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Making Sense of Euthanasia
A Foucauldian Discourse Analysis of Death and Dying

A thesis presented in partial fulfilment of the requirements for the degree of

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in
Psychology

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This thesis is dedicated in loving memory of three remarkable, inspirational women:

Mary-Anne Ryan (née O'Brien) 1896-1968

Monica Vera Ryan (née Isaacson) 1926-2009

Rebeca Anne Nathan (Bex) 1986-2013

Abstract

A hugely contentious issue in society today is whether individuals have the right to choose when and how to die. This project examines how people make sense of euthanasia through both a genealogical perspective and an analysis of discourse. The first study presents a genealogy, a Foucauldian ‘history of the present’ that addresses the issue of how euthanasia has emerged as a possible solution to the problem of terminal illness. It investigates the conditions present at particular periods of time and a specific but disorderly collection of incidents that have enabled our present constructions of euthanasia. This genealogy challenges both the origins and functions of our present day ‘knowledge’ regarding euthanasia and the assumptions of self-evidence and inevitability that accompany prevailing discourses.

The second study involved interviews with 28 healthy people from the general population in Aotearoa/New Zealand to explore how they talked about and made sense of death, dying and euthanasia. A Foucauldian discourse analysis of the data revealed meanings of euthanasia that drew on three categories of construction: *identity*, *reciprocation*, and *burden and duty*. The discourses that enable these particular meanings of euthanasia to prevail in our society today and be accepted as ‘common sense’ provide the potential to act in certain ways, while marginalising alternative practices. The way in which people are positioned within these discourses will inevitably shape their understanding of themselves and the world and are pivotal to decisions regarding euthanasia. The power implications of these discursive constructions for vulnerable groups in society are considered in light of the euthanasia debate.

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Ehara taku toa, he takitahi, he toa takitini

Prologue

NORMA

I'm putting up 30 mgs over 24 hours ... even though she's unconscious from the morphine she's had already.

LESLEY

She was unconscious before I gave her the morphine.

Norma finishes with the syringe and turns to face Lesley.

NORMA

And you gave it for pain?

LESLEY

Yes ... I guess...

NORMA

Unconscious people don't feel pain. To give that much is to attempt...

LESLEY

(interrupting)

Euthanasia?

NORMA

(taking a sharp breath)

Euthanasia is illegal in this country.

They are facing off against each other, both deadly serious.

LESLEY

But it's cruel ... she's been through enough ... she's dying ... there's no hope anymore...

(From "...to die like a dog..." Martin, 2002, p. 160-161)

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INTRODUCTION

Death is inevitable and universal, thus it is unsurprising that the approach taken to this final event will provoke strong debate and controversy. Euthanasia is seen by some as the panacea for a problematic dying process with growing demands for its legalisation being fuelled by the increased secularisation of society, advanced medical technologies that can prolong life, rising life expectancies, burgeoning health costs and expectations of individual autonomy. In contrast, other sectors of society, often supported by such powerful institutions as the law, medicine and the Church, express the view that there is no unalienable right to choose when and how to die, but rather a responsibility to continue to maintain life until it reaches its 'natural' conclusion.

Although the great majority of countries including New Zealand have continued to endorse the latter view, a few European countries and a handful of American States have confronted this issue by formalising the right-to-die through legislation. The Netherlands in particular is an example of a society whereby euthanasia is permissible in cases of unbearable physical and psychological suffering and as such is viewed as a 'normal' part of end-of-life decisions. The refusal by other governments to emulate the Dutch 'solution' and permit what many regard as a fundamental human right has led to vociferous opposition and debate.

New Zealand has not been immune to the implications that have arisen from the lack of agreement around this contentious issue. However, it was the Lesley Martin case in 2004 of a daughter 'helping' her terminally ill mother to die and the subsequent criminal trial and resulting publicity that was a defining moment in the trajectory of the euthanasia debate in New Zealand. It polarized the nation and brought into new focus the complexity of the concerns and viewpoints of different factions of the population in a way which previous attempts to draw attention to the matter had failed to achieve.

