which the media achieve this persuasion are observable. Identified within the following analysis are examples of how reporters use frames surrounding *identity*, *agency* and *injustice* to provide their readers with real-life anecdotes presented in ways that largely construct ‘victims’ of those identified. These personal stories are frequently based on a tacit favouring of euthanasia legislation. By rousing sympathy for the victims, they are shown, often through lack of agency, as having no other option owing to perceived injustices being inflicted by external parties.

In addition to the discussion and analysis of media discourse, and compared to the largely uninformed view from which these assessments are made, I also present findings from a TA of stakeholder interviews. The opinions and views held by these individuals are largely informed by the bioethical debates I discuss in the following two chapters, and are articulated in the findings I identify. Unstated within these personal discussions is a general belief that the speaker is correct in their positioning. I do not take an evaluative position on these stances in this chapter; rather, my aim is to highlight the pervasiveness of well-understood bioethical principles in the public language of assisted dying. (Critiques of these principles and proposed new approaches can be found in *Chapter seven*.) The interview participants in this thesis are all viewed as authorities within their respective fields. The knowledge they hold is of value in understanding the end-of-life in New Zealand as it can be used to inform debates. It is also vital in understanding the concerns of those who work with people at the end-of-life and with the views of those who understand the complex social and religious history of ethical analysis. Furthermore, included in the discussion needs to be the appeals made by those who theorise about end-of-life practices and those who are seeking to bring change within our society.

Although these two data sets are distinct, the differences in the discourses they each present helps to highlight the significance of these two public sources of moral judgement and ethical viewpoints. These discourses therefore represent a snapshot of assisted dying coverage in the public domain and how the availability of that data informs lay opinions. This data is disseminated, on the one hand, by the mainstream media and, on the other, by stakeholders and interest groups who try to alter the nature of the debate and the points that arguments are premised on. The articles and the interviews work together to highlight the ways that individuals' knowledge is shaped and informed by personal experiences with the end-of-life and public portrayals of everyday 'Kiwis' who are afflicted at the end-of-life. The results of the following two analyses can therefore be viewed as providing insights into the frames and themes that are used to persuade and inform public attitudes.

The Articles

The frames discussed in the following data are used by the media to characterise certain actors in specific ways, creating sympathies and ensuring that those being condemned by the courts are not necessarily also condemned by the community. The approach I have taken to analyse the findings follows William Gamson's (1995) work on collective action frames. This analysis is divided into component frames of injustice, agency and identity. Many readers of New Zealand media will not engage in social protest regarding assisted dying to the extent that Gamson applies these frames. However, they can still be effective tools for understanding the ways in which seemingly everyday language can be shown to further specific agendas by way of its use. This is done as readers engage with symbolic interpretations of rhetoric, which they take as signs to empower themselves as agents of their own history.

With ideas around injustice in relation to the assisted dying debate, it is the framing and salience of the issue that is most important. It is not the movement itself that is relevant but instead it is the media's role in fostering a sense of injustice. Injustice frames present the facts of the case with a sense of producing what Gamson (1995) calls "righteous anger". In this way, the stories are laden with emotion and impart a feeling of moral indignation against the actions portrayed within the report. Important for an injustice frame is that the reader has something or someone to direct their anger against. This is referred to by Gamson (1995) as a "concreteness in the target", even if the anger is completely misplaced and directed away from real causes of hardship. In the media articles selected, this anger is most often directed

against a perceived lack of compassion from the legal, and at times, medical systems. An injustice frame requires a motivated human actor who is able to carry some of the onus of bringing about harm and suffering. The issue with injustice frames is that by concretising the targets by framing, readers are in danger of missing the underlying structural conditions that have actually brought about this injustice in the first place. Anger is misdirected towards the actors, as opposed to the circumstances, which led the agent to carry out their actions. However, pertinent for an injustice frame is that actors do not have to be autonomous agents within the situation as they are also framed as lacking in agency.

Gamson (1995) believes that the forces that discourage a sense of agency among citizens in most societies are overwhelming. In this way, culture and social structure combine to induce a collective helplessness. The media reporting on the assisted dying debate positions the actions of the main characters in the stories as stripped of their agency and as those who cannot resist the power or pressure that comes from voluntary euthanasia organisations. In fact, it is normally these same people who have sought contact with these groups themselves. However, framed as they are within the media they remain devoid of agency, as victims to external forces. They are devoid of agency though, these hapless victims. When people are shown as having agency there are attempts to diminish its importance or to almost belittle the choices that were made by the actors in question. Again, this allows the reader to ignore the structural conditions that influenced the actor's decision. Instead of getting angry at the system, their anger is instead directed at groups like Exit International. The individual actor, trying to further this social change, instead gets associated to the collective, in this case Exit members, and becomes weighed down by the identity politics that entails.

The identity frame is significant in the process of defining a 'we', which is situated in opposition to a 'they' who are held as having different interests and values. Importantly for us, with assisted dying cases they are held on this sliding scale of moral judgement. These identities are constantly being elaborated upon and negotiated with, and they become an important feature for ensuring an opposition is built against someone or something, and thereby furthering a sense of injustice. Actors' identities within media reporting are constructed in relation to something or someone else, this juxtaposition ensuring that the reader is able to identify with the character to help them to understand the importance of their voice and where their authority to speak comes from. The larger collective becomes defined by the identities that are implicated within it. It provides a form of identification which makes

the identities appear as if acquainted with the reader, like normal characters in the play of life. A table of article count by year and source publication can be found on page 150 in *Chapter six*.

Identity

News stories that appear to portray narratives of human interest can be found to predicate themselves on the lives of those who ‘make the news’ and, in doing so, attempt to invoke a relatability between the reader and those depicted. The identities constructed within the news pages can be seen to largely fall into two categories of framing. Where a deviant frame is applied, it denotes the idea, often applied to a group, that there was a wrongness in the association, in some cases even a suspicion, which emphasises the transgression of a norm and works to undermine the question by affiliation with the group or activity. Within the cases selected for this analysis it is apparent that the deviant frame is applied, particularly to those who have had any form of contact with end-of-life advocacy groups. Where individuals have had access to the materials produced by these groups, it is emphasised continuously throughout and within articles, and implies that it could be the source of any wrongdoing or raises questions over the moral integrity of their actions.

Where deviance is not drawn on, alternative scripts of martyrdom and heroism are instead selected and applied by journalists. Within this frame is a sense of victimisation on the part of the person in question, as if it is not the deceased but they who are the real victims in this. Where they were passive bystanders in the actions of others, a victimisation ensures that the actions they did, or are now taking, are viewed in a positive light. Where they have in fact undertaken illegal actions, martyred individuals are depicted as having fallen on their swords because of the unjust regime of society’s laws. Martyrdom verges on being explicit when it comes to the case of Sean Davison, who helped to end his mother’s life by placing in her hands a glass of water laced with an overdose of morphine tablets. Davison pleaded guilty to aiding in procuring another’s suicide and never denied the actions he took. Following her death, he also became a strong advocate for assisted dying legislation and established Dignity South Africa, a right-to-die advocacy group in his country of residence.

However, journalists have painted an altogether different picture of Davison. He is more often than not described as a *scientist* or *microbiologist* accompanied by his surname. This phrasing works to again give an air of authority to his stance and never is this as evident as

when he is referred to in a headline by the *New Zealand Herald* (10 Jan 2012) as a “right-to-die scientist”. By placing ‘right-to-die’ alongside it, this works to give the part of science a reliable and trustworthy, if not over-emphasised, role in accounting both for Davison’s activism but, more importantly, to what can be viewed as ‘right’. The expert view that the position of scientist holds raises Davison beyond a mere lay person reacting to a sad situation, and instead implies a deeper knowledge or understanding being applied to the actions he took. Although Davison’s *scientist* moniker was perhaps the most readily applicable title that could infer a sense of confidence and knowledge to his actions, there are also other examples across the selected articles that engender a sense of authority by virtue of the person’s profession.

The way that Davison’s ankle bracelet is seen as a burden to him as “he talks about his hopes for the new year” plays into the martyred identity that is constructed around him by the media. He is quoted in the second line of a *New Zealand Herald* (10 Jan 2012) article as saying, “it’s [the home detention anklet] a bit degrading and terribly frustrating”. This, placed prior to an explanation of why he is wearing the bracelet in the first place, attempts to detract from, or quite simply overlooks, the fact that he helped to end the life of another person. In doing so, the media alters the boundaries around Davison’s actions, the degradation inferring an injustice being brought upon him. This line of reasoning is also prominent within descriptions of Davison’s mother as his “cancer-ravaged mother”. The use of the word “ravaged”, in particular, constructs in the mind of the reader an ailing woman who was spared by her son and again justifies to the reader the actions he took. The *Oxford English Dictionary* (2017b) defines *ravaged* as an adjective describing something, “That has been devastated or laid waste; severely damaged or scarred”. The implication here is that Patricia Davison’s cancer-ridden body had been damaged beyond repair and turned to waste; that it is something beyond repair or improvement. This suggests that a cancer-ravaged body should be disposed of, and in doing so vindicates Sean Davison of any wrongdoing while underlining his heroic character.

It is through appeals to Davison’s heroism that his role as a family man also becomes a significant aspect of his created personality and further inferences of an injustice being borne are evident. Davison’s partner and two children are often referred to within the stories about him, especially as they had “been waiting for his return to Cape Town” since sentencing. His children, in particular, are drawn on as victims in the situation. Davison is quoted as saying

that, “They are the people who have been hurt most by this, because my children have had no father for seven months” (*New Zealand Herald*, 10 Jan 2012). In saying this, the reader’s mind is once again drawn away from the knowledge that he ended someone’s life to the poor children awaiting their father’s return. Speaking of his home detention it is further stated that, “Davison said it had been a terrible toll on his family back home”. Neglected from any mention, however, are the family that Davison has in New Zealand, among them those he shared with his mother. In fact, unlike another case which will be discussed in due course, the Davison family, apart from those in South Africa, are altogether absent from any discussion surrounding him in the media and nor are they drawn on to comment on his actions or character. Whether this is because they may have spoken against the martyred personality of Davison can only be speculated. However, their absence is glaring in the face of what is found in many other similar cases.

These same claims to a martyred status are applied to the personality of Lecretia Seales who, even more so than the other cases, endured wide-scale coverage throughout the progression of her disease. Seales is provided as an all-round perfect candidate for the media spectacle that surrounded her case. As a high-powered Wellington lawyer with ties to a former Prime Minister, along with her photogenic smile and articulate manner, Seales provided a compelling figure for supporters to relate to as a front for their campaign. Dying just hours following having been informed of her trial outcome, it provided the media with another opportunity to press upon the readership the morality in her actions, and how she had martyred herself for the betterment of all New Zealanders. Her widower, Matt Vickers, also became a prominent figure in the cause following her death, much like Ralph Vincent was thrown into the spotlight following his wife’s death, and he was subsequently called on as a spokesman for the assisted dying cause. Vickers was included in the handing over of the cross-party petition to Parliament and also published a book detailing Seales’ story (see Vickers, 2016).

Tied up in this also was the ever-prominent fact of Seales’ legal career. Seales is very rarely referred to without the qualifying title of ‘Wellington lawyer’, which was also more often than not preceded by the adjective of ‘terminally ill’. Much like Davison being a scientist, Seales’ role as lawyer adds weight to her attempt to seek clarification of the law. The implication is that as a lawyer from Wellington, she must know what she is doing in taking a stand against the legal system. The expertise that her profession entails once again provides a

discernible understanding that what she is doing must be right because she is in full knowledge of the law. Prior to her death, Seales was often referred to within headlines as a ‘right-to-die lawyer’. This title presumes that the subject of lawyer is in some way related to the adjective ‘right-to-die’ that accompanies it. Interestingly, Seales had never before worked in her profession with cases relating to right-to-die matters and it was not until her illness debilitated her to an extent that she became involved with the cause.

Not only this, Seales is also referred to as a ‘right-to-die campaigner’ where others are more likely to instead be given the qualifying title ‘euthanasia’. Using this language pitches Seales’ argument as having a legal basis, as opposed to euthanasia with the moral connotations and judgement that the term implies. As evidenced from a number of quotes, Seales was not looking for a change in the law but instead wanted clarity for her personal situation. Arguing a case along the same lines as had been taken in *Carter v Canada (Attorney-General)*, Seales looked for clarification over points of law. It was publicly indicated a number of times that Seales was not looking for a change in the law, with her lawyer, Andrew Butler, stating in an article in the *Taranaki Daily News* (25 Apr 2015) that, “the case was not about euthanasia generally”. Another article from the *Dominion Post* (23 May 2015) states that, “Seales, 42, says the court case is about her and her circumstances only”. Following Seales’ death, a later article from the *New Zealand Herald* (5 Jun 2015) on her life and trial declared in the headline that, “She never planned to be poster girl for right-to-die”. In light of this, however, her case was thrust into the media spotlight, providing an experience many New Zealanders could relate to owing to the ‘average Kiwi girl’ having to face this ordeal. It also worked to give rise to a number of similar stories of everyday New Zealanders experiencing these tragic situations (see for example, *The Press*, 16 Oct 2015).

Most prominently, Seales was given the title of *New Zealand Herald* New Zealander of the Year in 2015. In the article announcing the designation on 19 December 2015 there is a discrepancy in the way in which Seales is depicted compared with the personal motivation behind her actions. Seales is framed to highlight the communal reach of her trial and being described as “brave and inspiring, sharing something as personal and private as her death for the advancement of a human right”. This was further described as a “courageous effort” even though “... she was only doing what was right”. This framing of Seales as someone who set out seeking law change for the betterment of society is, as already pointed out, quite the antithesis of Seales’ trial, which was pursuing clarity in the law surrounding her personal

circumstances. In this same article are also listed other prominent New Zealand figures who Seales beat out to secure her title including, amongst other names, All Black ‘superstar’ Richie McCaw. This emphasises the celebrity-based profile that Seales achieved and it worked to elevate her status among many other high-profile New Zealanders.

While Davison and Seales’ professional affiliations place a poignant emphasis on the expertise they are constructed as having, other affiliations that are continuously drawn on work to highlight not a greater authority, but also the presence of good character within those portrayed. This is especially seen in the case of Evans Mott whose career as a “skilled craftsman” (*New Zealand Herald*, 10 Apr 2012; *Southland Times*, 24 May 2012; *Waikato Times*, 5 May 2012) and “master boat builder who has worked on super yachts around the world” is used to highlight the quality of his character, which is then used to emphasise the goodness of his reputation and to imply his innocence. More generally for the story, the particulars of Mott’s career are wholly irrelevant to the case itself, even though they are constantly drawn on.

Much like Davison, the inability to travel that would come from being convicted and serving a custodial sentence are drawn into the discussion, an injustice being formed on Mott’s behalf that he could be robbed of being “an internationally recognised boatbuilder”. The importance placed on Mott’s work and his quality of character are also stressed in one *New Zealand Herald* article from 10 April 2012 in which it states, “Mott is considered a skilled craftsman and spends long periods overseas building super yachts for billionaires including Graeme Hart’s⁴³ \$100 million *Ulysses* and the *Mirabella V*, the world’s largest single-masted vessel”. In this sense, it is Mott’s relationships with the wealthy that provide him a degree of respectability, as this idea that he is helping the well-off works to let him off the hook by way of association. The implication that can be drawn from this statement is that anyone who rubs shoulders with New Zealand billionaires and builds record breaking super yachts has no place in jail among the ‘riffraff’.

The claims made on authority and expertise by depictions of individuals alongside their professional lives becomes even more salient regarding Lesley Martin. This is not because Martin’s 12 years of experience as an intensive care nurse is repeated and constantly drawn upon as it is with Mott, Davison and Seales, but because of the notable absence of its mention when referring to Martin. Whether this is because labelling Martin in this way could have

⁴³ Graeme Hart is a high-profile New Zealand business man as well as the country’s ‘richest man’.

wider implications for the nursing community can only be presumed. Granted, it could also be entirely due to the different time periods across which these cases are reported. However, it should also be noted that the figure created by the media surrounding Martin differs wildly from that used to portray the others who are depicted. Especially owing to the similarity of circumstances between Davison and Martin, the discrepancies in their portrayals become all the more obvious.

As noted earlier, mention of the Davison family was largely centred on his wife and children at home in South Africa. By comparison, Martin's husband and sons are much less frequently referred to. Where they are drawn into the narrative one instance is a 'tell all' by Martin, in which she discusses telling her youngest son Sean (9) that she was going to prison. Articles also refer to Martin's marriage and to then divorce from Warren Fulljames (*New Zealand Herald*, 10 Sep 2005; *Sunday Star Times*, 11 Sep 2005; *Taranaki Daily News*, 11 Mar 2003), tending to account details such as a heated argument between them that occurred on a documentary. Referred to on a number of occasions is the relationship between the Martin sisters who fell out after the death of their mother. The reason given for this argument was provided by Lesley Martin who is depicted as being, "bitter over lack of help" (*The Dominion Post*, 19 Mar 2004), which included that from her sister. Where Martin's family are referred to, it therefore becomes differently portrayed to Davison's, whose family are often reported as missing their father. Martin's family, when they are rarely mentioned, are not shown to be close and tight-knit like the Davison's or another couple to be discussed, the Green's, but are instead emphasised by their separation and fissures. Instead the articles referring to the Martin case draw on prominent right-to-die groups, especially "Australian euthanasia advocate" Dr Philip Nitschke.

In one such article from the *New Zealand Herald* in 2005, it described how then Immigration Minister David Cunliffe was to receive a briefing from officials on the proposed visit to New Zealand by Nitschke and his plan to shift operations to Auckland. The article is based wholly on Nitschke, his plan and the New Zealand law that could stop him from carry it out. That is until the final paragraph which reads "He [Nitschke] was a strong supporter of New Plymouth woman Lesley Martin, who was released last December from Prison halfway through a jail term for trying to murder her ill mother." Besides the largely redundant nature of this statement in relation to the rest of the article, the positioning of Martin in relation to Nitschke, and the negative affect that the line has towards Martins character, is indicative of

the ways in which Martin is negatively represented in the media. In these portrayals, Martin is not shown to be courageous or heroic in her actions of ending her mother's life. Instead, quotes from academic Dr Kay Mitchell about Martin such as that saying the trial "highlighted the risks of a health professional caring for a terminally ill family member, such as impaired judgment and lack of objectivity" (New Zealand Herald, 2 April 2004), show Martin as being a failed nurse as opposed to a loving family member, acting on what they believed were the best intentions. The article title "Better Pain Relief Needed" also emphasises the idea that Martin required further help because of her character flaws, rather than viewing her as acting from the position of grieving daughter.

Claims made about an actor's identity throughout the articles can be found in their roles, most prominently, as advocates for the euthanasia cause. They are variously referred to by qualifying adjectives that provide an active determination in their decision-making. In cases of particular individuals, such as Martin, Davison and Vincent, they are invariably labelled by 'euthanasia' alongside terms like 'campaigner,' 'advocate', 'activist' or 'reform campaigner'. This move provides them with authoritative voices and an air of expertise when it comes to subsequent matters relating to assisted dying that the media present. By placing actors in these positions, journalists construct these individuals as being authorities on the matters they are discussing and thereby override any need to draw on expert or informed opinion in these situations.

Where these so-called campaigners are given due authority in providing advocacy for law change surrounding assisted dying, those in opposition were not accorded a comparable portion of views. In the articles that do provide a negating view they still do not always make reference to euthanasia, instead advocating for stronger palliative care services being provided around the country. So, while the spokespeople who advocate for assisted dying are given prominence, the same balance of views is not given to their opponents who, if given any mention, will be attributed a couple of gratuitous comments at the end of the article. Accounts of the Martin and Seales cases were the most frequently to be accompanied by views of those in opposition, although as mentioned in Martin's case particularly, it was largely to vocalise the need for more palliative care services around the country than it was to outwardly negate the views of those advocating for euthanasia (for example see New Zealand Herald, 1 May 2004).

The first mention of the views of the opposition in relation to Seales is when interest groups petitioned to be allowed to state their opinion in her trial. They were in fact given a headline surrounding her trial declaring that the ‘Euthanasia case risks start of slippery slope’ (The Dominion Post, 23 May 2015). However, this was only a month after the same newspaper had referred to the decision to allow the groups’ opinions in court as “their intervention” (The Dominion Post, 27 April 2015). The *Oxford English Dictionary* (2017a) describes the word *intervention* as a noun referring to the act of “stepping in” or “interfering in any affair”. This idea of an intervention suggests that time is being wasted on working to distract from the overall point and therefore diminishes the views of Care Alliance who were one of the most outspoken interest groups given the opportunity to have a say in Seales’ case. Additionally, it is in line with, and helps further, her lawyer Andrew Butler’s argument that, “Allowing other parties to weigh in on terminally ill Lecretia Seales’ euthanasia bid would cause intolerable and unfair delays to a forthcoming court hearing” (*New Zealand Herald*, 21 Apr 2015). Premising the article upon this claim means that all subsequent content is then framed for the reader on this idea. The result of this is that when groups like the Care Alliance are given space to present their views it is contextualised by this pre-framed supposition.

The identities that are constructed in the mainstream news media are based on categories which help to make the characters in the stories relatable and familiar to readers. In doing so journalists work to create relationships between readers and depicted identities. Consumers of the news thereby feel that these stories are significant for them as they could happen to them one day, but also help to encourage affiliations with the characters so that they might feel sympathetic to their cause. Subsequently, stories of martyrdom and seemingly heroic acts work into this manipulation by providing persuasion in favour of this emotional relationship. In order for an emotional bond to form, readers are encouraged to perceive the actions of those identified as being reduced of agency owing to social forces that place outside pressure and have influence over those involved. In this next section, I show how promises formed over long marriages, having no other way out, and group influence prescribe a specific framework which supports a certain way of reading.

Agency

The deaths of Edna Gluyas and Greta Appleby just a year apart led to condemnation of Parliament by the Chief Coroner Ian Smith for not moving sooner on deciding a line on assisted dying (The Dominion Post, 15 Oct 2015; Waikato Times, 15 Oct 2013). Details of the deaths were released following coroner’s reports, in each case owing to the nature of

death. Both deaths work to highlight the tragedy that euthanasia is portrayed as being, along with the heart-rending impact it has on society. On first reading of the articles mentioning Gluyas an altogether different picture was formed. However, after closer analysis of their content it quickly became apparent that the media had framed her death to again attempt to uphold her case as another clear reason toward legislation. Gluyas is described as an “elderly woman” who “chose to suffocate herself with a homemade contraption” (*Nelson Mail*, 15 Oct 2013; *Southland Times*, 15 Oct 2013; *The Dominion Post*, 16 Oct 2013), in a way that posing her death proposes the idea that she could see no other way out. The undertone of inexperience that is used in the word “contraption” devises an idea of an amateur attempt after tinkering in the garage following a momentary inspiration. The combination of the active phrasing of “chose to suffocate” herself with the description as “an elderly woman” provides the reader with two contradictory images. On the one hand, these images work to captivate the reader, but on the other, they also hold the presumption, based on a membership categorisation, that an elderly woman would never choose to suffocate herself if she did not really have to, least of all with a homemade contraption.

It is this sense of a lack of prevailing ownership over their actions that is also afforded the three husbands who aided (or in the very least did not impede) their wives’ deaths. Mott, Vincent and Green were all implicated in their wives’ ends. However, this fact is largely overlooked by the media. Instead, they are portrayed as being somewhat hapless victims in their wives’ determined decisions, who got into trouble by association, as much as anything else. Mott and Vincent are both stripped of the agency of their decision-making by having, in their wives, an outside force whom, it is proposed, they have no sway over. Thus, the wives are viewed through the conviction of their decision while the husbands face the aftermath purely through their close association to the deceased. In the case of the Greens, a suicide pact between the couple years earlier again discharges Mark Green of any agential power through the suggestion that he was powerless to go back on a promise to his wife. The stripping of agency from Green ties into the narrative that ‘love trumps all’ and provides a premise for readers to view Elizabeth Green’s death as a mercy killing rather than murder.

Emphasised in the articles about the Greens is that the couple had “celebrated their 60th wedding anniversary one day before the wife was found dead”. Connotations behind statements imply a happily married couple who were supported and loved by their family. Depictions help to mark the situation as being all the more tragic. In one particular article by the *Dominion Post* (02 Nov 2004), it starts with the line, “A terminally ill Kāpiti Coast

woman suffocated when her husband put a plastic bag over her head on their 60th wedding anniversary”. One cannot help but feel for the couple referred to in this line. Her terminal illness provides an introduction which works to inform the reader that, most importantly, Mark Green’s actions were not motivated by selfish reason. The compounding fact that she was suffering from a terminal illness on the day of her 60th wedding anniversary plays into the idea of heightened sympathy, as what should have been a happy time was instead marred by misfortune. The contradictory image that follows is seen in the description of Elizabeth Green as being, “suffocated when her husband put a plastic bag over her head” (The Dominion Post, 02 Nov 2004), followed by mention of the wedding anniversary works in the same way it did with Gluyas who “chose to suffocate herself”. These lines both carry a sort of shock that these elderly people could commit these grim acts, and thereby works to construct the idea that there was no alternative to their actions.

This can be seen to be based around social conceptualisations of old age and illness that are fostered on an assumption of frailty, and to a certain extent innocence, owing to physical vulnerability. This idea is predicated on the idea that a frail and ageing person must have been pushed to the brink to carry out these actions. Burdened by age and illness there is a moral judgement made. As Featherstone and Hepworth (in Bond, Coleman, Peace, 1993) believe, old age is negatively charged with ugliness, idleness, degeneration and moral failure. Degeneration in this sense is as it was for “cancer-ravaged” (*New Zealand Herald*, 22 Jan 2012) Patricia Davison. The identities of these women are tied into imagery of degraded entities who are otherwise hopeless, but who with idle hands build contraptions to end their own lives, following a manual and all alone in the garage. Especially where the ‘death manual’ produced by Exit International is concerned, coming into contact with one is portrayed as a dangerous action that corrupts those who do so. Victoria Vincent, it was also noted, had two books relating to voluntary euthanasia at her home. One contained several suicide options and details to carry them out. Mrs Vincent ended her life through suffocation by plastic bag so it is questionable if the books she owned had much sway over her final actions.

In accounting for an individual’s affiliations, two prominent end-of-life groups continually reappeared in the reporting, the Voluntary Euthanasia Society New Zealand (VESNZ)⁴⁴ and Exit International (more on these groups can be found in *Chapter one*). Acting as the

⁴⁴ Now called End-of-life Choice Society of New Zealand.

producer of deviant sources of behaviour, these groups are portrayed by the media as tainting the lives of those reported on, as if they have had a hand in bringing about their deaths. Rosemary Mott, for example, is described in a number of articles as having, “accessed a book which, co-author and Exit International director Dr Philip Nitschke says is, partially censored in New Zealand, about voluntary euthanasia” (Manawatu Standard, 11 Apr 2012; *Nelson Mail*, 11 Apr 2012; Taranaki Daily News, 11 Apr 2012). There are two points of note in this line that are worthy of discussion for this analysis. The first is that Mott is described as having “accessed” the book, but the extent of that access remains unclear. Mott may have taken the book out of the library, or she may have picked it up briefly one afternoon while walking past an information stand. The fact that she accessed it is never elaborated on, but a number of articles also point out that, “Mrs Mott had not been an active member in the Auckland chapter of Exit International”. Viewed in this way Mott’s actions point to a woman who, when vulnerable to influence, found something she believed would help her and acted on the base of this influence, which further research would contradict (see for example, *R v Mott* [(2012) NZHC 2366]).

The second point to be made about the quote from Nitschke is the frequency with which Exit International and the doctor himself are mentioned in relation to Mott, along with other characters represented in the articles. The case of Mott is prominent in its references to Exit International, owing to Rosemary Mott’s brief association with them, and throughout articles discussing her case are quotes and opinions from Nitschke emphasising the sadness of her isolation, alongside advocating for the group. As with Appleby, “as noted (*The Press*, 18 Sep 2012), Gluyas who “attended seminars” (*Southland Times*, 15 Oct 2013) and both the Vincent’s, “the couple had been long-time members of the Voluntary Euthanasia Society” (*Nelson Mail*, 23 Sep 2003), the Motts and the Greens were drawn into the media by the association with the VESNZ. Their relationship with euthanasia is predicated on this affiliation and helps to maintain the heroic narrative as the deceased is positioned as quite literally fighting to the death.

The presumed villainous nature of Philip Nitschke is particularly prominent in one article from the *New Zealand Herald* titled ‘Dr Death on recruiting mission’ (*New Zealand Herald*, 15 Dec 2004). The article begins by accounting how, “Australia’s ‘Dr Death’ yesterday started recruiting the first of four New Zealand voluntary euthanasia advocates who will next year learn how to make a life-ending potion”. The article then carries on to make numerous

references to “the potion” and describes that, “Dr Nitschke said he would show 30, mostly healthy, people, including four New Zealanders, how to create a ‘peaceful pill’ which would allow them to end their lives – when they were ready”. There is a strange combination in this article of the airing of Nitschke’s opinions and helping to provide publicity to his cause and actions, while also vilifying him with words like “potion”. This word holds connotations that encourage imagery of wizards and witches with steaming test tubes, and poisons they brew in castles, up high in the hills.

In the case of Ralph and Victoria Vincent, associations become particularly prominent. They had been supporters of euthanasia, but it was not until after her death that he became outspoken in favour of the cause. He is noted as going to Australia to speak to Exit International members in that country and is quoted in one article as being “utterly devoted to the voluntary euthanasia cause” (*Nelson Mail*, 14 May 2003), as well as claiming in another that his, “sole aim in life is to try and relieve suffering of people who are in pain, for whom the medical profession is unable to give ready relief, or are just incapacitated to the extent that they no longer want to live” (*Nelson Mail*, 29 May 2003). It is these statements that position Vincent as a strong campaigner and voice for the assisted dying community in New Zealand. Following his return to this country, he often appeared in the media speaking on matters relating to the debate. He was, for example, given the opportunity to provide his opinion regarding the “appalling” situation of Martin, who was “like a daughter to him”, being sent to prison, and this was voiced across a number of papers (*The Dominion Post*, 1 May 2004). It is also important to note that following Mr Vincent’s death, not Martin but Vincent’s family are called on for their opinion on the situation, and describe him as an individual, although his support for her cause is noted in an article about his death (*Nelson Mail*, 18 Apr 2005).

It is in this sense that those who feature in these storylines become intertwined in the stories of others, and their voices become interwoven with each other to construct one overall narrative, which can be drawn on as a form of representation of social discourse. Where the identities depicted in these articles are reduced of their agency by affiliations with end-of-life groups, they can often be seen as the victims of pressure from outside groups at a time when they are at their most vulnerable. This not only helps to remove the blame of guilt from those discussed, but also works to provide an emotional, often sympathetic, response from the reader. Most notable is the idea that the readership may relate to the stories, being in those

situations themselves or having ill relatives contemplating similar options. A sense of injustice is formed in turn, which is premised not only on depictions of elderly women, but also on a sense of legal wrongs being carried out by not simply allowing the relief of suffering for these women.

Injustice

Absent from these newspaper articles is reference to bioethical principles as they are typically applied to the euthanasia debate. Instead, stories that demand further sympathy from the reader are depicted that fundamentally change the nature of the debate among lay society. Instead of being informed about the complexities of the euthanasia discussion, the wider public develop their views from accounts that have been popularised by the media and reinterpreted to ensure that attention grabbing narratives enthrall the readership. Examples of this are particularly evident when it comes to the case of Evans Mott, who was widowed when his wife Rosemary took her life following her illness with multiple sclerosis. Headlines following her death referring to Evans Mott variably as an “absent man charged for aiding wife’s suicide effort”, “Accused absent for suicide”, and “Man accused of assisting wife’s suicide not present”. Sympathetic headlines followed Mott as his plight became more and more public.

As it happened, Evans Mott had in fact assisted in bringing about his wife’s death by procuring parts of the means through which she was to take her life. Further, he knew in advance when she asked him to leave the house what her subsequent intentions were. Interesting in these headlines is that they seek to form an injustice being depicted onto Evans Mott and seemingly surmise his innocence by way of his absence at the time of death. There is nothing in the *Crimes Act (New Zealand Crimes Act 1961)* to indicate that the aiding and abetting of suicide becomes legal if the person providing assistance is elsewhere at the time of death. The headlines, however, provide a different image altogether in the way that they, admittedly without the full information about the case, profile Mott as a victim who was in the wrong place at the wrong time. Like Patricia Davison, Rosemary Mott is also described as being “ravaged” by the disease that afflicts her, once again providing a form of justification for Evans Mott, which presupposes a negation of any moral wrongdoing on his part.

Also evident is a perceived righteous anger. As discussed in the previous chapter, the conceptualisation of anger has at times had a theological base, typically being viewed as a sense of injustice and the only form of anger not deemed sinful according to biblical texts.

Righteous anger is born from a strong sense of what is right and what is wrong and comes from a belief of having been mistreated or insulted. This belief is centred on a knowledge of what is seen to be morally right and justifiable, entailing with it connotations that a person has been judged. Righteous anger can be perceived in the way that victims, heroes and martyrs are made of those depicted, situating them on one side of the debate. It conjures up empathy and sorrow for the newly-framed victim and anger against those portrayed as having done them wrong.

Beginning with this image, a description of Gluyas is constructed that emphasises the particular tragedy of her situation. It is noted in articles by the *Nelson Mail* (15 Oct 2013) and *Southland Times* (15 Oct 2013) that she had, “waited for her family to leave from a visit and lay down in her bed for a final time, alone, before setting in motion the process that would kill her”. The article then follows on, with the next line starting, “Less than two hours later, her daughter returned to find her dead”. The emphasis that is made on Gluyas’ isolation in her death is something that can be found within many articles as they seek to form a sense of injustice in the current laws. This injustice stems from the perceived lack of understanding, or even compassion, which means that people must suicide away from their families and without their knowledge for fear of family members being criminally implicated by the death. This is also an argument that assisted dying advocates repeat often throughout the articles and it is often a compassionately-based argument upon which campaigners base their advocacy. It can be seen, for example, in an article surrounding the death of Rosemary Mott that contains the line, “Voluntary euthanasia supporters say Rosemary Mott should not have had to die alone” (The Dominion Post, 11 Apr 2012). Viewed in this way it promotes a sense of sympathy that surrounds the sadness of a long-married couple who never got to say goodbye. This helps to form an idea of a perceived injustice and of a sad situation made even sadder.

It was being complicit in the knowledge of their wives’ deaths that led both Mott and Vincent to be questioned by Police in relation to them, but again prominence is given to the sad truth that they could not be there with them when it took place, and the indication is one of having been stripped of the right to do something. The Vincent’s final night together becomes the focus of one article in *The Press* (29 Sep 2003), telling the story of how, “he said they had shared what he later realised would be their last meal together before Mrs Vincent told him ‘I’m going now’”. The description as a “last meal”, beyond its religious connotations, holds a symbolic value. Once again one’s sense of justice is drawn to his lack of knowledge about

that meal, highlighting the sad innocence of his naivety and the injustice of the cruel world that would take from him this one last moment.

There is a sense that reporter Lane Nichols does not hold back when it comes to further description of the couple's final night. Following dinner, "They hugged and kissed before she headed upstairs to bed. Mr Vincent went to follow her but 'she waved me back and I obeyed her'". "Mr Vincent said tears poured down his face as he watched his wife walk away". Lines like this, it would seem, are just as likely to be found within the pages of a *Woman's Day* magazine as they are the *Nelson Mail*.⁴⁵ It becomes evident how the media works to incite an emotional reaction in their readers by drawing on sympathetic tales that tell stories of love and loss. These emotion-creating tools are also seen in the constant reminders of the extended length of marriages between the couples. The Greens are contextualised by their 60th wedding anniversary while the Vincent's 56-year marriage is referred to on numerous occasions throughout the articles when introducing their case.

The nature of these emotive stories is altogether different when presented by stakeholders and interested parties as they contrive them in allegorical ways. While also furthering the claims of a particular side, these narratives that are drawn on help to soften the bioethical qualities of the debate and ensure that associations can be drawn between theory and real life. This is quite distinct from what has been shown in this analysis, with the media employing the use of narratives almost entirely, and therefore lacking the substantive and balanced opinions of the various parties involved; instead, continually calling back to those identities built by them and those recognisable and appreciable to the public eye. Although the narratives and discourses employed between reporters and stakeholders may appear to be disparate, the two different data sets are publicly available ideas that are accessible to the general public and are likely to inform their views on the debate. These two data sets are of course also not exclusive, with the information gained by individuals from the respective sources also being used to constitute and be constitutive of further discourse production. It is the publication of stakeholder views, for example in Letters to the Editor, editorial columns or on institutional websites, which provide news consumers with frames of reference to persuade or encourage them to garner certain viewpoints from the information being provided.