The intense nature of the debate in New Zealand society today was very evident as I began my PhD in 2009. This was highlighted very early on when I tried to attend a seminar/workshop being organised and facilitated by Dr Philip Nitschke, often dubbed by

the media as 'Dr Death', an Australian advocate of euthanasia and founder of the EXIT organisation. The venue at a Presbyterian church in Wellington was suddenly cancelled following strong protests from pro-life organisations and it was only at the last minute that a suitable alternative was found and the meeting was able to go ahead. While Nitschke accused Church officials of attempting to silence the euthanasia debate, his intention to launch a new suicide kit at these meetings was strongly criticised by fellow euthanasia advocate Lesley Martin who described his actions as, "repackaging death like it's a cheap hamburger" (Williamson, 2009, p.3).

Shortly after this event, my own small hometown was rocked by the tragic case of an elderly, terminally ill local man who was charged with being party to a suicide pact that he had survived but had resulted in the death of his chronically ill wife (Blundell & Williamson, 2009). Despite his death from cancer before the trial could take place, the ramifications of the incident opened up fault lines in the community that reflected the deep divide in opinions engendered by the euthanasia debate.

An on-going, steady stream of media-highlighted euthanasia cases in New Zealand continued to be aired throughout the period of this study. These included for example, a 60-year-old woman who elected to starve herself to death after 20 years of living a totally dependent life following a brain haemorrhage. Three psychiatric assessments found her to be mentally competent and her right to refuse treatment, in this case food and drink, was upheld (Newton, 2010). Another high profile case the following year that shared many similarities to the Lesley Martin situation again saw an adult child charged after administering a cocktail of crushed morphine to a terminally ill mother and writing about the experience. Sean Davison was convicted of procuring and inciting suicide and sentenced to 5 months home detention (van Beynen, 2011). As this research draws to a close, euthanasia is again in the spotlight with a coroner urging Members of the New Zealand Parliament to make a decision on the issue. This call has come as a result of his ruling of "euthanasia by suffocation" in the death of an elderly woman who procured her suicide in accordance with her strong support of the right-to-die (Duff, 2013, p.1).

The widespread media coverage here in New Zealand and indeed internationally is indicative of a society grappling to come to terms with the difficult issue of euthanasia. However, this research does not propose to engage with concerns of morality or ethics that are often seen as being fundamental to the debate. Rather, it is interested in how people make sense of euthanasia as I would argue that this could provide essential insights into who we are in relation to each other. I propose to utilise a Foucauldian perspective to explore the discourses that people draw upon to construct euthanasia. The central focus on language in this study is a reflection of what Willig (2001) describes as the importance of discourse not only for the way we perceive the world and the things that can and cannot be said and done, but for the wider social implications of the relationship between discourses and institutions and the corresponding issues of power and legitimatisation. The following is an outline of the structure and content of the thesis that takes a critical stance to the current euthanasia debate.

Chapter One introduces the topic by critically examining the literature surrounding euthanasia and in doing so demonstrates the importance of the present study. The key concepts and terms relevant to the research area are investigated and the problems regarding terminology and meaning are highlighted. A variety of key studies concerning areas of incidence and prevalence, vulnerable groups, and attitudes are then reviewed with particular attention given to the lack of consensus in the current literature as a consequence of the impact of issues of methodology and definition. Juxtaposed with these studies is a small selection of qualitative approaches that consider the social construction of euthanasia. These provide a glimpse of the possibilities offered by the present study to contribute to our understanding of 'how people make sense of euthanasia'.

Chapter Two outlines the theoretical framework that provides the guiding structure to this research project. Social constructionism is seen as offering a critically different but potentially more productive approach to the research question. Drawing as it does on alternative understandings of ontology and epistemology from that of positivist methodologies, it is argued that it will enable a more far-reaching consideration of the issue. The importance also of engaging with the theoretical constructs offered by the work

of Michel Foucault is shown to be essential if we are to be able to view euthanasia through a fresh lens. His particular conceptualisation of concepts such as power, knowledge, discourse, subjectivity and governmentality are explained and shown to be part of the very foundations of the present study.

Chapter Three utilizes the device of a Foucauldian genealogy to examine how euthanasia as a possible solution to a problematic dying process has emerged. It considers a small range of events within different historical periods that have allowed certain discourses and practices regarding euthanasia to emerge. The importance of this work in undermining presuppositions and assumptions of inevitability about euthanasia are highlighted. Thus, this chapter attempts to emulate the work of Foucault by questioning whether present understandings of euthanasia and the ‘apparatuses’ that surround it are an obvious response to terminal illness or a peculiar arrangement specific to this historical period and cultural milieu that has the effect of limiting the possibility of alternative ways of thinking and acting.

Chapter Four turns to the methodology adopted in undertaking a Foucauldian discourse analysis. It assumes a reflexive approach in order to provide the reader a clear indication of the methods employed and the rationale for those decisions. In line with the theoretical underpinnings of the study, the chapter begins with a consideration of the researcher’s own impact on the research process and reflects on issues of recruitment and ethical and safety concerns. The participants are introduced in order to both highlight their pivotal role in the research and to contextualise the data collection process. The interview schedule and organisational procedures are discussed and the tasks of transcription and analysis are explained.

Chapter Five commences the analysis that encompasses the importance of the context in which the study is undertaken. Aotearoa/New Zealand is a bicultural, post-colonial society, therefore the relevance and significance of exploring both Western and Māori understandings of euthanasia is recognised. The analysis begins by considering the important concept of identity at the end-of-life. Discourses of physical appearance, leaky

bodies and a mind/body dichotomy are seen to contribute to constructions of identity that are very problematic to the Western notion of autonomous selfhood. The lack of synchronisation between social and biological death that is characteristic of modern, protracted ways of dying is viewed as contributing to the uncertainty surrounding what it means to be a living human person. The significance of the desire for life's project of the self to live on after death is explored with a particular focus on Māori cultural perceptions of the wairua. Finally, the implications of these constructions of identity for end-of-life decisions are considered.

Chapter Six explores the centrality of reciprocation to meanings of euthanasia. The obligation to repay what we receive from others is a strong societal norm that extends into all facets of human interaction including final decisions regarding 'life's worth'. This concept is measured against criteria that include present and potential value to society, but the assessment is tempered by claims for a 'fair deal' from society in repaying past contributions. However, a differing cultural perspective in regards to kaumātua reciprocation is highlighted with suggestions as to the potential consequences this may present for Māori in the future. Discourses of religious reciprocity and ownership of life itself are also considered in this chapter in light of the influential role they play in the current euthanasia debate.

Chapter Seven deals with the inter-related notions of duty and burden that are also closely connected to the construction of reciprocation discussed in the previous analytical chapter. In particular, the temporal dimension of the different modes of dying is viewed as significantly impacting on the sense of duty and the perception of burden. This is especially salient when viewed from a standpoint of intergenerational responsibility. The objectification of the elderly and terminally ill as a burden, leads to a loss of selfhood that is to be resisted at all costs. This is further reinforced by the inherent threat of this new classification to the highly prized ideals of autonomy and independence. The subject positions offered by these various discursive constructions provide certain perspectives of the world and ourselves that have far-reaching effects for end-of-life decisions.

Chapter Eight brings together the findings of this research with some accompanying commentary. It reiterates the problems and constraints presented by a positivist approach to the topic and the perceived benefits of the present study. However, some of the methodological decisions and pathways taken in the research are critically examined and the limitations of the study explored. The insights offered by the genealogy of euthanasia, coupled with the discourses identified in the discursive analysis are considered in light of how they shape the ways in which people make sense of euthanasia. The implications of these ‘findings’ are then discussed.

CHAPTER ONE

Critical overview of euthanasia literature

This literature review engages with a poststructuralist perspective that recognises that there are many ‘versions’ of truth and as such it is important to critically examine a range of research approaches in order to attempt to make sense of euthanasia. Therefore, it will consider both the wealth of mainstream, largely quantitative studies alongside more qualitative research that all highlight in different ways the present uncertainties and contradictions that characterise the debate on euthanasia. Furthermore, it will lay the groundwork for how this present study is able to contribute to the body of knowledge in this area.