⁴⁵ *Woman's Day* is a weekly entertainment and celebrity gossip magazine and distributed in New Zealand.

Thematic Interviews

The results from this TA confirms the hypothesis that there are significant discrepancies between the views of stakeholders and interested parties versus the views that are being promulgated by the media to inform public opinion. Perhaps, unsurprisingly, a largely more nuanced view of a complex situation can be seen within the discourses employed by participants. Evident within the interview transcripts is a way of defining and addressing issues raised through the application of bioethical principles and by reference to many of the traditional ideas and concepts that have aided in determining an outcome for the assisted dying debate. Within these frames religious ideologies are often drawn on, alongside legal theories that highlight the wide-reaching and interdisciplinary nature of the debate. The themes identified can be viewed as categorical devices that provide a structure to the spoken dialogue and endeavour to capture how these are negotiated in the construction of arguments around assisted dying.

The TA uncovered what can be viewed as overarching themes across the five discourse-based structures. This was unforeseen, although not altogether surprising, as these overarching concepts largely reflect the background and experience from which the participants come, these being sociological, religious, legal or bioethical. These frames were not exclusive and it was not uncommon to see overlap, with discourses being used in relationship to one another. Altogether different frames had been chosen prior to analysis, these were disregarded once analysis began as the results themselves highlighted more significant themes across the interviews. As has been identified in the following results, the discourses engaged with by stakeholders and interested parties to the assisted dying debate show how they are negotiated by the participants, who themselves are informed by everyday experience, whether that be in health care or otherwise. The participants draw on these experiences to infer the moral boundaries of their work and their opinions. They show the complexities of the debate and the more substantial approaches and understandings, which help to maintain its status as a controversial practice, but do not necessarily inform the views of the public. The following analysis therefore features some of the significant findings from these discussions.

Rights-based discourses

Discourse surrounding the rights of individuals was raised by a number of participants, many of whom engaged with right-to-die rhetoric. To a lesser extent, the sanctity of life or the

inherent right-to-life was discussed in relation to theological ideologies. While the right-to-die was a topical point of conversation for participants, engagement with rights-based discourse also extended to the rights of those beyond the individual patient. In this sense, participants were likely to engage with a broad understanding within a framework of rights, which viewed the debate within the bounds of duties and obligations that are understood to be a countervailing force within arguments.

This was particularly so for one participant, who for privacy reasons has been given the name Kerry Weaver. This interview started with a discussion around the right-to-die, which Weaver did not believe existed. Like Jonathan Kleinsman and Susan Buckley, Weaver discussed a concern around what she referred to as “an increasingly individualistically focused society” that she claims has given rise to “a really rather overblown view of what our rights are” (KW 11/14). In this regard, Weaver understands rights-based rhetoric to have built up:

... momentum, without stopping and thinking rights sit alongside responsibilities. Rights are balanced by what ill effects might come as a result of exercising that right. We all live in a society with other people and so, you know, we kind of need rights and responsibilities to function (KW 11/14).

Like Kleinsman and Buckley, Weaver also viewed this increase in rights-based rhetoric as stemming from an individual desire of others to have greater control over “everything about their lives, including their deaths” (KW 11/14). Here the interweaving of themes becomes evident as Weaver’s summary also draws on dangerous discourses by highlighting the shifts that have already occurred and the negative effects that have transpired as a result. In this sense, further danger becomes a logical extension by way of the apparent cultural shifts in approaches to rights-based discourses.

Most notably in the interviews in which rights are discussed, the use of the phrase right-to-die remains somewhat ambiguous. Even those who are in favour of assisted dying legislation, it would seem, do not necessarily believe that this is necessarily invoked by a ‘right’ to die. As Rob Jonquiere, Communications Director of the World Federation of Right-to-die Societies, states about the term, “... that is just used for words. I mean, there is no real right-to-die. You talk about right-to-die, and we talk about it, and we mean [the] right to make a choice about how we die” (RJ 03/15). Here Jonquiere highlights how the right-to-die is negotiated by those

who use it to engage with an understanding of it but, more importantly, how what it aims for is contingent on the idea behind it, as opposed to the words itself. Considering the wealth of literature that is dedicated to the right-to-die, this admission by Jonquiere could be taken as somewhat counterintuitive for the campaign. However, he goes on to express that an encoded right-to-die is not necessary because unlike the right-to-life, which is used to ensure personal security, death is an unavoidable characteristic of life, which at some stage cannot be evaded and so need not be enacted into law as such. This is a significant finding in relation to how the right-to-die is understood and used by others within the debate, as it can often be seen as a right, the acknowledgement of which is fundamental to assisted dying.

In this same way, Jocelyn Downie, Professor of Law at Dalhousie University in Canada, also reconceptualises how the right-to-die is understood explaining that she thinks that individuals “have a right to non-interference in access” to assisted dying (JD 08/14). Thus, she understands an individual’s right to have been violated in cases where assisted dying or suicide is prohibited by the state. It can be seen in the following statement that Downie views the right-to-die not as the antithesis of a right-to-life, but instead as an almost fundamental part of constituting the value of life. Speaking of the right-to-life Downie states:

I think that it is a right that resides in the individual and they can exit. I mean, they are allowed to say it is something of value to me and I don’t want to continue any more. I don’t think the state has any role enforcing a competent individual to stay alive. Because the state’s value in life, the state has a value in it, it values our lives, and that is fine but I think it is trumped (JD 08/14).

In this sense, it is the individual sanctity held in the right-to-life that entails alongside it a right-to-die. Almost as an extension of autonomy, the right-to-life is conceptualised here as entreating a personal right to end that life without restriction by the state. With regards to the traditional view of suicide, this is a potentially controversial approach to both the right-to-life and to-death as, when expressed in a way, it entails really quite a broad understanding of an individual’s autonomy over their life. Distinctly, a reconceptualisation also defers from any obligation or duty that one has to maintain life for the public good. Redefined in this way, statements from Weaver and Kleinsman regarding a social emphasis on individual control are quite telling for what those on different sides of the debate hold as being of importance with regards to rights and their application in individual life. Further, however, as is about to be

shown, the role of the physician and the implications for the medical profession are also considered within the dialogue of this debate.

The medical profession

The doctor-patient relationship and how it will be, or has been, impacted by the legislation of assisted dying was raised by a number of patients. Generally, those in favour of assisted dying viewed these impacts as affecting the doctors themselves, with the doctors bearing the brunt of having to end their patients' lives. For these participants, the slippery slope was not something that was viewed as leading to explicit risk between patient and doctor. Instead, assisted dying was seen as a practice that could be beneficial for the relationship by encouraging an open discussion around end-of-life care and preferences. For some participants, the toll that providing an end to suffering took on doctors personally was identified, with Jacob Kohnstamm sharing a story about a friend of his who was a doctor who performed one or two euthanasia cases a year. Kohnstamm describes this doctor as having:

... stopped smoking twenty years ago. After euthanasia he, he cancels all his appointments, buys a packet of cigarettes, goes down to the Amstel river [which is the river in Amsterdam] and sits smoking there for two or three hours and [pause] trying to recuperate (JK 06/16).

For Kohnstamm, this highlights some of the difficulties that are faced by doctors in providing assisted deaths, and he continues on to say that:

I think most doctors would have this two-sided approach to it. They think they should be there if patients ask them to die and the other part of the doctor would say, 'I would rather have this not [pause] needed to do'. There is no doctor who thinks, 'ha!' (JK 06/16)

Notably, Kohnstamm highlights here the tension present between doctors upholding patient autonomy and their own desires for preserving human life. This view was also echoed by, for instance, the husband of Lecretia Searles, Matt Vickers, who discussed the rights of doctors to consciously object to providing medical assistance in death to terminal patients. Vickers says at one point in the interview:

There are two aspects to consent here. There is the consent of the patient and the consent of the doctor, and without the two of them this is not going to happen. So, the doctor has autonomy in this as well (MV 07/15).

Clear consideration, it would seem, has been given to the issues surrounding concern about the changing nature of medical practice. While those advocating for assisted dying were likely to view the negative impact on the medical profession to be of minor significance compared to the positive impact it would provide some patients, this was not felt as strongly by those who opposed the practice.

Palliative medicine specialist Sinead Donnelly was one of those who believed that any changes to end-of-life legislation would have a wholly detrimental impact, not only on the medical profession but society as a whole. She claimed that “the idea of the state legislating for doctors to kill people, other members of the state, citizens, is a very bad idea for society because you can’t trust doctors, you know” (SD 07/14) Along these same lines, Donnelly believes that it does not fall under the ambit of doctors to carry out assisted dying and held that the idea of having tutorials and modules teaching medical students how to practice euthanasia is an appalling idea. In the interview, Donnelly draws on common rhetoric used by those against legislation in stating:

The other thing is that it is not difficult to kill somebody. So Margaret Somerville, who has a degree in law and is a Professor of Bioethics in Montreal, [she] is opposed to euthanasia. She said she was talking at a conference and she suggested to the audience the best way from a legal point of view, from a water tight point of view, if you want to make sure all the legislation is water tight and you want to legislate for euthanasia, the best way is to allow lawyers to do it. And the response from the audience was a man stood up and said ‘but that would be killing’. So if you, the phrase is, if you remove the protective cloak of medicine from it, society mightn’t have the same view about it (SD 07/14).

This idea, while common among both lay people and doctors, that physicians should not have anything to do with terminating the life of a patient, did not resonate among all the medical practitioners who were interviewed. In the interview with Jocelyn Downie, she held the view

that assisted dying cannot be separated from health care practice. In questioning her about her views on the above option given by Donnelly, Downie said in response:

... it doesn't have to be for the final act. But doctors have to be involved, or doctors or health care providers, because you need a clear conversation about diagnosis, prognosis, treatment alternatives, capacity assessment and method. Those are all things that fall within the expertise of a medical health care provider.

Also, they are regulated, they are regulated professions so we have a capacity for oversight that is already built into the system. So, if you hand people that authority you are able to discipline them and regulate their engagement so there is an efficiency in having it be them. [Ahm,] they also will often frequently have that kind of relationship with the patient.

[Ah,] and it enables you to place it within the spectrum of end-of-life care, which is where it belongs. It is a whole spectrum and so suddenly to say the doctor will do all of this end-of-life care except this thing. It is sort of saying it is not part of the spectrum and healthcare providers, for instance in Quebec, have said clearly they view it as a form of end-of-life care (JD 08/14).

In terms of this statement by Downie, end-of-life is an integral part of health care and medical practice that trying to unravel it by allowing the provision of end-of-life medications by lawyers would be a somewhat fruitless exercise. Extending this idea in the same interview, Jennifer Llewellyn continues by referring to the role of doctors and what she almost deems as a duty to provide medical care. She comments:

I think even those of us who, who move quite strongly to say that end-of-life decision making ought to not only be the preserve of doctors that in fact they have a role to play but not the only role to play, view doctors as actually public servants in some significant way. They are the access and conduit to a resource, and an institution of healthcare that we've decided to provide as a society and that we want to be done with, you know, equipped with the

appropriate knowledge and the appropriate resources and in a way that is regulated and publicly accountable so it would be part of their job as public servants in that system (JL 08/14).

Llewellyn here reconceptualises what she views as the role of the doctor, and this is particularly evident in her reference to doctors as “public servants”. While this is not an altogether untrue statement, the way it is framed in Llewellyn’s rhetoric means that the term holds connotations of an obligation that physicians have to society which therefore leads her to conclude that assisted dying is part of their profession, whether they agree with it or not. Fears are constitutive of opposition to the legalisation of assisted dying and, as will be shown in the following sub-section, are founded on the grounds that any proposition in which the discourse is based on condoning death will always be dangerous.

Dangerous discourses

Dangerous discourses were premised largely on the fear of ‘what could happen’. The concepts and ideas that are drawn on within slippery slope rhetoric are used to highlight the possibilities of future abuse and emphasise the concerns with the current system and practices. Prominent in these discussions is the identification of underlying elder abuse and discrimination against those living with impairments. The idea that assisted dying could be dangerous for individuals is also spoken about, answering a question on what causes more harm than good to a patient at the end-of-life. In relation to this, bioethicist John Kleinsman states that:

The question really is to what extent do you recognise, or are you willing to take into account in your decision-making, the consequences what one ethicist talks about, what do you call it, the accumulated effects of hundreds and hundreds of individual cases. This idea of somehow what I do here individually has no effect on anybody else (JK 08/14).

Evident here are the ways in which interested parties articulate the wider social effects that could be impacted by assisted dying, encouraging the idea of a slippery slope that will eventually encroach on the way we die and have an everlasting impact on how individuals remember another’s end-of-life. This idea is framed in a way that pits the individual against the public good.

In the same interview, both Sue Buckley and John Kleinsman talk of the “rich time” that death can be for everyone involved. While being “incredibly hard” it is also spoken of being a “powerful thing”. Both Kleinsman and Buckley highlight the inherently natural process occurring, and the notion of counteracting this by controlling the process of death, with Buckley remarking that:

I don't know what it means or what it is about really, I haven't figured it out but there is something about interfering with natural processes I think, which intuitively is, you know, it is not going to end up in a good place somehow, you know (SB 08/14).

In this sense, the risk of danger from assisted dying is applied not only to the human population, but also to the social structures and rituals that societies have created over time. The danger therefore befalls not only the vulnerable open to abuse, but humankind as a whole.

Drawn into this discussion is also the fear that the moment chosen might be a moment too soon. In one example Kleinsman provides an anecdote about a man, with whom he had several phone conversations, who had been diagnosed with terminal cancer. This individual had struggled with pain control as well as his prognosis and stated on numerous occasions that had an assisted death been legal he could not have been talked out of taking it. Without that option he subsequently lived at least another two years, which allowed him to dance at his son's wedding and travel to Holland to meet his first grandchild. All of which, Kleinsman concludes, the man would have missed out on had it been legal.

Discussions about what people might miss out on should they opt for assisted dying (or suicide while they can) were raised by a number of participants. For instance, Jeanette Wiggins, an advisor for the Wellington region Huntington's Disease Association, raised the issue regarding outsiders' perspective of disability and how goals often shifted when one is faced with the end-of-life, which make advance directives or welfare guardianship difficult in practice. She begins by highlighting that others do not know what is happening in someone else's mind, which renders it difficult to make treatment decisions for others. She carries on to say:

Because you know, when people have got degenerative diseases their world becomes smaller but we can't judge what is

significant or valuable to them. And people look at the people at Amaryllis House and think, 'what a terrible life for them', but they [the residents] don't think that, you know. And if the big thing in their day is, um, drinking a berry smoothie and that makes them happy (JW 07/14).

Wiggins draws here on common rhetoric amongst the lay public which tends to view people with degenerative diseases or disability to be hapless victims who have lost everything in life. However, she describes how the will to live is stronger than many people think, stating:

... But years before, if they had said 'when I can only drink berry smoothies I want to be euthanased'. But people's thinking changes and that happens all the time, I mean if you talk to the general public they say 'I never want to have cancer or anything like this, I would rather be put down and be out of my misery.' But the will to live is so strong. When people get to that point, the goal posts change (JW 07/14).

This is why Wiggins posits a danger in allowing assisted dying, especially when decisions are premised on previously expressed opinions and before the degeneration of disease. A notable feature of the interviews with those who were at the 'frontline' of health care provision and services was the anecdotes that were provided and how these were engaged with as devices to show what medical practice is really like when applied to real-life situations and to complex individuals. Drawing on an anecdote to describe the life of one resident at Amaryllis House, she describes:

There is one boy out there, whose mother spends a lot of time with him, obviously, I mean he is 40 or something but he is very end-stage and they have already decided he won't be peg fed and he won't have life extending treatment of any sort and he has been hospitalised, hmm, three times probably in the last nine months with aspiration pneumonia and he has survived every time. He can't walk, he can't speak, he has to be fed, and he has to have totally thickened food. I mean if you looked at, saw that written down, you would think actually what is the point?

But then, on Friday, which is happy hour at Amaryllis House, the first Friday of every month, they have this busker called Wooggy who comes in and sings and plays the guitar for two hours and we have party food and wine and beer ... He gets so excited about it he actually needs a mild sedative because that is such a big deal.

So ya know, if 10 years ago you'd said to him 'do you want to still be alive when all you can do is get excited about Wooggy coming?' People would probably say, 'no what else is in my life?' But, that changes, there is totally a will to live and that changes (JW 07/14).

In a role dealing with those who had been diagnosed with Huntington's disease, Wiggins particularly used these anecdotes to emphasise the importance of understanding the will to live, especially when determining end-of-life choices. She provided the previous, quite touching, vignette as a way of highlighting the danger of not being able to communicate these decisions. It is these stories, however, which are often lacking from bioethical discourses that remove the individual patient from how they get negotiated in everyday practice. This next sub-section looks at some of the approaches that have, or can, be taken to extend and interpret notions of autonomy.

Autonomy

A significant point of discussion for all of the participants centred on the concept of autonomy, and what it meant for them in the practice of health care. As someone whose daily tasks revolve around the provision of medicine, Kerry Weaver reconceptualised the term to highlight the complexities of its definition compared with the more simplistic way in which it is often applied in practice, describing that:

... working in the health system, we talk a lot about autonomy without a great deal of [pause] sort of without the more complex understanding of what it means. We have quite a, well a lot of, people in the health service have quite a simplistic idea of what it means and autonomy can be seen as just a respect for people's

views rather than an absolute black and white that must be followed (KW 11/14).

Weaver goes on to discuss social networks that people are embedded within, stating that, “we are all dependent to a certain extent on other people that none of us is completely independent and completely in control of our lives” (KW 11/14). It is this through this idea of interdependence that Weaver holds can and does provide limits on self-determination in everyday life. As she provides, having building codes that regulate building standards, obeying road rules, or only driving cars when in possession of a driver’s licence are ways in which the state places limits on citizens’ complete self-determination. Also, as she states, “We already have limited autonomy in other fields and I don’t see why there is a problem with it in healthcare and end-of-life” (KW 11/14). In this way, Weaver negotiates the concept of autonomy and engages with it in her own medical practice by understanding how the concept is used in broader aspects of individual and social life. She thereby questions its eminence as a concept within the medical field.