Introduction

The study of death and dying has a long history of representation within the research literature. Furthermore, the changing face of death in our post-modern medicalised society that values choice and autonomy has also ensured that a wealth of ‘knowledge’ has been accumulated around the phenomenon of euthanasia. The present study seeks to elucidate the ways in which people make sense of this end-of-life decision. Their understanding will inevitably be shaped by the common sense knowledge about euthanasia that abounds in our particular historical period and cultural setting. Therefore, it is important in laying the foundations for this research, to begin with a critical overview of the existing knowledge base.

The review is structured so that it commences with a crucial aspect of the literature – the terminology and meaning of euthanasia. This involves a consideration of the issues surrounding the complex negotiation of a tangled web of concepts and their meanings, including the relationship between suicide and euthanasia. The challenges that these on-going attempts at categorisation pose for incidence and prevalence data are then discussed. Possible interpretations of the alleged ‘slippery slope’ associated with the legalisation of euthanasia are also considered. This is followed by a critical examination of the large body of research into attitudes towards ‘hastened death’. Finally, the literature review traces a

path through some studies examining representations of a good death and media portrayals of euthanasia. It is through these particular approaches that the fundamental importance of reflecting on the social and cultural perspectives of euthanasia is brought into clear focus.

Definitional issues and terminology

There is a myriad of terms within the euthanasia literature to explain the phenomenon, all conveying different meanings in different contexts; for example, passive and active euthanasia, voluntary, non-voluntary and involuntary euthanasia, assisted suicide and mercy killing, to name but a few. It is important to highlight these definitional issues as different terms will have diverse connotations that have the potential to influence and shape our perceptions of the phenomenon. However, as Kelleher (1998) points out, no one can claim the right to determine the meaning of a word, it is only in its everyday usage and scholarly treatment that the meaning becomes negotiated. The navigation around terminology and the negotiation of meaning is an on-going activity and the stakes are high as the terms and definitions most accepted by society will undoubtedly mould the way people make sense of euthanasia.

Euthanasia is perhaps the most common term used to describe the taking of another person's life to end intolerable suffering. Today it is usually accepted as either the administration of a substance to bring about the death of a person, referred to as active euthanasia; or the withdrawal or non-commencement of life-sustaining treatment, passive euthanasia. It should be noted however, that the latter case of non-intervention in the dying process is often strongly resisted as being considered a form of euthanasia (Rosenfeld, 2004). Indeed, Allen (1998) suggests that switching off life support systems is so widely practised and accepted that many medical practitioners refuse to categorise it as euthanasia. Yet another category of life-ending behaviour has been coined 'auto-euthanasia' in the Netherlands by Chabot (2007, cited in Norwood, 2009). This is described as a type of suicide usually carried out for medical reasons and in consultation with others but without the assistance or sanction of a physician. It typically takes the form of discontinuing nutrition or taking a lethal dose of drugs.

The administration of pain medication in large dosages with the intention of relieving suffering even though the harmful side effects may hasten death does not fall under the 'established' umbrella of euthanasia in either a moral or legal sense. Such a situation is termed 'double effect' because although the intent is to ameliorate pain, it is recognised that it may also have fatal consequences. This however, is accepted as permissible by many traditional religions, indeed Catholic moral theology argues that in these circumstances it is justifiable to cause evil in the pursuit of good. The focus on the intention of the act is also the critical issue at stake in criminal matters (Kelleher, Chambers, Corcoran, Keeley & Williamson, 1998). Thus, if the intention is to alleviate pain and distress rather than to cause death it is not considered an illegal act. However, there are others who would argue that the commonly used morphine drip is just euthanasia by another name (Humphrey & Clement, 1998). The strong resistance to the categorisation of this medical procedure as euthanasia, supported by the full weight of the moral authority of the Catholic Church and the legal system, is very indicative of the intense struggles involved with negotiating terminology.

Analogous to the morphine drip and viewed in much the same way is terminal sedation where a coma is induced by the use of barbiturates, and artificial nutrition and hydration are removed, leading to death by starvation and dehydration. Proponents of right-to-die legislation have ridiculed the situation where although the result of terminal sedation is death, it does not meet the legal definition of killing. There have also been concerns expressed about the problematic nature of attempts by the American Medical Association to differentiate between terminal sedation and euthanasia in the U.S. (Battin, 2005). Griffiths, Weyers and Adams (2008) have argued that there needs to be a distinction drawn between terminal sedation where the practice itself causes hastened death and what they term 'palliative sedation' where the intention is to procure a deep sleep until death. Again, it is the notion of intention that is being utilised in this effort to distinguish between the meanings of these acts. Raus, Sterckx and Mortier (2011) suggest that yet another term, 'continuous sedation' is more descriptive and circumvents the debate surrounding intention and the associated use of these different labels for sedation at the end of life.

A distinction is also made between voluntary euthanasia, non-voluntary euthanasia and involuntary euthanasia. The term voluntary euthanasia refers to the definition that many people would like the meaning of the concept to be limited to, that is, a lethal substance is given to end life by agreement and at the specific request of the patient. However, as emphasised previously (Kelleher, 1998) language is a living thing that cannot be limited or subjugated in such a way. Therefore, despite the desire to categorise euthanasia in a certain manner, the on-going tussles over definitions and terminology are unavoidable.

Non-voluntary euthanasia is the ending of a life when the person is incompetent and cannot give consent. This is also sometimes referred to as LAWER; life-terminating-acts-without-the-person's-explicit-request, and is often instigated by the family or physician on behalf of the patient and in their 'best interests'. The distinction between voluntary and non-voluntary euthanasia can also involve a time element (Kelleher et al., 1998). It may be that a person has indicated a desire for euthanasia at an early stage of illness while still competent but due to the progression of the illness may become incapable of competently confirming this request.

Involuntary euthanasia, on the other hand, is bringing about the death of a competent person in order to end their suffering but without their consent. Although legally regarded as murder, the fundamental difference between murder and involuntary euthanasia lies in the motive. There is no malice in involuntary euthanasia but rather the intention of doing good and benefiting the person; a principal of health care known as 'beneficence' (Rosenfeld, 2004). In a similar way, more common in jurisprudence literature, mercy killing is a term that encompasses voluntary, non-voluntary and involuntary euthanasia and while highlighting that a person is killed, it emphasises the compassion involved in such a killing.

Assisted-suicide involves a person terminating his or her own life with assistance in the form of provision of a lethal substance or device with guidance on its correct use. However, the substance or other methods of termination must be self-administered. In many cases the assistance is from a physician (physician-assisted suicide, PAS) and it is this particular

mode of ending life that has been the focus of attempts for legalisation in the United States. The more general term 'elective death' includes the decision to cease life-sustaining treatment (passive euthanasia) as well as assisted suicide and voluntary euthanasia. It tends to emphasise the optional nature of the choice to die. In a similar way 'hastened death' can be used to describe all aspects of ending life prematurely but it implies that the person is already dying. Another general term used to cover all of the above, which also emphasises the medicalisation of death, is medical behaviours that potentially shorten life (MBPSL).

Acknowledging and examining the connection between suicide and modern day euthanasia is important for clarifying the distinction between terms that often include conceptual overlap. For example, Kelleher et al. (1998) point out that suicide, PAS and voluntary euthanasia all involve the individual choosing to bring their death forward in time. However, they make a distinction regarding suicide on the grounds that not only is the method frequently more painful and unpleasant but it is usually carried out alone as opposed to being the result of the implementation of a contract between at least two people. Canetto (2008) also highlights the variability in the definition and recording of suicidal behaviour, particularly within different cultures. For example, in some countries a death that is not self-inflicted or even chosen voluntarily can still be treated as a suicide such as the ritual killing of widows in parts of Papua New Guinea and the practice of sati in India. In contrast, other behaviours that in the Western world would be termed suicide or even murder may be reported as accidents, for example the often fatal domestic burning 'accidents' of young married women following dowry disputes.