In a similar vein, van de Vathorst discusses the intricacies of decision-making and allowing a patient full autonomy over their health care decisions. Highlighting the rejection of palliative care, in a wider discussion of patients not always making what the doctor believes to be the ‘best decision’, she comments:

So, I think there are also some doctors who say, well you know, it is that just you have to deal with patients wanting antibiotics, even if you don’t think it is helpful. There are people who want to go to the medical specialist when you think it is not useful and there are also people who are pushing for euthanasia when it is not [pause] so you know, why that is not a special issue. People in general get more demanding towards their doctors so you have to learn to cope with it (SvdV 06/16).

Here it is evident that paternalistic tendencies envelop a wide range of situations in medical practice and van de Vathorst raises the significant issue of doctors feeling pressure to allow their patients assisted dying, drawing once again on the potential risk involved. Van de Vathorst highlights here, however, that the risk of widening the scope of medical decision-making is inherent in all aspects of medical practice and is therefore not isolated to assisted

death. She therefore highlights what is more of a systemic issue within health care provision at all stages of life and so something to be remedied beyond the scope of end-of-life care.

Contrary to many of the concerns expressed in the *Dangerous discourses* sub-section above, Maryan Street, who was at the time a Labour MP, believes that advance directives should be viewed as instrument for increasing the self-determination of patients. Her *End-of-life Choice Bill* was drawn from the ballot, and in the following sentences she describes why she chose to allow New Zealand patients with terminal prognoses to medically end their lives when they are given 12 months to live. This is unlike other places, such as jurisdictions in the United States, where they rule that patients must have a six-month prognosis. Street discusses here why it is she chose this extended timeframe:

... all my bill does is give them permission to seek assistance to die at a time and in a manner of their choosing so it doesn't. Half of my bill is taken up with advanced directives and so when someone has got, is given a terminal diagnosis [my], and it may not be that they will die in 12 months because people live with terminal conditions for a long time given our medical improvements, but what they should start thinking about is their advanced directive.

So, when they get to the point where they recognise the deterioration in themselves, and their consulting specialist says, 'I reckon another year might be all you've got', then they have thought about what they consider to be a point of, at the point where their life ceases to have the dignity and the autonomy around it that they wish to have.

So, underneath everything else my bill is predicated on the ability of autonomous, self-determining adults to be autonomous and self-determining at their end if possible, which is why the advanced directive part is so comprehensively covered in the Bill and why if somebody were to cease to be of sound mind the advanced directive remains in place and does not expire (MS 07/14).

This is the point that concerns many people about the legislation of assisted dying, as it presents an ultimate challenge about what to do with those who are unable to make competent medical decisions. However, as can be seen in the above statement, the complexity of the imprecise nature of bioethical principles is articulated in the formulation of quite the opposite argument. Street's emphasis on allowing autonomous and self-determining adults to be just that highlights a subjective and altogether moral undertaking that occurs when weighing up one's life and its quality. As portrayed by Wiggins earlier, it is the changing goal posts?? that occur throughout a person's life that make the use of advance directives, for life-changing concerns like assisted dying, a potentially dangerous tool to undermine one's autonomy in later life. Conflicting approaches seek to highlight the difficulties present within the current discourses and how the frames that structure them have been unable to provide reason enough for compromise on either side.

Discussion

Discourse informing the assisted dying debate is constructed in a variety of ways that become embedded in and constitutive of the rhetoric used by the public. As discussed in the previous chapter, the analysis of stakeholder interviews provides a snapshot of opinion that is not limited by a time delay and therefore represents the dynamic nature of discourses and rhetoric which are used by the public. These constructions, which inform the public debate, are premised on the frames that are provided by the media, the use of which are underlined by a subtle persuasion. This ensures the reiteration of select narratives, which help to reinforce the relationship between this dominant discourse and the dissenting voice of the minority. Evident in the analysis, of both the interviews and newspaper articles, is the repeated use of anecdotes and stories that work to humanise the debate and provide relatable information for the reader or listener. Both reporters and stakeholders engage in personal narratives that show identities portrayed as being lacking in agency and as experiencing enduring injustices. Stakeholders, however, do not exploit this position or these characters but instead use them to inform the literature on the topic. As informed voices, the stakeholders and interested parties present an altogether more complex understanding of the assisted dying debate than the media does.

The media presents a different story entirely that is naturally influenced by a drive for sales, or what has more recently been dubbed by mainstream media as "clicks". As David Altheide (1997, p. 647) discusses, the mass media is part of what he refers to as a "problem-generating

machine”, which is geared towards entertainment and voyeurism. Stories such as the ones analysed in this research highlight how such a mix of entertainment and voyeurism works to encourage an approach to risk that is premised on the sad fact that it could happen to anyone. Emphasised through continual reference to loving couples and supportive families who missed out on the final moments, these fear-inducing stories enable a “quick fix” (Altheide, 1997, p. 647) approach to both entertainment and voyeurism, but are devoid of understanding the complexities tightly wound up in the issues. The media industry has seen phenomenal growth that parallels the rise in information technologies, which have become a key tool for the dissemination of news and entertainment. The growth of this industry has enabled media organisations to sell news as a commodity, which has fundamentally shifted the way reports are produced and consumed.

It is these approaches that, in the 1980s, led to the emergence of the buzzword “infotainment” (Altheide, 2004), a phrase that encapsulates the idea of genre-mixing information and entertainment in news and current affairs. While a lot of infotainment is specifically focused on TV news media in relation to the portrayal of assisted dying, it can also be taken as having spread to print journalism, particularly with the rapid and pervasive rise of social media. The problem frame, Altheide argues, has been an important development that provides for an entertainment dimension within the news. As he claims (1997, p. 653), problem frames are a practical solution to the question of “how can we make real problems seem interesting?”. To this end, the media creates scenarios which spark a sense of relatability between character and readers. As Altheide (1997, p. 654) describes, “For entertainment and audience identification purposes, the closer the reader/listener/viewer is to the actual event, the more salient the report”. In this way reporters construct news stories that contain narratives focused on actual people and events to ensure that the report comes across as realistic.

Whether or not the readership has had an experience with the related problem, the problem frames reinforce particular experiences and perceptions that stem from a narrative, which from the outset concludes that there is something wrong. It takes the aspects of a complex situation that are generally familiar and uncontested, to then use them to illustrate the underlying, often moral, truth (Altheide, 1997). By integrating elements of an entertainment format, reporters are thus able to attain audience attention while simultaneously ensuring they are informed enough, but not educated. In this way, Shanto Iyengar and Donald Kinder (2010) argue that in the case of TV, an effect is used called “priming”, where by providing

accessible chunks of information viewers can draw upon these segments for help in interpreting other events.

The missing information that is not provided, and the statements that are left unsaid, encourage readers to fill in the blanks. The blanks themselves are then filled in with incomplete knowledge that construct victims as being everywhere and abuse and social exploitation as being rife within society (Altheide, 1997). This exacerbates the sympathetic tilt to the real-life stories as a deeper sadness as these couples and families managed to escape the terror of dysfunction only to be struck by death. The emphasis and gossip-like quality that surrounds Lesley Martin and her marriage is significant in relation to this point, with her divorce helping to emphasise the deviant quality of her character. The lack of mention of Martin's family, especially her sons, alongside this continued reference to the rift between her and her sister works to ensure her identity is bound up with killing her mother and not the sorrowful tale like that which is imposed onto Sean Davison.

The most recent high-profile cases regarding assisted death that have been in the media, Lecretia Seales in New Zealand and Brittany Maynard in Oregon, provided audiences with these images of two attractive women who do not necessarily reflect what it can look like in a person's final six, or even two months, of life. They were somehow perfect for media and created this quite gripping, almost soap opera type, scenario which gripped the media in both America and New Zealand. The apparent simplicity of their lives, however, overlooks the realities being lived by many with terminal illnesses. Here were two reasonably young women who did not have any children, appeared to be relatively wealthy,⁴⁶ and had supportive and loving husbands. This however, is not necessarily going to be the situation for quite a considerable number of people who may be limited or bound in choice by family, finances or other circumstances. The production of discourses surrounding Seales and Maynard does not fully address the structural relationships between the aged and disability sectors, and those in more powerful positions who advocate for the legislation of assisted dying. The relationship between vulnerable individuals, groups and the key actors in this debate is one of dominance, power and control which can overlook, or more accurately override, the view from those more vulnerable in society.

This is why stakeholder and interested party voices are important in the further construction of discourse. However, if the articles analysed are any reflection, their dialogue is largely

⁴⁶ Lecretia Seales and her husband Matt Vickers both held well-respected professional roles in New Zealand.

absent from the discourses being analysed. The commitment to bioethical principles and sociological concepts regarding assisted dying is apparent in the previous analysis. While the participants each negotiated and engaged with rhetoric in a different manner, the morality of conversations reflected much of the literature devoted to the topic. In this way discussions diverged from media reporting by way of their attachment to the complexities of end-of-life and assisted dying and therefore included more in-depth portrayals of the debates. This is not to overlook or conflate the media reporters and the participant's roles in society, but to highlight the divergence of promoted and fully informed opinion, and seek to promote it *alongside* the respectful accounts of those willing to be identified as 'euthanasia campaigners' or the 'face of the euthanasia debate'. This would work to encourage a more fully-formed understanding of the intricacies and ramifications involved in assisted dying.

Concluding Remarks

The themes and frames discussed in this chapter work together to construct a comprehensive view of the landscape of discourse surrounding assisted dying, which is accessible within the public realm. The distinctions between the discourses that are created depend on who they are being produced for. This enabled the proliferation of disagreeing voices, but these are largely marginalised to the views of those who are informed about the present debates. It does not also reach to the public. Instead, social actors who consume the media, nowadays quite voraciously, ensure the continued production of narratives that confirm their own beliefs, maintaining dominant voices and enabling further marginalisation of those who the current laws seek to protect.

The following chapter moves away from qualitative analysis to look at the literature behind the assisted dying debate. It shows how the views represented in the current chapter are conceptualised sociologically and have established the foundation for contemporary practices that surround death and dying. Inherent within these discussions remains the social nature of death with its role as a communal event at the forefront of ritualised behaviour. Even if one believes, as some of the participants did, that we are moving into individualised societies, the sociality of the process remained important. Technological development has seen medical practice grow to an unprecedented level that brings with it many largely unintended consequences. Irremovable from this are individual patients who must endure circumstances far beyond expectation or hope. However, alongside many of these individuals are the *whānau* who provide a range of support and informal care throughout the course of an illness.

As has been shown in this chapter, individuals and the relationships they form are an innate part of how we conceive of experiences and everyday life, and of discourses that are constructed to validate opinions and provide moral judgements. The prevalence of different approaches to dialogue, yet the stalemate between the two sides of the debate, shows the need for broader perspectives. These perspectives must properly articulate the experiences of those with terminal illness without distorting or over-emphasising the identities that they represent.

Chapter eight: The Right-to-Die and the Communal Body

Introduction

In this chapter I identify what I perceive to be the shortcomings of the assisted dying literature, practice and debate. In so doing, I suggest the inclusion of further discourses that explicitly engage with theories of the body. When employed alongside bioethical notions of assisted dying, these discourses provide a more far-reaching account of the lived experience of individuals at the end-of-life. Recognising the effects of a social death on an individual, this research shows that while strong social policy changes are needed surrounding care for the elderly and those at the end-of-life, so too are strong social and cultural changes needed that seek to re-present the identities of the aged. These elder subjective identities that may contradict the external identity, perceived by those they interact with, need not trump or counteract the lives of those whose physical bodies afford them only pain and suffering. Perceptions of the aged must change, especially as the Baby Boomers reach retirement age. Along with this there is urgent need for changes to be made to elder and end-of-life care, both institutionally and for those out in the community. These matters stand regardless of what occurs surrounding the legislation of assisted dying. They should not, however, preclude the possibility of those with terminal illness accessing such legislation because of what is largely a political and economic issue for the state. The following research questions, which reiterate the four earlier identified in *Chapter one*, are to be specifically addressed within the work that follows:

- What role can a patient's social death be seen to have in relation to suffering?
- What part can the 'dying role' play in how we approach current understandings of the end-of-life in relation to assisted dying?
- How can relational approaches to autonomy benefit current assisted dying and bioethics literature?
- How does the communal body affect, and how is it affected by, current claims around a right-to-die?

This chapter concludes that sociology can aid bioethics more comprehensively by endeavouring to untangle the networks and context of the socially embedded individual-turned-patient and provide an insight into the lives of those facing the end of a terminal

illness. In doing this it seeks to answer the fourth research question set out in *Chapter one*, “How does the communal body affect, and how is it affected by, current claims of a right-to-die?” The need for discussion surrounding end-of-life care and dying is well recognised. The promotion of such discourses have been seen to benefit both the patient and those around them throughout the dying trajectory. However, the practical application of such discussions still falters between doctors, patients and their families, potentially largely because of the discord between doctor versus patient information. What is required are concrete methods of engagement that ensure the provision of informative dialogue between these parties. The production of appropriate discourses of the body can help to encourage the conversation surrounding assisted dying and end-of-life care to incorporate the expression of lived experiences by patients facing the end-of-life.

This chapter is positioned by two approaches to the body. The first views it as the corporeal physicality that constitutes a person. This is the body that people can ‘do to’ and that can be modified through material application. The other body is that of the community. This is constituted by the physical bodies as they are situated within the geographical contexts of their own environment. The social bonds that are created through interaction by these bodies tie them into a community of their own to provide the structural conditions through which subjective moralities can be expressed among and between others. Reconceptualising the way arguments within the debate are approached can illuminate potential new avenues for discussion and provide for the range of experiences and subjective feelings that are felt by individual patients and those around them.

Sociology in Bioethics

In light of the traditional approaches towards the bioethics literature within recent years, a number of authors have turned towards emphasising the role that sociology can have in aiding bioethics in practice. However significant the contribution to the wider assisted dying debate that this literature has made, it is easy to see that such arguments have done little to find a balance between those strongly opposed to and strongly for assisted dying. If anything, this is evident in the ongoing discussion that takes place around assisted dying legislation in New Zealand. The polarising nature of the topic itself certainly raises questions as to whether there is a way to reconcile these two different sides. It would, however, appear there are new

ways to try and solve the dilemmas and currently irreconcilable differences that the debate entails.

Much of the current literature has approached assisted dying and bioethics from the point of view of lawyers, theologians and medical practitioners, without looking at the wider social effects that the practice could subsequently have on communities. Although the relationship between sociology and bioethics is still relatively new, there remains space for expansion (De Vries, Turner, Orfali & Bosk, 2006), as many of the sociological analyses of assisted dying currently look at the social conditions in which assisted dying has emerged, as opposed to sociological critiques of the practice or the place of sociology within current debates. Sociology finds in bioethics a lack of what actually *is* amongst an abundance of what *ought to be*. That is to say, sociologists have critiqued bioethics owing to the normative quality of its conclusions along with the application of principles. These are often viewed to have been thought up in the ivory tower of academia and away from the clinical situations with which bioethics concerns itself. In 2003, Raymond De Vries wrote an article depicting the traditionally tenuous relationship between sociology and bioethics. While identifying the progress in this relationship, De Vries also advocated for a widening of the sociological field, moving beyond what has become the dominant sociology *of* bioethics approach to the pursuit of knowledge of a sociology *in* bioethics.

In the article titled ‘How can we help? From “sociology in” to “sociology of” bioethics’, De Vries discusses the “cultural myopia” of bioethics, as it was described by Fox and Swazey (1984, p. 337). De Vries (2003, p. 279) draws on Fox and Swazey (1984), saying that bioethics “generally manifests itself in the form of systematic inattention to the social and cultural sources and implications of its own thought”. While de Vries highlights the interdisciplinary nature of bioethics that has drawn on work from a range of academic fields including law, medicine, philosophy and theology, he argues that this interdisciplinary reach has typically excluded sociology from the fold, subsequently leading to the aforementioned cultural myopia. It was in 1984 that Fox and Swazey first referred to such a phenomenon, and another 20 years following that De Vries wrote of the continually fractious, although improving, relationship between sociology and bioethics.

De Vries emphasises the distinction between a sociology *in* and a sociology *of* bioethics in his 2003 article, viewing it along a continuum that distinguishes between descriptive ethics at one end (sociology *in* bioethics) to the examination of the context of bioethics at the other

(sociology *of* bioethics). Significantly with such a continuum, a sociologist can be located at any place along the spectrum. It becomes problematic, however, when they attempt to position themselves at multiple junctures along the spectrum. The problem here specifically arises from sociologists in bioethics aiding bioethics in their endeavours, while sociologists of bioethics operate from independent positions and attempt to maintain a neutral stance on and remain external to the bioethical project.

It has been a decade or more since De Vries' original article, and over this time a number of authors (see for example Borry, Schotsmans, Dierickx, 2005; De Vries et al., 2006; Hedgecoe, 2004; López, 2004; Shaw, 2015a; Solomon, 2005) have discussed the ongoing attempts at bridging the relationship. The reason for this strained relationship can be found embedded in critiques of the normative outcome of principle-based ethics, which have been outlined in *Chapter seven* and on which other disciplines have tended to focus their bioethical reasoning.

Typically, sociology has isolated itself from institutionalised forms of bioethics and, if it has engaged, it has confined itself to critiquing bioethical approaches from the perspective of a sociology *of* bioethics. This approach to study of the field has meant it has been largely concerned with the context within which bioethics has emerged since around the 1970s, and to understand how it is situated within the social world. In this way, it sought to answer sociological questions by looking at the roles, values, organisations and rituals that are embedded within what is now the field of bioethics. Sociologists of bioethics do not therefore aim to aid bioethics research to resolve ethical dilemmas, instead remaining as outsiders viewing bioethics and its institutionalisation as “the object of analysis” (Shaw, 2015a).

The expansion of research that encourages discourse surrounding a sociology *in* bioethics, has been welcomed by many sociologists. As described by Shaw (2015a, p. 100), this approach allows for a “collaborative enterprise” between sociology and bioethics that concerns itself with people’s attitudes, views and experiences, along with the impact of programmes and policies on individual’s conduct and experiences. Within end-of-life care, and especially as it relates to assisted dying, the strengthening of this relationship can be particularly illuminating. In 2005 Mildred Solomon wrote of the “Ten ways “is” can help “ought””, in which she claims that bioethical analysis generally assumed an “implausible degree of rationality in human motivation and action”. This meant that, “Getting from an ideal vision of the good to an embodiment of those ideals in practice depends as much on

structural factors like power, money and socialization as on espoused values and ideals” (Solomon, 2005, p. 40).

Solomon suggests that by applying social science to work *in* bioethics it could help to uncover individuals’ opinions, structural forces at play within organisations, and the impact, effectiveness or efficiency of new practices and policies aimed at aiding health care practice. By enabling a deeper understanding of meanings and action that people ascribe to their own situations, sociology in bioethics can, for example, help untangle and make sense of the networks and context of the socially embedded individual-turned-patient or individual-turned-doctor. It is this approach that can be beneficial to move forward our understanding of assisted dying, and in the terms of addressing the concerns and desires of opposing parties.

In a 2015 journal article, Shaw developed a contribution to knowledge in sociology regarding the bioethical dilemmas surrounding organ exchange through qualitative sociological studies. The aim of the article was to expand the “conceptual toolkit” that could be used in the development of ethical guidelines and health policy discourse. This conceptual toolkit was perhaps, more importantly, available immediately to health care professionals and those involved in the organ exchange process and could be used to inform more open dialogue between different parties. This article highlights what can be gained from an, at least, amicable relationship between sociology and bioethics. One research finding noted by Shaw (2015b) indicated that those in the studies she interviewed did not think about organ donation in indisputable moral terms.

This draws upon the overwhelming disjuncture between principle and normative-based bioethics as it has been historically characterised, and the everyday lived experiences and understandings of those interacting with the health care system. Furthermore, such findings can also be useful for illuminating discussion around assisted dying as it relates to the current deficiencies in discourse and rhetoric being employed in the debate. In order to enhance an interdisciplinary understanding of the assisted dying debate, I suggest that a similar toolkit is required to negotiate and engage with the subjective realities of those seeking an assisted death. Further empirical work, such as that done by Shaw (2014); (2015b), is thus needed in this area to provide data that could contribute towards such a proposed toolkit.

It is important to note that the historically uneasy relationship sociology has had with bioethics does not result in it being banished from the fold now that tensions have eased.

Sociology has instead worked with the principles of bioethics by using them as an adaptive framework to underpin not only the qualitative research that goes on (through a commitment to informed consent and research ethics), but also to bring objective analytics into empirical knowledge. By reconceptualising some of the assumptions and negotiations upon which the assisted dying debate is premised it can be advantageous for illuminating further avenues of discussion. It is from here that sociology and bioethics have the opportunity to work together to renegotiate the terms of reference employed within the debate on assisted dying. The following section looks at how the body has been understood and engaged with in its material and discursive formations, and such literature can help to advance an understanding of the body at the end-of-life and its relation to assisted dying.

The Material and Discursive Body

Anthony Giddens (1991), among others (see for example Berger & Luckmann, 1991; Goffman, 2002), has written about the body in sociology and how it is self-reflexively developed in relation to the identity(s) of those engaged within the everyday experiences of social interaction. Giddens' account of self-identity in the late 20th and early 21st centuries has been influential, both within sociology itself and in terms of influencing government policy and analysis of social life. Giddens (1991, p. 53) takes self-identity to be the "self as reflexively understood by the person in terms of his or her biography". This identity he considers to consist of not only the reflexive awareness of the actor but also a recognition of such an awareness in others. Giddens contends that the modern individual engages in a "reflexive project of the self", consisting of constantly revising biographical narratives, which although flexible, maintain the coherent identity of an individual. The possibility within modern social life to engross oneself within lifestyle choices is identified by Giddens (1991, p. 5) as being "increasingly important in the constitution of self-identity and daily activity". With such an expectation placed on the reproduction of "normal" bodies comes an individual responsibility of discrete actors to portray bodies that are deemed acceptable by society and to configure those bodies for inclusion within social life.

In a 2001 study conducted by Annette Street and David Kissane they argued that the body has been neglected in debates about assisted dying. Their qualitative discourse analysis looked at the period in Australia when assisted dying was legal in the Northern Territory between July 1996 and March 1997 (for more details on this see *Chapter two*). It focused specifically on

the texts from interviews, letters written by those seeking assisted dying, medical and coronial reports, and media reporting relating to five of the seven individuals who requested assisted deaths over this time. Through their textual analysis Street and Kissane hold that within medical discourses, while there has been an awareness by health care professionals of the effects that the dying body has on individuals, this has largely remained an unspoken about consideration. Many of the realities that face people at the end-of-life, therefore, remain undiscussed when it comes to the effects on decision-making. They offer in place of this neglect a construction of discourses of the body that show it as symptomatic, dependent, shameful and temporal, and which helped to shape the decisions of those who accessed the Australian legislation. They conclude their discussion by suggesting further research surrounding the discourses of the body, for those individuals requesting assisted dying and, to help them with what they describe as their “unspoken and unspeakable bodily needs” (Street & Kissane, 2001, p. 169).

The discourses analysed in earlier chapters of this thesis, along with the findings, highlight a similarly unspoken about consideration reflected in media reporting on euthanasia. The processes of legitimation that are evident in the moral communication of public discourses, largely dictated by the media, helps to rationalise certain actors and actions and morally evaluate them through specific rhetorical nuance. One newspaper article from 2003, opened with the line “In one year, 39 GPs have performed euthanasia or helped a patient commit suicide, a researcher has found” (*Herald*, 2003). As was shown in *chapter one* of this thesis, the term ‘euthanasia’, especially when used without any qualifying adjective, can be prohibitively ambiguous. As it transpires, a few paragraphs down in the article, the GPs had not actively intended to euthanise their patients, but were in fact complicit in withholding or withdrawing treatment, or increasing pain medication. This is emphasised throughout the article as being an “ethical grey area”, because, as is conceded by the researcher only towards the end of the piece, doctors may in fact “have been intending to reduce patients’ suffering”. Such concessions show the difficulties in media reporting research that overlooks the intricacies of the rhetoric relating to assisted dying.

The self that engages with self-reflexive body, according to Giddens, becomes open to a world of betterment and progress. However, as evidenced through Street and Kissane’s study, this is not the case for everyone. The experiences felt by these bodies highlight the significance for inclusive discourses in anticipation of difference. Many of these differences were traditionally overlooked within sociological and bioethical literature. The body within

mainstream sociological discourse has largely remained a foregone conclusion. Along with the assumption of stability and complete control over one's body, many sociologists have neglected to account for those whose bodies do not fit this framework. As Giddens (1991, p. 59) believes, "How far normal appearances can be carried on in ways consistent with the individual's biographical narrative is of vital importance for feelings of ontological security". Absent from this is what happens when the body appears "abnormal" or when it is no longer consistent with the biographical narrative that the individual seeks to live.

Following the mediation of experience through social and cultural imagery, one can forever more seek to attain the slim and sleek body full of youthful vigour and health that, within the conditions of modernity, has become a symbol for success. The presentation of self that is negotiated within the performative act expressed through appearance, action and gesture within social interaction is defined in terms of access to self-actualisation and self-realisation. These ideological frameworks towards materialism and consumerism aid in the maintenance and have outward effects for decision-making around assisted dying, through external pressure that is placed on the individual to attain betterment and maintenance of their body. When bodies begin to fail, they encounter stigma from others or, as will be shown shortly in relation to social death, those who inhabit them can become excluded almost entirely from the communities within which they have resided.

Giddens holds that it is largely people who inhabit bodies that through illness and deterioration have been cast into a role of outsider and have been marginalised at the edges of society. These individuals have therefore remained ill-considered within an understanding of the body in the sociological literature. While mainstream sociologists have been able to identify their marginalisation, they do not necessarily seek to provide discourses for how their subjective experiences can be understood and negotiated within a community of bodies. As Giddens (1991, p. 6) states, "Modernity, one should not forget, produces *difference, exclusion and marginalisation*". While it may produce such effects, however, it is the absence of these notions around the sociology of the body that emerges as a significant absence also within assisted dying literature. Giddens recognises that lifestyle choices may be constrained by conditions of material poverty which can be viewed as a rejection of normalised social and cultural habits. These, however, still work to create a view of the body as a passive form which one can symbolically embellish and which helps an individual to perform their identity in the community and society.

The body is often notably absent in discussions of the self within sociology. These accounts instead consider the development of an individual's identity to stem from the consumption of material goods and lifestyle branding (for an insightful discussion see Turner, 2008). According to Turner (Turner, 2008), this exclusion reflects a theoretical focus that sociology has traditionally adopted and which saw it emerge as a discipline interested in the social meaning of interaction as its primary motivation for research. This strand of sociological thought developed on the basis of believing that, "the natural world is socially constituted and transformed by human activity. Human beings do not simply apprehend the natural world as a given, since nature is always mediated by culture" (Turner, 2008, p. 34). Emphasised within this is the idea that the boundary of a body provides an external division between one's self and others. Its outline thereby sets a limit on complete expression as the performative acts of communicative action are confined by its physical nature.

The body, constituted by its social and cultural history, has therefore remained an absent-presence within sociological discourse, as a rather taken-for-granted given of individual life. Additionally, the body, understood from this particular sociological perspective, often fails to account for differences in its corporeal body. It cannot be overlooked that the body in sociology has been the site for social and cultural inscriptions that are *done to* the body, but in this same way it has neglected to account for the 'natural' side of difference that happens to the body as it goes through illness and death. In much the same way as bioethics has premised its notion of the individual as being a rationally active agent, not constrained or influenced by the social worlds within which it is engaged, so too has sociology seen the body as a physically-able entity able to provide its labour in return for capital as other active bodies do.

In reality, just as the individual is a social being constituted by their everyday experiences and interaction, they are also contained by bodies that are "uncertain and flexible" (Turner, 2008, p. 173). Turner states that, "To be born and to be embodied do not in themselves guarantee social membership". Dying, in as much as it is a social process, does to an individual what few other processes can do by taking away identities, personalities and behaviours, a combination peculiar only to them and leaving instead a physical body inscribed by the marks of disease. As Turner (2008, p. 176) discusses, the concepts of "illness", "disease" and "health" can be used to highlight how the "language of disease" involves an evaluative judgement based on perceptions of desirability and undesirability. Through the burden of disease, the body, and therefore the person, become isolated from

active membership in the community as the everyday experiences that secure such membership are no longer possible because of the now spontaneous nature of the corporeal body and its functioning.

It is more recent literature focused on the body within sociology that can be useful in moving away from Giddens' account and that of other mainstream sociologists. These authors have sought to extend the understanding of embodied practice to identify the ways that the body has become constructed within the discursive practices that shape everyday life and interaction. Others, especially those considered to be feminist scholars, have also pursued the body and its significance within the subjective experience of individuals in its relation to the mind. This has, however, been done in attempts to move beyond traditional Cartesian dualism that has been widespread throughout a great deal of literature, within sociology and across a number of other disciplines such as philosophy and medicine. As discussed by Moss and Dyck (1999), in trying to overcome the dualism of the discursive and material body, Elizabeth Grosz (1994) offers a "material reading" when it comes to discourses of the body. While operating outside the Cartesian subject, Moss and Dyck (1999, p. 376) note that Grosz does not separate "its thought from its matter".

Grosz (1994, p. 27) instead suggests that, "the constitution of the subject as an integrated and functional physical totality is an active ingredient in the constitution of the body". She argues that as such, it provides the subject with a body, all and each of which have a set of "socially distinctive, and culturally determined attributes and abilities, individual idiosyncrasies and styles of behaviour" (Grosz, 1994, p. 27). By not entirely separating the body from the mind, and in recognising it in its corporeal form, Grosz identifies the importance of such an understanding in end-of-life care that may otherwise view the body as a representation of a diminished self. In reality, however, the external identity understood by others fails to capture the nature of a subjective and dynamic self which has found itself caught in a disintegrating body. Margrit Shildrick (1999), in her work on anomalous bodies, helps to unravel some of the western discourses that prescribe a view of certain states of corporeality as being monstrous and the nature of its monstrosity itself. In this work, she suggests that while the existence of monstrosity may help to define, by its comparison, opposition and in being un-monstrous, the perceptively subjective nature of such state. What is more important, Shildrick (1999, p. 79) proposes, is the realisation that while being un-monstrous, the standard that it provides is not normal, but normative.

Analogies of the body constructed in discursive formation and relating to the subjective experience of individuals can thus be useful in reconfiguring the role of the subject within their material body. To this end, they can be useful in accompanying other debates on the topic of assisted dying to play a transformative role in how the body is conceived alongside its constitution of a seemingly normative self. By engaging with the body in this way, it becomes possible to interrogate the multiple forms of embodiment that people face through illness. It helps to understand how discourses beyond those that have become mainstream, and that seek to access the lessons of the unbounded entity and all that it represents, can be beneficial for understanding the body that is implicated within end-of-life care. It is not just the bodies of the ill and dying that are important in the constitution of the communal body; the bodies of carers, both formal and informal, must be taken into consideration for their role in the shaping of everyday social interactions.

As discussed by Julia Twigg, Carol Wolkowitz, Rachel Lara Cohen and Sarah Nettleton (2011, p. 171), body work is the work that is done to directly focus on the bodies of others, “assessing, diagnosing, handling, treating, manipulating, and monitoring bodies, that thus become the object of the worker’s labour”. It is such work that is done to the bodies of those in illness that makes up the central components of health care and medicine. Body work, of course, stretches beyond the boundaries of medical practice to include, as identified by Giddens among others, those modifications and manipulations that are impressed and inscribed upon the body in the formation of dynamic identities. These exist alongside those who use the body in work: using it as an instrument for the sex trade, as a tool for domestic labour, and for commercial purposes in the fashion and entertainment industries. These are the bodies that constitute society and that provide an ethics of everyday life, as by imbuing themselves in discursive practice they evince the moral attitudes and values that are upheld by societies. Their presence manifests itself in the values and opinions which are communicated within social interaction and normative judgements, by and between beings. This body work is defined by Twigg et al. (2011) as excluding work which is done to one’s own body. However, it is the integration of the ideas of body work, alongside intersecting notions of the body in illness, that can also be significant in helping to expound further understanding.

In a further work by Rhonda Shaw from 2014 she attends to expanding the conceptual tool kit, in this instance in regards to the notion of body work and live kidney donation. In seeking to move beyond the notion of live kidney donation being viewed as a “gift of life”, Shaw

suggests that current terminology surrounding the procedure is inadequate in accounting for the costs subsequent to donations. It therefore fails to acknowledge the risks and pressure that doing so might entail (Shaw, 2014, p. 498). Such costs can be disruptive for families and particularly for the lives of women. Providing a discussion on care and body work, Shaw argues that owing to technological innovation and health care reform, the cost and provision of body work has largely fallen onto female family and whānau who are increasingly responsible for the care of ill family members. The care that has come to be provided within the home is considered as body work and, as discussed by Christina Victor (2013), can be recognised for its essentially sexist and exploitive nature. Following Shaw (2014, 2015), the expansion of the conceptual toolkit regarding assisted dying would also pay to be expanded. In doing so, it would ensure that appropriate rhetoric for the circumstances is engaged with and applied. With changes regarding recompense for donors coming into effect in law on 5 December 2017 the advantages of such studies, and of using an approach which expands the toolkit available, can be evidenced in the creation of policies that benefit the lives of New Zealanders.

Communal Bodies

The notion of the communal body refers to individuals who share meaningful life experiences and are tied together through these by social bonds (Diprose, 2005). The communal body de-emphasises the significance that traditional models of medicine have placed on individual autonomy, which can have a significant impact on the way assisted dying legislation is enacted. The communal body can be understood as being constituted by the physical bodies of the communities that make up society. Each of them are understood to express meaning and communication. This section shows how discourses surrounding the meaning of the body and its space within the expression of meaning and the community can be useful for the assisted dying debate. As was shown in the previous two chapters, public discourse surrounding assisted dying highlights the ways that the media are presenting the debate and is contrasted with the discordant views of data from stakeholder interviews. These discourses are negotiated by and between various institutions as they seek to share with the public the possible range of views on this matter.

This chapter has shown that bringing into this conversation new dialogues on the body, its place at the end-of-life, and how this in relationship with the communal body will have benefits for conversations around a right-to-die. These discourses are not bound by a

commitment to principles, or a person's social standing determined by structural forces. Instead, they engage with an understanding of the body as it is viewed within specific times and places. It seeks to integrate bioethics within the bounds of social interaction by identifying the integral part that the body plays in determining moral action and judgement. The following section emphasises the failure of mainstream sociology to attend to discussion of the body, or where it has done so, to fail to consider the significance of the unbounded and unstable body in the constitution of self and identity.

Looking to what has been written from a bioethical perspective, alongside that which has been written in sociology in relation to assisted dying, these contributions can be viewed as constituting knowledge imagined as filling in the bottom of a pyramid. These are the foundational stones that enable us to understand the most fundamental debates. However, as has been identified in this thesis, while generous in their contribution, this involvement has not fully informed the discussion. More accurately, the current knowledge that is engaged with stops short of fulfilling or properly articulating what happens to the individual in terminal illness. By incorporating discourse surrounding bodies, both physical and communal, we can endeavour to provide the tip of the pyramid that ensures a more critical discussion of how these bodies actualise the experiences of patients and their community.

As Marcel Mauss states in *Techniques of the Body* (1973, p. 75), "The body is man's first and most natural instrument. Or more accurately, not to speak of instruments, man's first and most natural technical object, and at the same time technical means, is his body". For a community of people who have lost the communicative events that make up social life, it is easy to understand how and why the body becomes a primary tool by which terminally ill patients close to the end-of-life are able to maintain control. By ensuring that they have access to a means to an exit they are able to secure an end from the social isolation and bodily degradation that has resulted from their illness. The body conceptualised in this way is not just a body but also an embodied, even entombed, form of the self. The mind, as extension of the body, therefore provides a tool for the enactment of what cannot be communicated or expressed by the disintegrated body.

While minds may technically be free to wander, and to take the liberties that their bodies cannot, they remain trapped; the self, confined within the walled cell of the body. Arguably this is the very basis of imprisonment, and it is through this idea of the trapping of the self that we can come to understand how patients nearing the end of terminal illness can be

viewed as a negation of the self and as peripheral to the “community of bodies” (Diprose, 2005). David Schenck (1986, p. 46) elaborates this idea, saying that it is through the body as a physical being that an individual has communion with the physical world. He contends that “it is literally ourselves expressed”. It is this physical connection, the mind defined through its corporeal connection, which allows individuals to create personal identities at the boundary of the human body. It allows one being to be distinguished from another. The body is also a means through which individuals are able to come together and express themselves as social beings (Diprose, 2005). The body itself is a means of expression for the individual and it is through the body that a person connects with other beings. The mind, physically expressed, creates meaning that becomes socially significant for the other bodies around it by picking up signs and symbols through which they are able to connect. The body is thus seen as socially constituted and arising from the social world in which it finds itself.