The language used to talk about suicide has also changed over time. The word 'suicide' was not coined until the mid-seventeenth century. The ancient Greeks and Romans used a variety of verbs to describe the deliberate act of taking a life, with the Greek term *autocheir* (to act with one's own hand) used to cover a range of acts. Szasz (1999) argues that this term implied a voluntary choice and the linguistic transformation to the noun suicide was a later Western European invention. This had the effect of avoiding stigmatising references to murder, albeit self-murder, but also had the consequence of shifting the responsibility from

the actor to an act for which he may not be able to be held accountable. He contends that this paved the way for suicide to be aligned with mental illness.

Émile Durkheim, a French social philosopher published the first scientific study on suicide in 1897 by analysing statistical data on rates of self-destruction (Evans & Farberow, 2003). He developed four typologies of suicide related to an individual's relationship with society. According to Durkheim the most common type of suicide is egoistic which results from a disconnection with, and alienation from society. Anomic suicide is triggered by major changes in society to which a person cannot adjust, while fatalistic suicide is a consequence of over-regulation such as experienced by prisoners or slaves. Finally, altruistic suicides are acts of self-sacrifice where a person's integration into society is so complete they are ready to give up their own life in the interests of the wider group.

We need to bear in mind the possible impact that these categories of self-destruction may have on end-of-life decisions. Norwood (2009) for example, evaluated whether flaws in the relationship between the individual and society, as suggested by Durkheim, could be contributing to the desire for and practice of euthanasia in the Netherlands. In particular she considered whether euthanasia was a form of altruistic suicide, with the Dutch being over-integrated within their society to such an extent that they choose an early death as a response to a terminal prognosis for the benefits of the wider community. This altruistic approach to end-of-life practices has certainly been proposed by others as a concept for consideration, as we will see later.

A further issue addressed by Norwood (2009) was the potential for other types of suicides to utilise the legal channels of euthanasia to disguise a non-legal act. However, she contends that in the Netherlands euthanasia and assisted dying are not an expression of a death wish but rather provide "an insurance policy for future suffering" (p.76). Moreover, she suggests that quantitative data supports this view in that only a small proportion of those who initiate requests for euthanasia or assisted suicide in both the Netherlands and Oregon actually die in this way. However, Hendin (1995) argues that there is no significant difference between a suicidal person and a seriously or terminally ill patient requesting

euthanasia and in countries where euthanasia and PAS have been legalised there is the propensity to confuse the two groups. He points to the reduction in suicide rates for the over 50s in the Netherlands as coinciding with the legalisation of these end-of-life options. Norwood (2009) also acknowledges this concern in that data is reliant on physician self-reporting and thus may disguise some problematic situations that could possibly be categorised as suicide.

The process of finding similarities and differences in the behaviours related to end-of-life decisions can be seen as an attempt to discover pre-existing categories in some 'objective reality'. This labelling procedure is a discursive activity and the particular categorisation decided upon will have significant moral implications (O'Connor, 1997). Furthermore, the various concepts that are constructed will provide a framework for our understanding of euthanasia that will have power implications. It is unsurprising then that as pointed out by Rosenfeld (2000) the differences among the terms are significant enough to lead to varying degrees of acceptance by society. Many of the definitions are keenly contested and it is important that consideration is given to how the meanings may be functioning and what they are achieving when drawn upon in certain contexts.

Incidence and prevalence

Attempts to uncover the incidence and prevalence of euthanasia are fraught with the difficulties associated with the continuing negotiation of definitions and terminology. Rosenfeld (2000) warns that many studies designed to provide empirical data regarding euthanasia practices have been limited by a range of procedural issues. Critical to these concerns are the problems that arise in operationalising the dependent variable. If medical practitioners have differing conceptualisations and understandings of euthanasia then the measurement of its occurrence is likely to be highly variable. Indeed, Emanuel (2002) in a review of data for the frequency of euthanasia and PAS in the United States found rates that varied more than 6-fold between some studies.