As Diprose (2003, p. 37) writes, in such situations that there is no acknowledgement that “what drives community in the first place is a relation to the difference that would be effaced if unity and mutual recognition were ever fully realised”. When it comes to the right-to-die, this idea expresses a belief in the acceptance of difference which needs to account for the experiences of others. The absolute prohibition against taking the life of another, conceived as the “sanctity of life”, is held as a virtue to be upheld against all odds. It positions those who are willing to negotiate the terms on which this decree is made as formulating an absolute opposition to this sanctity, being prepared to open up to danger, by allowing a variety of homicidal acts. Again, the contextual and ambiguous nature of the expression of meaning works to provide a buffer for the oppositional party which, while recognising them as other, as disabled-body against their able-body, still believes in the common experience of the entire community. Comments highlighted in *Chapter four* show the emphasis that is placed on judgements which take the form of comments such as, “I never want to have cancer or anything like this, I would rather be put down and out of my misery”, and “when I can only drink berry smoothies I want to be euthanased” (JW 07/14). These statements fail to attend to the range of everyday embodiment and being-with that is experienced by individuals making up the communal body.

Diprose also discusses the expression of violence in relation to the body and how it can violate its formation of meaning, believing that violence can be understood as an event that halts the expression and circulation of meaning. Diprose (2005; 390) says that:

... if, in the name of government policy, we are asked to condone treatment of other bodies in way that deprives them of the ability to signify their uniqueness then with this loss we not only make refugees of being but we also in the process reduce our sense of belonging to non-sense.

This idea of a violence being done against bodies can be applied to the assisted dying debate from two perspectives. Seen as following the argument put forward in *Carter v Canada (Attorney-General)*, this violence occurs when the lives of patients are cut short prematurely owing to the perceived necessity of ending their lives before they are no longer physically able. The second approach to the idea of a violence being done against the body is the continued insistence that even those most degenerated, disintegrated and disfigured must be kept alive at all costs.

Relational Autonomy

Catriona Mackenzie (2008) is a leading theorist on relational autonomy and she draws on the ideas of Maurice Merleau-Ponty to conceptualise her understanding of the body. Mackenzie believes that the body provides the tool for all of a person's mental processes, and that it is a necessary instrument for the physical and mental interactions that construct a person's experiences. Further, she believes that the socially constituted body is shaped and constrained by cultural meanings (Mackenzie & Leach Scully, 2007). These cultural meanings determine how a person sees themselves within the social world, or what Nancy Scheper-Hughes and Margaret Lock (1987, p. 16) refer to as a person's "body image". This helps to make sense of a person's experience and for a person to understand the social world they inhabit. Because the relationships and forces of the social world within which it finds itself shape the body, Mackenzie (2008) believes that the idea of autonomy needs to account for this and so stresses the importance of relational approaches to autonomy.

A relational approach is premised on the idea that a person's identity and self-conceptions are constituted in relationships with others and embedded in complex social structures. These provide obligations and non-voluntary responsibilities that in turn shape the choices, competencies and capacities on which people make autonomous decisions (Mackenzie, 2008). Further, this approach takes into account the belief that the choices and opportunities that a person has available to them are structured by powerful social and political forces. It is

thus not just the individual's social situation that is considered but also the wider social structures that are at play. Advocates of relational autonomy therefore believe that normative approaches to autonomy that do not take into account these social relationships and attend only to overt coercion fail to recognise social realities that account for a person's "autonomous" decision-making. By using a relationally autonomous approach to the situations being experienced by patients, the issue of respect for their autonomy shifts as it refocuses attention to the social context within which calls for medically-assisted deaths are being made. Power structures within relationships can be taken into account, providing a wider and more integral approach to principles of bioethics that have been raised within this thesis.

Relational understandings of autonomy take into account the social situation of the patient (see, in particular, Downie & Llewellyn, 2012; Mackenzie, 2008; Weiss, 2009). Although autonomy and personal decision-making is still upheld as an important principle within medical practice, and concerns about coercion and possible abuse by whānau are still safeguarded against, relational autonomy aims to consider the experience of patients and their social context (Sherwin & Winsby, 2010). It makes use of the complex social relations in which people are embedded, in order to enhance their decision-making processes. Such approaches deal particularly with a patient's concerns, priorities, beliefs and values as opposed to looking at decisions from a value-neutral and particularly rational perspective.

Other authors (Downie & Llewellyn, 2008) have used this concept to theoretically apply it to health policy, but it is still only a burgeoning and innovative approach to autonomy within the field of biomedical ethics. In line with the sociological approach to bioethics, the concept of relational autonomy has a role to play within both the assisted dying literature and policy. This chapter intends to provide insights into the ways in which relational approaches to autonomy may be advantageous for decision-making around assisted dying to occur in the future, and how these differ from traditional approaches. As was shown in *Chapter five*, the current principle-based approach to bioethics has shortfalls that has allowed debates around assisted dying to flounder. By reconceptualising standard approaches to autonomy, this work addresses current inadequacies that autonomy has within bioethics in order to work towards a productive notion that takes into account the diverse nature of 21st century New Zealand society.

The doctor-patient relationship is an important starting point for recognising the autonomy of a patient. In one of the interviews undertaken and analysed for this thesis, gerontologist Kerry Weaver speaks of such a relationship with regards to those suffering from neurodegenerative illness. She states “the doctors as individuals, and also the patients as individuals, and for people with your neurodegenerative conditions, there is a strong bond developed between doctors looking after those people, them and their loved ones, and I think we should trust a bit more in the wisdom of that relationship” (KW 11/14). What sets this statement apart from the bioethical literature is that, instead of focussing on the paternalistic nature of this relationship, Weaver speaks instead of the bond that grows between a doctor and patient suffering from chronic illness. One way that sociology can aid bioethics is in identifying not only the negative and vulnerability aspects of the doctor-patient relationship, but how building on positive qualities can help to strengthen and empower patients in their decision-making.

Tony Walter (2017) describes the hospice movement as being rooted in holistic, multi-disciplinary care where the patient gets reconceived from being viewed as a sick body and into a “whole person”, recognised as having emotional, psychological, social and spiritual, as well as physical, needs. This is the commonly held goal of palliative medicine which seeks to fulfil the psycho-social needs of patients and their families. It should not be beyond traditional health care practice to consider these goals as frameworks for medical provision that is not limited to the end-of-life. In much the same way that hospice care realises a greater variety of human experience, relational autonomy too attends to the social differences and distinctions that exist between patients. Taking these discourses on the body into account helps to explain why it is that some individuals face such a profound loss of self when their bodies no longer express the way their mind feels. In these circumstances, the patient experiences what has been referred to as a social death, which manifests itself in their isolation from the social world and interaction within it.

Dignity in the Medical Context

As discussed in *Chapter four*, there are a number of ways that we can understand what dignity is and the range of effects that its violation can have on a person. It has largely fallen to qualitative studies to elucidate the ways in which people feel their dignity has been violated. I will now look at some of these perspectives to shed light on how the term ‘dignity’ has been understood in the assisted dying debate. As noted by Chochinov, Hack, McClement,

Kristjanson and Harlos (2002), despite the wealth of information critiquing the different approaches to dignity, there is little empirical evidence that examines dignity from the viewpoint of the patient themselves. We have already discussed the ways that dignity is presented within academic literature, but it is also important to understand how it becomes known and experienced by the patient as part of everyday life.

The work of Chochinov et al. (2002) is a qualitative analysis of the perspectives of patients in a palliative care setting. Using content analysis and comparison techniques, the authors analysed the content of interviews with 50 patients. They sought to develop a conceptual framework that defined dignity from the perspectives of those who were receiving treatment from a specialised care unit for palliative care services for terminally ill cancer patients. Chochinov et al. identified three major categories which emerged from the qualitative analysis of interviews. The authors interpreted these categories as referring to the “experiences, events, or feelings, where dignity or lack of dignity becomes a salient concern in the course of the patients approaching death” (Chochinov et al., 2002, p. 435). The three categories identified were illness-related concerns, a dignity conserving repertoire, and a social dignity inventory. Each of these categories is further broken down into themes and sub-themes. With these categories Chochinov et al. neatly summarise the concerns that many people have when it comes to being treated with dignity in the context of health care.

Like much discussion in the health care context we can see that the impact of terminal illness on an individual is entrenched across the whole of the patient’s life. As identified by other authors, dignity – along with its violation – is a subjective, dynamic, multifarious and situational concept. The different categories identified by Chochinov et al. (2002) help to identify both the short-term and long-term effects of experiences on a patient’s perspective of their own dignity. We can see in these themes and sub-themes how the different approaches to theoretical understandings of dignity all have a role to play within health care. Themes such as the *level of independence* and *physical distress* may both be affected by symptoms and reflect situations in which the progression of the disease might take place over an extended period of time. Others, such as the sub-themes included under *dignity conserving repertoire*, reflect the interactive relationship between the patient and health care professionals, which may vary from a day-to-day basis or over the long-term progression of illness.

The allowances made under dignity conserving repertoire preserve the incidence of the sub-themes listed under the *social dignity inventory* and show how the continuance of social relationship aids in the overall wellbeing of a person. The idea of a social death is pervasive in the literature around death and dying. Social death is regarded as separate to the physical death of the person, and affects the psyche of the patient who is unable to maintain many, if any, social relationships. This is reflected in the violation of the sub-themes listed under *dignity conserving perspectives* and relates directly to the diminishment of those social aspects that define and help in the advancement of a person's identity. This idea is further detailed by Sabine Pleschberger (2007) in her qualitative study that looks at the residents' view of dying in a nursing home. Pleschberger identifies two forms of dignity, both of which reflect the grouping of notions discussed above, and which she thinks can be identified as an intrapersonal concept and relational form of dignity.

According to Pleschberger's definition of dignity as an intrapersonal concept, we can understand it as a Kantian or biblical approach to dignity, which sees it as an inherent characteristic of a person in even the most unfortunate circumstances. Pleschberger equates this idea of dignity with a personal refuge that sits at the core of an individual. Surrounding this core, Pleschberger believes, sits relational dignity, which is socially constructed in the act of recognition upon which it relies to flourish. It is this idea of relational dignity that Pleschberger believes is evident in the nursing home, as she notes within the context of the home there are few opportunities for socially dignifying relationships to flourish. There is an interplay of these two approaches identified by Pleschberger that she believes can be identified within the nursing home, and it is here that we can see how her concept of intrapersonal dignity can be viewed as the core of the relational sense.

For Pleschberger, the lack of opportunity for socially dignifying relationships in the nursing home results in the added necessity to maintain relationships with family members. In order to maintain these kin-ties, the nursing home residents aimed to avoid becoming as much of a burden as possible. Financial independence, maintaining self-care and sound decision-making are identified by Pleschberger as being important ways the patients within the nursing home felt they could retain as much of their relational dignity as possible. In conflict with these attempts though was the betrayal of the body by illness and the daily reminders of the impact this has on any bid to maintain dignity. No longer can the patient carry out the routine tasks of everyday life. It is here that we see that core of intrapersonal dignity cave, to give way to the hollows made into the individual's relational dignity. The constant maintenance of dignity

becomes difficult, if not impossible, and we begin to understand more clearly how the concept of dignity is reflected and interwoven in the wider identity of the patient.

Pleschberger highlights the interconnection between these two types of dignity, but to an extent overlooks the serious impact that existential and spiritual angst has on what she might refer to under the category of intrapersonal dignity. As highlighted by Sue Hall, Joanna Davies, Wei Gao and Irene Higginson (2014), the effects of symptom distress and loss of independence owing to a loss of function might be more obvious to the eye when viewing a patient. However, it is also important to take into account a patient's existential issues that may concern their need or desire to find meaning and purpose towards the end of their life. Hall et al. (2014) call for a deeper understanding, within palliative and end-of-life care, for an understanding of how patients experience distress and suffering as well as a wider perspective on their causes. This, they believe, will help many health care professionals provide more effective end-of-life care. What many of the qualitative studies undertaken into patients' perspectives on dignity show, is that most individuals have clear views about how they want to be treated and how they believe their own and other's actions can violate or diminish their sense of dignity.

The identification of these categories, themes and sub-themes helps to realise dignity as a multifaceted concept in both a theoretical and empirical sense and highlights the multitude of ways that disease affects both a person's physical and social being. Most importantly for our discussion, we can see how the social, psychological, and physical aspects of dignity all play a role in determining a patient's attitude or request for assisted dying. It is largely the meritorious and aspirational approaches to dignity that are most commonly employed in respect of pro-assisted dying. As we are about to see, the dignity that is most commonly violated, or closest to being violated, is the result of actions directed toward the patient, most commonly from those providing health care services. For those individuals approaching the end-of-life or the stages of terminal illness, the fear behind a loss of dignity, especially inflicted when one is at their most vulnerable, is particularly strong and it is important that health care professionals take this into account during the treatment of patients.

Dignity and the Ethics of Care

With the slow decay of physical function, bodies quickly become impediments to daily life. Largely, what terminally ill patients come to rely on is an increasing need for aid in the most

mundane of daily tasks. The taken-for-granted physicality of the everyday throughout a well person's life becomes limited for the patient, and results in a further restriction of social and cultural activities for them. In an article analysing dignity, Carl Leget (2013, p. 949) looks at the "traditional" approaches to dignity before he moves on to what he describes as an ethics of care with an integrated view on dignity. Leget uses different terminology to the traditional dignity phrases discussed in *Chapter six*, although he continues to base the new names on the approaches and understandings that we have seen before. Leget (2013) also draws on only three approaches to dignity by combining Schroeder's aristocratic comportment in order to categorise his as *social and relational* forms of dignity.

Leget defines social dignity as, "a tool to distinguish human beings from one another and to place them in a certain social order or ranking", and relational dignity as a sense of experienced dignity that means people are treated so as to make them feel respected (Leget, 2013, p. 948). For Schroeder's meritorious concept of dignity, to describe a sense of self-worth and esteem, Leget adopts the term *subjective*. Lastly, he describes an *intrinsic* dignity that mimics Schroeder's Kantian approach. Like most of these similar approaches, Leget can also find holes in the application of dignity he takes and so looks elsewhere to locate a definition for dignity that covers the range of meanings and manifestations attributed to it. To this end, Leget has integrated ideas of dignity within the framework of an ethics of care and, in doing so, highlights the importance that social relations have in influencing moral understandings. Leget discusses this inclusive approach as being able to provide an account for the social context, level of vulnerability, and emotional attachments of the patient. Leget also emphasises the asymmetry in power relations as a crucial theme within the ethics of care, and believes that it is of particular importance within health care and the vulnerable situation of an individual.

Following this framework, Leget proposes three questions that he believes can help to reformulate the experience of, and approaches to, dignity. It is around this idea that we see the first of the questions Leget puts forward, "What is the meaning of the concept of dignity as used by patients who express their subjective experience? The previous illustrations of approaches to dignity can be important in helping a patient understand the different ways they can and will experience dignity, by showing the sheer range of lived-states that a patient may experience. In particular, this question highlights the greater importance of studies such as Chochinov et al. (2002) who aim to understand the subjective and lived experience of the patient. As Leget argues, by reformulating our approaches towards the patient's lived

experience, it calls for an open-minded approach to dignity. This approach removes the patient from using the predefined concepts of dignity that fit within a health care professional's framework, which can reinforce power dynamics between the two parties.

The next question that Leget poses is, "What is the quality of the caring relations in which the patient is involved?" These caring relations, he identifies, can be further refined into the categories of: (a) the caring relations with professionals; (b) the personal web of reciprocal relations between a patient and his close family, friends, relatives, neighbours, etc; and (c) the caring relations in which a patient is actively involved. Encompassing these three aspects of an individual's social and caring relations ensures that steps are taken to make the patient's lives meaningful and fulfilling. It also covers the range of relationships that are likely to have an influence on how a person believes they are expected to behave and how their everyday experiences outwardly manifest themselves in the patient's self-esteem and sense of self-worth.

Where these first two questions situate the patient's story at the centre, Leget's third question, as we have seen in other concepts of dignity, approaches it from an outsider's point of view by asking, "What is the social position of the patient?". While many of the previously discussed authors (see *Chapter four*) have viewed dignity from this social approach, Leget takes it a step further than these others. As well as focusing on the individual's social position and where the patient themselves stands within society, it is equally important to look at the social and cultural context within which the patient lives. By doing this we can understand how the wider dynamics within a society are going to affect the relationships of power and dominance in a patient's life. Here Leget uses the example of societies in which there is a tendency to confine sickness, vulnerability and death within four walls, while in others, old age is a status that merits great respect.

These different approaches to care that can be aided through answers to Leget's questions are expressed through the narrative identity of the patient and create the end of their story which, as Foster (2011) points out, is particularly important to many individuals. If we are to better understand, or perhaps better articulate, the needs and desires of patients who feel their dignity has been lost, then it is important to also understand how these same patients have come to understand themselves and formulate their own identities. The range of definitions devoted solely to the complex term of dignity, as outlined above, has practical implications for how care is provided and what is expected within that term. Outside the realm of bioethics

and within everyday language, a wider understanding of the term is generated and made on general assumptions being drawn owing to the context within which it is being used.

When it comes to the bioethical debate, however, the nuances that can be discerned from the above terminology put an inconclusive veil over policies, practices and tools that rely on the use of the word dignity. The previous discussion has highlighted the growing dissonance within the academic community over whether dignity itself is a useless and altogether unnecessary word, whether it needs further refining to enable it to be better used, and whether changing approaches to 21st century bioethics should employ the term, although under the guise of a more socially applicable understanding. Recent qualitative studies into how elderly and terminally ill patients experience dignity within everyday life have further illuminated how different applications of the word can be used within the context of real-life health care.

It is Leget though who provides the most effective use of the term ‘dignity’. While Leget does little to illuminate the debates that go on surrounding the term, he provides a novel way to apply dignity within health care settings that appreciates the myriad contexts within which the term is used and the range of circumstances within which it can be applied. By focusing on breaking down the barriers between the patient and the predefined concept, the term ‘dignity’, as Leget shows, can be used to articulate an overwhelming range of feelings and experiences that a patient might be going through. The term ‘dignity’, along with its nuances, is too deeply embedded in our everyday language to be disregarded entirely as a term. Maybe in the long run dignity will not provide us with a stronger grasp on our approaches and views on larger bioethics debates, but it will play a part in showing us how we are able to show decency and regard for the care at the end-of-life of all people.

What is perhaps needed instead is a different toolkit from which to choose and refine the characteristics of care that have come to be expected in the age of the modern hospital. As was discussed in the methodology chapter, it is the beauty of discourse that it both constructs and is constructed by social praxis, discourse and action. Here it is all three of these that need to be employed – not to deter the use of the term ‘dignity’ or to define it as ‘useless’ – instead when discussing terms with a nature of importance to open up what is meant when it is being used. In this sense, it enables health care professionals, patients and family alike to provide dignity with a relational ethics, which asks each person, “What does dignity mean for you in the context of your situation?” Although the term ‘dignity’ provides a catchall phrase to cover the human rights bases, for the future of health care it may be the way in which we open up

what it is that people are afraid of losing that helps us to reimagine some of the policies and practices that are in place going forward regarding end-of-life care. Dignity is not useless, but it is useless in trying to help in the assisted dying debate. The states that it expresses do not fully represent the lives of those with terminal illnesses, because even beyond its ambiguity as a concept it leaves too much undefined or provided for.

Along these same lines, relational autonomy seeks to counteract or reconstruct the prevailing issue of social death at the end-of-life, which commonly occurs before biological death has taken hold. This is emphasised by the sequestration of unbounded bodies that within western society are isolated within institutions of care and excluded from the social life of the community. The following section considers the idea of a social death, and its implications for the aged and ill population, before proposing an altered frame for the assisted dying debate.

Social Death and the Dying Role

The idea of social death was most notably theorised by Glaser and Strauss (1966; 1968) and Sudnow (1967) in their ethnographic studies undertaken within modern American hospitals. These studies researched the social nature of death and dying and thereby came to distinguish between the social and biological death of the patient. Following Goffman's approach to the idea of a "non-person" as the source of a social death, they viewed these patients, or non-persons, as those who are sometimes treated in their presence as if they were not there. Goffman takes these to include the very old, the very young, and, most importantly for this work, the sick. This is not to say that this class of people are completely and overwhelmingly ignored at all times, but that their identities may often be overlooked in the everyday, highlighting that one's social existence is not necessarily continuous.

In the words of Mulkay and Ernst (1991, p. 174) these individuals "can come to be regarded as living biological organisms without social attributes". They identify that within a hospital setting a social death is subsequent to the recognition that a person is dying. When such a recognition occurs those who they come into contact with respond in part by imposing a "special frame of reference" which determines how future interaction is to be organised (Sudnow, 1967 cited in Mulkay & Ernst, 1991, p. 174). Frequently this results in a social death whereby the social life of the individual is eroded, as those around them increasingly begin to restrict contact and help to amplify the issue along with the physical decline of the

body that limits opportunity for further social interaction. As Mulkay and Ernst (1991, p. 179) explain, social life depends on the continuation of experiences and activities in order for patients to sustain an existence among the living. When these experiences and activities then fail to occur, the resulting experience is the social death of the individual.

Michael Mulkay and John Ernst discuss in their 1991 article the point at which the “death sequence” begins and an individual becomes exposed to the experience of a social death. Discussing the situation in Britain and the United States, they contend that a major transition occurs when individuals, particularly men, retire as it tends to produce a strong reduction in their degree of social interaction. In this same way, the social life of a terminally ill patient also has a downturn when they are forced to end their employment because of physical or mental decline. As was noted in *Chapter two*, males have on average a lower life expectancy than that of females. This results in social death being “a more significant feature” of women’s lives (Mulkay & Ernst, 1991). As Mulkay and Ernst acknowledge, in modern society many women are likely to experience an extreme form of social death once their spouses have died biologically.

Mulkay and Ernst (1991, p. 187) describe that women are less likely to experience such a severe entry into the social death sequence than their male companions following retirement. Having cared for spouses as a primary activity while they aged or became infirm, widows will then face a “greater acceleration” in their progression toward a social death. This Mulkay and Ernst concede is when their social death sequence properly begins. In light of this, however, the authors also draw on Michael Kearl (1989) who proposes that women in present day society, who are less likely to be defined by their spouse’s identity (owing to economic opportunities outside of the home, partnering-up later in life and a greater likelihood of separation), may not experience such a strong exclusion from social life. The impacts of this hypothesis have not been recognised yet, leading Mulkay and Ernst to conclude that of the extra years gained in life expectancy by women over the last century, most of them are spent in isolation as their death sequence progresses.

The first research question this thesis posed is, “What role can a patient’s social death be seen to have in relation to suffering?” The answer to this lies in the use of discourses that bring the lived realities of those experiencing bodily deterioration together with more coherent understandings of how this affects and has implications for a patient’s everyday social interactions. The negative effect of bodily deterioration on relationships with others can lead

to severe social isolation for not only the patient, but oftentimes also the primary caregiver and especially those still living within the home. The burden of this on the patient, along with the guilt from the perceived burden on a loved one, can exacerbate the suffering felt by the patient and highlights the strong relationship between body and mind when it comes to the isolation felt by some patients.

As discussed by Hallam et al. (1999), sociological discourse surrounding the body has overlooked the self-reflexive subjectivities of the patients, especially when accounting for social death. In this sense, Hallam et al. view these discussions as falling short of including the dying experiences of those people, the state of whose bodies no longer correspond to the state of their mind. Going beyond the traditional approach to social death, the authors propose that what is needed within contemporary theories of the body is a new theoretical stance that moves beyond the body's physical boundary to take into consideration those "who have no body or who are nobody". As they discuss, although literature on the sociology of the body is effective in making sense of a person's corporeal life, it remains incomplete by its failure to consider those at the margins and edges of life (Hallam et al. (1999)). This helps to perpetuate social theories that attend to the beliefs and practices of already dominant groups and institutions, all the while undermining those of more marginalised communities.

Drawing back on what was stated in *Chapter one* regarding the conflation between old age and illness, and following the arguments put forth by Hallam et al. (1999), it becomes evident that it is in the conflation of these two physically impacting conditions that the risk of a slippery slope lies. This is why it is important that these two representations remain as separate entities, with elderly and the terminally ill being regarded as wholly different beings. As it stands the universalising of experiences of the terminally ill and the elderly, by people who oppose *and* advocate for legalised assisted dying, is dangerous insofar as it seeks to present death to those who are otherwise well and takes from others its possibility.

Without such an approach, critics of assisted dying are right to assume that the burden of death will be placed onto the elderly and vulnerable as their physical bodies do not reflect the vigour and youth expected by society, although it might be internally present within the individual. Here there is also an important point to be made regarding disability and the risk those in the disabled community face in relation to assisted dying. It is once again such a conflation that occurs between representations of the impaired body and that of the terminally ill that relationships are drawn between the two. Through the construction of clear

boundaries, helped by cultural imagery and social education, it would seek to emphasise the differences between those who have learned to live and are living with disability, and those with terminal illness who must learn to die with a disability.

Hallam et al. (1999) suggest further that while the concept of a social death is able to shed light on an “externally imposed exclusion”, it does not necessarily provide the full range of experiences that are being lived, nor the ways some individuals may attempt to resist the progression of the social death sequence. Writing on those individuals experiencing old age in relatively good health to others of a comparable age, they propose that the central concern becomes the discord between the ways that the self is experienced by others in its corporeal form, potentially as unbounded and unstable, as opposed to the way it is experienced through embodiment. This research, as noted in *Chapter one*, has sought to avoid any confusion regarding the ill and the elderly. Instead, it regards them as separate identities, so in this sense the work by Hallam et al. (1999) is useful for expanding the notions by which the social death is understood.

Depictions of slim and slender bodies that pervade cultural and social imagery and which further perpetuates stereotypes and stigmas around bodies do not fit up to this standard. Hallam et al. (1999) hold that the social death of an individual is an imposed condition, a dynamic progression, not to be viewed as a single event or state but through a series of social processes that increasingly marginalises those at the boundaries of life. Crucially, they suggest, it is the body that “betrays” the individual as the body’s disintegration is increasingly constitutive of their external self-identity. The body disrupted then comes to inform the presence of interaction within the social world. When this interaction breaks down because of the absence of a stable body the individual as a socially constituted being begins the progression along their death sequence, neither being with the world nor apart from it.

Furthermore, the binary oppositions that are conceived as life and death are the reasons that discussion needs to be formulated at the end-of-life which provides a constructive representation of the process, as opposed to event, that is dying. Throughout this process the individual adopts what has been referred to as a dying role, whereby they put aside their “normal” responsibilities and obligations to fulfil the part that is expected of “the dying person”. Stemming from Talcott Parsons’ (1975) concept of the “sick role”, this idea labels an individual when they are unable to fulfil their “normal obligations” due to impairment or illness (for a detailed account of the sick role see Parsons, 1975). Bound within this role is the

expectation that it will be temporary and that the afflicted individual will return to being an active agent and satisfying their obligations and social beings. Problematically for the dying role, this becomes a permanent condition for just as long as the terminal individual remains alive.

As discussed by Debra Parker-Oliver (2000), the dying role prescribes what is expected of a person who is dying along with what is expected of those around them as the drama unfolds. This process is mitigated by the medical personnel and care workers who attempt to ensure that the final role is played out with as few dramatic turns as possible. Parker-Oliver (2000), and Emanuel, Bennett, and Richardson (2007), identify that in the position of lacking a dying role the terminally ill individual will instead remain confined to the sick role, which may present futile opportunities for the continuation of curative treatments. Such a prolongation of attempted curative care does not in many cases allow for the fulfilment of a good death, as it could otherwise be actualised with palliative care.

As was mentioned in regards to life extension in *Chapter three*, the preservation of life, quantity over quality, might not always benefit patients but it is this shift from the sick to the dying role that encumbers. It is important therefore that patients are allowed to and made comfortable about taking on their dying role and recognise when the time for that may be. Regarding research question two then, namely, “What part can the dying role play in how we approach current understandings of the end-of-life in relation to assisted dying?”, it is the shift from cure to comfort (Parker-Oliver, 2000) that allows a terminal patient to engage with their own death rituals (Seale, 2000) and help patients to have closure in personal matters at the end of their lives (Glaser & Strauss, 1968). Further, as noted by Emanuel et al. (2007), an awareness of the dying role can aid health care practitioners in the provision of effective and suitable care. Whether assisted dying is legislated for in New Zealand or not, such discussions at the end-of-life, and the continual questioning of its practice brings to the fore conversations that should be requisite for terminal patients and the whānau involved in their care.

Following the work of Dame Cecily Saunders, the founder of the modern day hospice movement, Emanuel et al. (2007) proposed that the dying role comprises “interactive yet distinguishable domains”, which influence each other and can help patients at the end-of-life to accomplish their own realities of a good death. The three domains they identify are: practical (physical and logistical), relational (social), and personal (psychological and

existential). These domains are held to represent different aspects of individual life and to inform a complete understanding of holistic experience of the terminally ill patient. By satisfying these features of social life, the individual is then able to have control in death. Such a role does not seek to impart a formulaic method by way of a checklist by which a person should embrace the dying process, but instead highlights the experiential possibilities through which a person can attempt to achieve a good death. This is especially through engagement with palliative care, the central purpose of which is to ensure that a patient's physical, social, mental and spiritual needs are met so that death can be attended to in the respectful and ritualistic manner that it traditionally has been.

The Right-to-Die and the Communal Body

The assisted dying debate, although a prominent discussion within many countries, remains a contested and divisive topic across many communities that see its provision, or the absence of its provision, as a breach of their rights as individuals obligated to society by way of their social membership. At the crux of this debate is the undisputable advance of medical technologies and end-of-life care, that can sustain a patient at the borderlands between life and death, neither invested in their social environment nor entirely removed from the presence of others. Strong contributions have been made to both sociology and bioethics as they relate to the end-of-life and, more specifically, to when that life is ended by active means. Their presence within the debate has been formative in expanding notions of how death is achieved with medical intervention, whether in the home or an institution. Although these notions have been useful in attempting to delineate the boundaries of end-of-life care until 2017, they do not cater to, or equip communities with, an understanding of how future changes will affect their being. To this end, it is the reconceptualisation of the toolkit as discussed above that can be used to inform and constitute our discussions on assisted dying that is necessary for the further provision of care and, more importantly, for the overall wellbeing of the terminally ill individual and their communities.

Required at this point is an expansion of the boundaries that chart the experiences of the terminally ill, along with how they are implicated and invested into their decisions regarding whether to seek assisted dying or not. This would not force an individual into such an end. It would, however, provide the option to those who want it based on a complete picture of how their choices are being informed and what their motivations are. By engaging in a relational

approach to the individual, the dangers inherent within any community of bodies can be identified and mitigated against through more extensive and informative dialogues based on open communication from both sides. For the physician, this involves viewing the individual as they are and have lived their life within their community, and not as the patient that they become when they entered into a relationship with the medical community. For the doctor, this means also attending to the physical form that the individual embodies and comprehending how the differences that are afflicting their body will impact the individual themselves.

This can be achieved by regarding the individual within their social and cultural context and approaching principled autonomy from a relational perspective, before then understanding the importance of that context for their experiences and interactions. This will go some way to ensuring that individuals are able to maintain an adequate sense of dignity, if that term must be used. If not, an understanding of relational dignity alongside relational autonomy can attempt to socially constitute the patient. This is done along with the subjective ramifications that terminal illness and the end-of-life has for them as a body within and, physical body with, the community. Integral to these discussions are the lives of individual patients and the subjective conditions on which they premise their beliefs as to what constitutes a good death or otherwise. The range of these conditions needs to be recognised so that they can be actualised following practical and effective frameworks, policies and guidelines. Although existing within the boundaries of institutional practice, they must still maintain the integrity and holistic wellbeing of the patient along with thoughtfully understanding how their community will feel the ramifications of their eventual death.

Chapter nine: Conclusion

Chapter Overview

As outlined in *Chapter one*, the discussions set forth in this thesis have been formed through the study of the interdisciplinary literature that has sought to clarify the various facets of assisted dying and its legislative practice. This has been done with the aim of recommending changes and new approaches that will help to create innovative avenues for dialogue and discussion relating to assisted dying. These are outlined towards the end of this chapter. By seeking to answer four questions relating to assisted dying, as identified in *Chapter one*, this thesis has looked at the literature that has been significant in informing the assisted dying debate. This research has presented an examination of the media influence, ethical principles and stakeholder attitudes existing in New Zealand and that relate to assisted dying. It has shown that the rhetoric being employed on both sides of the debate is no longer useful in acknowledging the range of realities that people are expressing and living. Towards this end, I have used a demonstrated the benefits of an approach to sociology in bioethics that emphasises the importance of recognising the socially situated individual within the assisted dying debate and medical practice more generally.

The anecdote that began this thesis provided a reflection of the experiences that I, as a researcher, encountered throughout this work. My own experiences and the information they provided were not altogether different from what it would appear are relatively frequent practices within medical care. New Zealand researchers have, for example, identified that the act of assisting in a patient's death occurs in the provision of health care and is not altogether uncommon (Malpas, Mitchell & Koschwanez, 2015; Mitchell & Owens, 2003). Although this may, for the most part, mean that passive assisted dying is what occurs in practice, it does not provide the regulatory frameworks to safeguard against abuse of these methods. My concern is that if the routinisation of passive assisted dying grows unabated and continues to remain unregulated then the New Zealand health care system is at risk of tacit acceptance of methods which undermine medical practice itself. Although the enactment of legislation must not become a foregone conclusion there remains, as has been shown in this research, new opportunities for the inclusion of additional discourses and alternative approaches to care within the medical context as it is applicable to assisted dying.

I have identified some of the shortfalls apparent in the sociological and bioethical literature and have provided new methods of approach for understanding the individual as socially and culturally situated as they proceed within the health care system. This relational approach to dignity moves beyond the traditional principle-based approaches that were considered in *Chapter five*, towards an understanding of the individual and the influences that exist within their health care decision-making. By taking a view of the individual as such, I suggest that it can aid in the assisted dying discussion by ensuring that an integral view of the patient is taken and that any undue influences being placed on them is identified and eviscerated. Beyond this, it would also provide for further recognition of the individual experiences that are being had by patients and those around them. The communal body, within a relational health care framework, is not taken to override the autonomy of patients but to work alongside their individual self-determination and to elucidate the options available to them throughout their dying trajectory.

Chapter two looked at the social context for legislation should it become enacted into New Zealand law. Such a social context can be seen to be constituted in and by the communal bodies that exist within New Zealand. This chapter showed the medical and legislative frameworks that are integral in the discussions and development of the provision of assisted death. It identified the shortfalls affecting how health care is provided to New Zealand communities, especially those in rural areas or outside larger institutional catchment areas. Finally, *Chapter two* sought to highlight the significant factors at play when it comes to the ways in which these communities live and die, and that will be implicated within any changes to end-of-life care.

Chapter six discussed the methodological foundation from which this research has been premised and identified the method by which analysis of the collected data sets would be carried out. Following Fairclough and his work on media analysis, this chapter considered the approach to be taken in carrying out a CDA. It looked to Van Leeuwen (2007) for his four strategies of legitimation that can be used in discourse as an acknowledgement of the legitimacy of explanations or justifications in relation to certain actions, actors or opinions (see also Fairclough, 2003). A second data set provided the basis for the second half of *Chapter six* to discuss the characteristics of the interview participants. A thematic approach to this analysis was outlined and the benefits of engaging in such a method were considered in relation to the data from the interviews.

Chapter seven provided the findings from the aforementioned analyses. Drawing on Gamson's (1995) approach to framing it showed how dominant discourses are produced and reproduced within the mediated culture of everyday life. The frames provide forms of legitimation for the words being said and help to morally evaluate them as "rightful" actions. It positioned this discourse against those of stakeholders and experts who inform another side of the assisted dying debate. Although appearing in the newspaper pages, their voices were this time provided in interviews and in their own framing, and produced themes useful in the consideration of how the different parties are represented. In this discussion, it becomes clear that the use of narrative structures can be beneficial in communicating and understanding the experiences at the end-of-life and of assisted dying. Without such stories, the knowledge gained by those living with illness and the lessons that they hold are unable to be actualised into practice and care.

The Benefits of Palliative Care

I believe that instead we need to look to the values inherent within the palliative care movement and where possible to implement these alongside care which is curative by nature. The rise of palliative care, as noted, came about in 1967 following Dame Cecily Saunders' establishment of the first hospice in Britain as a reaction against the medicalisation of death (Howarth, 2007). It subsequently spread into many western societies with the movement basing itself on a philosophy within which death is viewed to be a normal part of life. An approach like palliative care can be taken as being informed by a holistic and relational view of the individual. It endeavours through its philosophy to reassure the patient against the existential insecurity that faces us all in recognition of our own eventual mortalities. In contrast to the goals of institutionalised medicine that are discussed in *Chapter three*, the hospice movement instead seeks to palliate the symptoms of patients and to treat them by moving away from curative procedures and treatments (McNamara, 1994).

The central theme of palliative care is to provide comfort and support not only to the patient, but also to the family and friends who surround them during the final period of terminal illness. This is ensured through the use of interdisciplinary teams that include physicians, nurses, home care aides, social workers and spiritual counsellors (Howarth, 2007). The goals of such care are to provide not only physical support, along with pain and symptom management, to the patient but, and just as importantly, to also provide psychological, social

and spiritual care to ensure that the end-of-life is as life-affirming as possible. The framework by which palliative care applies itself can be useful for determining a shift within the current health care system.

That is to say, while the benefit of curative treatments in certain circumstances should not be withheld, it could be of benefit if the principles of the hospice movement, as seen in the provision of palliative care, could inform the broader aspects of generalised and specialist services pertaining to other aspects of health. This would allow for patients progressing through the medical system, and before they begin their dying sequence, to be provided with holistic care that seeks to inform them more generally of the social implications of disease and illness. By the time they become imminently terminal, it would mean that engagement with their own death progression would have been previously informed, with decisions at the end-of-life being had and goals accomplished. Furthermore, what is required is an integration between the palliative care and public health systems. In seeking to provide this extension it would once again enable those progressing through life with illness with a wholly more effective and adept provision of care. This would ensure that once the opportunity of palliation becomes beneficial such care could be actively and immediately implemented, enabling the patient the maximisation of quality of life through the provision of appropriate care for their stage of the dying process.

As discussed in *Chapter two*, the current challenges facing end-of-life care and the provision of health care for the ageing population will place further strain on the medical profession and system as it seeks to provide for an increasing awareness and anticipation of a good death. As Bone et al. (2017, p. 2) claim, “a robust understanding of where people die is vital to support health policies, resource allocation and service delivery, for example, to support the planning and commissioning of palliative care services”. Their study, conducted across England and Wales, sought to understand the impact of population ageing on the future provision of end-of-life care. They found that to sustain the present trends of population ageing, end-of-life care provision within care homes and the community will need to double by 2040 to ensure that the rates of deaths occurring within hospitals, the perceived antithesis to a good death, do not begin to increase.

The MOH *Review of Adult Palliative Care Services* (2017) maintains five priority areas for action within the development of care across New Zealand. These areas are listed in the report as aiming to:

- Increase emphasis on primary palliative care
- Improve quality in all settings
- Grow the capability of informal carers in communities
- Respond to the voices of people with palliative care needs and their families and whānau
- Ensure strong strategic connections.

If it is expected that the capabilities of informal carers are to be improved so that care can be provided within the home and the community, legislative and social policy must also occur reflecting the greater level of dependency on families and whānau. The expectation of greater care cannot be assumed to be altruistic. It is the burden that such care can place on individuals, which makes patients susceptible to abuses within their end-of-life care or, potentially, their eventual assisted death. Safeguards are therefore necessary to prevent against instances of abuse and the necessary resources must be given to the community of informal carers who are to be expected to minister to individuals.

Further, as noted in *Chapter eight*, feminist concerns that relate to the “essentially sexist and exploitive nature of family care” must be recognised (Victor, 2013, p. 134). The nature of the implications that illness has on understanding a couple’s resilience has been documented (see, for example, Gamarel & Revenson, 2015). Alongside this, work has been done that suggests that by promoting a sense of “we” between couples facing terminal illness, it can help in aiding long-term coping and resilience for both the individual and in partnership. The subjective experiences of how individuals perceive their realities, and taking on the care of a partner, must therefore be considered in the relational understanding of the patient and the care they receive. One must also not fail to appreciate how individuals experience the end-of-life, and how this subjectivity relates to their conception of dignity itself. It is widely understood that dying with dignity relates to those who are already in the active process of dying, and that this process needs to facilitate open communication to achieve, for the patient, the best in their end-of-life care.

Dignity reviewed

An inherent dignity of every individual cannot be violated. That is, the dignity that is imbued within every individual body. It provides them with a sanctity and, in the majority of cases, a personal security that cannot be violated by virtue of their very being. There is, however, a bodily integrity that can be diminished, a sense of self that can be harmed through the actions

of others and a disrespect of one's self. As was shown in *Chapter four*, a person's dignity that is most commonly violated, or closest to being violated, is often the result of actions directed toward the patient, generally from those providing health care services. For those individuals approaching the end-of-life or the stages of terminal illness, the fear behind a loss of dignity, especially inflicted when one is at their most vulnerable, is particularly strong. It is therefore important that health care professionals take this sentiment into account, in whatever reconceptualisation, during the treatment of individuals. Death with dignity and eudaimonia, as proposed by David Shaw (2009), are effectively advocating for much the same end. Shaw's argument creates a new term for dignity as it is ordinarily understood. He states (2009, p. 531) that "it doesn't matter how virtuous you are if you are unable to act virtuously through ill health" and therefore draws on Kantian virtues to preclude some enjoying a perceived good death.

The identification of different categories for dignity helps to realise it as a multifaceted concept, both in a theoretical and empirical sense. It highlights the multitude of ways that disease affects a person's physical and social being. Most importantly for my thesis, it shows how the social, psychological and physical aspects of dignity can all play a role in determining a patient's attitude or request for assisted dying. Again, this reiterates the above point, that integrated models provided in the context of palliative care could be beneficial alongside curative treatment and procedures. It is largely the meritorious and aspirational approaches to dignity that are most commonly employed in respect of pro-assisted dying. Therefore, if legislation is to be enacted, it must also accord provision to properly understand the impact of relying on these approaches when it comes to understanding other forms of dignity as they are commonly bestowed. This does not mean that, having had an inherent dignity, this is taken away from individuals in seeking to provide for an achievement of meritorious and aspirational virtues in life. Instead, the identification of dignities needs recognition within the everyday practice of health care, and drawing on the toolkit as proposed in *Chapter eight*. This must occur in order to actualise the reality of various lived-experiences and bodily malfunctions that people endure and how best to ensure their continued presence within the community.

The body itself, as also considered in the preceding chapter, is a means of expression for the individual and it is through the body that a person is able to connect with other beings. The mind, physically expressed, creates meaning that becomes socially significant for the other bodies around it by picking up signs and symbols through which they are able to connect. As

Diprose (2005) discusses, a body means only something through the expression and sharing of meaning in community with other bodies. The body becomes socially significant in this way as it becomes indicative of identity and value. It becomes something observed by the social groups within which it is embedded and is how a person is perceived by others. What must also be recognised, however, are the discrepancies evident between the dying body and the dying individual. The individual represented by their dying body may not be the individual who is experienced by the self and the reality of life for that being. The use of a dying role, and a more developed concept of such, must be developed to stave off the sick role being applied to those who no longer fit such a label. Further research could help to achieve this by once again pursuing the knowledge and lessons that are bound up within the experiences of the dying individual.

The body, and how it is affected and effected by claims of a right-to-die, has been identified among the literature. Much of this has taken the body, and its physicality, as inherently stable. However, other authors have also been shown to present thoughtful discussion regarding the work that goes into care for the body, and the body in its abject variations. The body cannot therefore remain absent in discussions of assisted dying, as it is a vital tool for informing phenomenological and experiential accounts of those with illness along with those living out their dying trajectory. These discourses, however, need to move beyond those depicted in the media. The mediated imagery provided to the public instead needs to present a reality that is able to both increase and secure the knowledge that informs the social discourses. The maelstrom now feeding off the tragic stories not only takes place within the pages of a broadsheet, but also infiltrates the minute locus of the everyday.

Not even *Shortland Street's* Chris Warner can survive the soap opera that is depicted across various media platforms. Theatrics aside, these portrayals of controversies show just how pervasive certain topics are within a community and their importance within the collective consciousness at the time. The carers have an incredibly strong role to play and their voice makes up the continuation of care that, as Aries (1974) showed, lies primarily within the domestic realms of family life. The (usually female) partners, along with their male counterparts, and children of terminally ill patients must maintain an appearance for the outside world that can no longer be continued for the person they are caring for. These mediated realities show the extent to which discussions of assisted dying are ingrained within the cultural imagery of contemporary society. Their depictions demarcate the boundaries of

discussion and provide readers, the everyday citizens of New Zealand, with frames of reference that help them to engage with and negotiate arguments relating to assisted dying.

Changing discussion and moving forward

Conclusively, it is up to the medical community to acquiesce to the ultimate change. They are the people at the frontline who see and understand first-hand the relationship of the community. The final push must come also from within that same community, as they express their desire for a widespread shift in the way that we come to experience the social process of dying. Much like Lecretia Seales' High Court case, however, everybody must have their say and maybe it is this that maintains the current status quo. Overwhelmingly, there is a need for greater end-of-life care discussion and for changes in attitudes surrounding death. To ensure that it becomes another aspect of life it must maintain its ritualistic structures and the social beliefs which have sought to prevent the idea of death and dying from becoming a threat to oneself. This research has suggested some alternative approaches towards theoretical notions informing end-of-life care. It has contributed to sociological discussion through its provision of such a suggestion and has identified the avenues that could benefit from further integration between interdisciplinary fields. By situating the communal body within the right-to-die argument in New Zealand, this thesis had shown that the current lack of available discourses has, for the most part, rendered a divide between those who campaign for change and those who do not.

To this end, it would be advantageous for further research to be undertaken that promulgates these methods to provide medical consumers with a wider choice of words to articulate their experiences. It goes without saying that these terms must also be brought into the wider health care vocabulary so that the articulations of individual circumstances can be realised in practice. For this to occur, further empirical research is necessary to provide insight and clarity into current actualisations of experience. This can be achieved by looking towards research that has already been done in this area, such as that of Shaw (2014, 2015), and by encouraging the interdisciplinary nature that necessitates end-of-life and assisted dying discussions. Furthermore, studies such as that by Street and Kissane (2001, p. 163) conducted in Australia, and discussed in the previous chapter, stress the importance of understanding individuals' embodied experiences around end-of-life decision-making. Their study analysed the texts from interviews, letters written by those seeking assisted dying, medical and

coronial reports, and media reporting. These methods highlight the difficulty of conducting empirical work in this area, as the nature of assisted dying means that those who access the legislation cannot be interviewed for their subsequent views after the fact.

Within these debates, it is also important to acknowledge how discourses come to be produced and reproduced, and how such discourses are constituted within the frames of reference that people draw on to demarcate their own positions. The inherent moral evaluation that occurs at this level cannot be overlooked. It is within such identification that the interplay between dominant discourses and those of marginalised communities can be evidenced, and it can be ensured that those marginalised voices do not become altogether absent. Perhaps, most poignantly, claims of a right-to-die that are prominent for a pro-assisted dying framework need to be reassessed. Claims to such a right undermine the foundations of other necessary rights. It must of course be noted that just because there have been no identifiable abuses within Oregon, The Netherlands and Belgium, it does not remove the risk that such practices inherently hold. The discussions proposed by the authors referred to in relation to the slippery slope argument posed in *Chapter four* once again highlight how the communal body might be affected by claims around a right-to-die.

There is currently a wealth of literature related to assisted dying, be that specifically focused on the topic or instead informing the wider debate within which arguments and claims are made. Much of the literature has made generous contributions to the formation of assisted dying legislation, and for the production and maintenance of identifiable safeguards that can help to regulate the practice and protect those vulnerable to abuse. Looking towards the literature, however, it also becomes overwhelmingly evident that the typical concepts and phrases that seek to elucidate the assisted dying argument no longer reflect the social situations that we find ourselves in. Instead, with development in technologies and medical apparatus, we have reached a remarkable level of ability. While this should be welcomed, the social ramifications it subsequently brings must be addressed and accounted. Current vocabulary, and the approaches taken within health care provision, provide lessons that ensure that they should not be considered as useless or otherwise obsolete. Instead, recognition is required of the full extent of human experience.

What is required are terms that accurately reflect the ranges of individual being in the world and how these are implicated within the body's deterioration in illness. After consideration, the variations for using the term 'dignity' can be seen as a clear example of the issue. By

emphasising the impracticalities of its use, new approaches that understand the whole body, and recognise its deterioration within the relational experience of others, are required. These must not, however, remain bound by the relative experiences of others, and must we must understand subjective identities by removing the presumption of a universal experience being felt by all. This will be of the utmost importance if Aotearoa New Zealand does indeed enact assisted dying legislation, and will be significant for maintaining the community of bodies in the face of changing, and potentially dangerous, social practices.

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Appendix one

MEMORANDUM

Phone 0-4-463 5676
Fax 0-4-463 5209
Email Allison.kirkman@vuw.ac.nz

TO	Sarah Revell-Dennett
COPY TO	Rhonda Shaw
FROM	Dr Allison Kirkman, Convener, Human Ethics Committee
DATE	12 May 2014
PAGES	1
SUBJECT	Ethics Approval: 20914 The Right to Die and the Communal Body - An examination of the ethical principles and public implications of legalised euthanasia in New Zealand

Thank you for your application for ethical approval, which has now been considered by the Standing Committee of the Human Ethics Committee.

Your application has been approved from the above date and this approval continues until 10 March 2015. If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with the research.

Allison Kirkman
Human Ethics Committee

Appendix two

Phone 0-4-463 5676
Fax 0-4-463 5209
Email Allison.kirkman@vuw.ac.nz

MEMORANDUM

TO	Sarah Revell-Dennett
COPY TO	Rhonda Shaw
FROM	Dr Allison Kirkman, Convener, Human Ethics Committee
DATE	10 February 2015
PAGES	1
SUBJECT	Ethics Approval: 20914 The Right to Die and the Communal Body - An examination of the ethical principles and public implications of legalised euthanasia in New Zealand

Thank you for your request to extend your ethics approval. This has now been considered and the request granted. Your application has approval until 10 March 2016.

If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with your research.

Allison Kirkman
Human Ethics Committee

Appendix three

Phone 0-4-463 5676
Fax 0-4-463 5209
Email Allison.kirkman@vuw.ac.nz

MEMORANDUM

TO	Sarah Revell-Dennett
COPY TO	Rhonda Shaw
FROM	Dr Allison Kirkman, Convener, Human Ethics Committee
DATE	1 March 2015
PAGES	1
SUBJECT	Ethics Approval: 20914 The Right to Die and the Communal Body - An examination of the ethical principles and public implications of legalised euthanasia in New Zealand

Thank you for your request to amend your ethics approval. This has now been considered and the request granted.

Your application has approval until 10 March 2016. If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with your research.

Allison Kirkman
Human Ethics Committee

Appendix four

Phone 0-4-463 5480

Email susan.corbett@vuw.ac.nz

MEMORANDUM

TO	Sarah Revell-Dennett
COPY TO	
FROM	AProf Susan Corbett, Convener, Human Ethics Committee
DATE	2 May 2016
PAGES	1
SUBJECT	Ethics Approval: 20914 The Right to Die and the Communal Body - An examination of the ethical principles and public implications of legalised euthanasia in New Zealand

Thank you for your request to extend your ethics approval. This has now been considered and the request granted. Your application has approval until 31 December 2016.

If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with the research.

Kind regards

Susan Corbett

Convener, Victoria University Human Ethics Committee

Appendix five

Participant Information Sheet

Research Project Title: The Right to Die and the Communal Body – An examination of the ethical principles and public implications of legalised euthanasia in New Zealand

Researcher: Sarah Revell-Dennett, School of Social and Cultural Studies, Victoria University of Wellington

I am a PhD candidate in the Sociology program from the School of Social and Cultural Studies at Victoria University of Wellington. As part of my dissertation I am looking at the ethical principles involved in debates relating to the legislation of euthanasia and how this will impact the community if it is legalised in New Zealand. In order to wholly understand the arguments and implications that such legislation would have I am inviting experts and stakeholders to participate in my research.

Interview data collected will provide contemporary and real life points of view from experts with a range of knowledge on the topic of euthanasia. This data will enable greater insight into the communal understandings and implications of euthanasia legislation. Due to the nature of this project any data used will be directly attributed to the interviewee and may be used in publication before the final dissertation.

Participants will be interviewed using semi-structured opened ended questions about a number of pre-defined topics. Should participants feel the need to withdraw from the project, they may do so without question at any time within six weeks following the interview.

No other persons beyond me and my supervisor Dr Rhonda Shaw will see the transcripts. This project will be submitted for marking in early 2017 to the School of Cultural Studies at Victoria University of Wellington. Assuming you consent to interviewing I would like to retain the data collected for further use with your consent. Please also note that data may be used prior to the publication of my dissertation in publications and/or in conference or seminar presentations undertaken in the future.

This project has received approval from the Victoria University Human Ethics Committee. If you have any further questions or would like to receive further information about this study, please contact me at sarah.revell-dennett@vuw.ac.nz or my supervisor Dr Rhonda Shaw, at the School of Social and Cultural Studies at Victoria University of Wellington, rhonda.shaw@vuw.ac.nz

Sarah Revell-Dennett

Appendix six

Participant Consent Form

Research Project Title: The Right to Die and the Communal Body – An examination of the ethical principles and public implications of legalised euthanasia in New Zealand

Researcher: Sarah Revell-Dennett, School of Social and Cultural Studies, Victoria University of Wellington

I have been given and have understood an explanation of this research project. I have had an opportunity to ask questions and have them answered to my satisfaction.

I understand that I may withdraw myself and any information I have provided from this project, without having to give reasons, by emailing Sarah Revell-Dennett at sarah.revell-dennett@vuw.ac.nz within six weeks following the interview.

I understand that any information I provide will be kept confidential to the researcher and their supervisor, however the published results will use my name and opinions may be attributed to be in a way that will identify me. I also consent to the information being used for future publications by the researcher.

I understand that the data I provide will not be released to others.

I understand that, as this interview is being audio recorded, I will have an opportunity to check the transcripts of the interview.

Please indicate (by ticking the boxes below) which of the following apply:

- ☐ I would like to receive a summary of the results of this research when it is complete.
- ☐ I agree to this interview being audio recorded.

Signed:

Name of participant:

Date:

If you would like to receive a summary of the results of this research please provide an email or physical address below, to which they can be sent.