A number of researchers have adopted a survey methodology to investigate incidence rates that despite the most careful wording is open to different interpretations. For example,

Emanuel, Daniels, Fairclough and Clarridge (1998) point out that some medical practitioners will categorise the withdrawal of life-sustaining treatment as euthanasia despite attempts by researchers to remove it from their definition. There will also be variations in reported frequencies depending on whether the survey is mailed or carried out by phone (Emanuel, 2002) where these differences in interpretation are possibly easier to control. Furthermore, the date that surveys were carried out will also impact on the reported incident rates of euthanasia because over time it has become more acceptable for physicians to acknowledge these practices (Emanuel, 2002).

Despite conflicting evidence regarding incidence rates and the methodological concerns discussed above, a number of studies indicate that although rare, some medical practitioners have carried out euthanasia or PAS in the United States despite its illegality in most States (Emanuel, 2002). In a similar way, results from a postal survey of practicing doctors in Australia (Kuhse, Singer, Baume, Clark & Rickard, 1997) revealed that despite the absence of legislation 1.8% of deaths involved euthanasia or PAS and 30% of all deaths resulted from a medical decision that had the explicit intention of hastening death. According to the authors, these findings indicate a much higher rate of hastened death in Australia than has been recorded in the Netherlands where such practices are legal.

In contrast, a national postal survey of medical practitioners end-of-life decision-making in the UK (Seale, 2006) using the same translated Dutch questionnaire as the above studies showed a quite different picture. Although there was some evidence of both voluntary and involuntary euthanasia and PAS, the proportion of these doctor-assisted deaths was extremely low. Instead, there appeared to be a high rate of non-treatment decisions that the author attributed to the strong palliative care culture found in the UK. It was also suggested that the low rate, particularly among general practitioners (GPs), might reflect the impact on the medical profession of the infamous UK doctor Harold Shipman and his conviction for killing of patients by lethal injection (“Harold Shipman”, n.d.).

A difficulty identified by New Zealand researchers (Mitchell & Owens, 2004a) in the analysis of previous incidence studies was that context was lacking for data on the

availability of palliative care. This is certainly a salient issue, particularly as Seale (2006) has claimed that the strong palliative environment in the UK has meant that few physicians have needed to resort to euthanasia or PAS. Mitchell and Owens (2004a) used the last death attended in the previous 12 months as a reference point in a national survey of New Zealand GPs using an anonymous questionnaire. Although this can only access incidence rates indirectly and may underestimate actual practices, it ensured that there was consistency with the prior studies discussed. Results showed that despite the absence of legislation for euthanasia some forms of death hastening were occurring anyway. In particular 5.6% of the 1255 general practitioners who responded indicated that they had carried out actions that were synonymous with euthanasia or PAS and it was apparent that this was not related to a lack of access to palliative care. Furthermore, there was at times a lack of consultation or discussion with the dying person prior to the life-terminating act. While seen by some as highly 'sinister' and controversial, the authors offered up a range of more benign reasons for the data. These included the patients' extreme closeness to death that led them to interpret the actions as "shortening dying rather than shortening life" (p.6).

Although these findings suggest that covert practices of euthanasia and PAS are being carried out both here in New Zealand and in other countries without legal sanction it is important that these studies are viewed with some caution. As previously discussed it is very difficult to ascertain absolute incident rates with this type of methodology due to the many limitations, but an even more fundamental question is how do we interpret these findings? For example, Mitchell and Owens (2004a) suggest that their data on the rate of euthanasia and PAS in New Zealand may be construed in a number of ways. In some cases it may reflect a lack of palliative knowledge on the part of GPs on how to achieve pain relief without causing death. Alternatively, they suggest that the participants may have in fact provided legally sanctioned terminal sedation but 'incorrectly' reported the act as euthanasia because it had hastened death. Yet a further possibility was that the time interval between the last attended death and the survey may have allowed for some cognitive rationalisation of the actions so that the response did not 'correctly' match the 'reality'.

Searle (2006) claims that it is important to have empirical data regarding the incidence of these practices in light of the current debate around the legalisation of euthanasia and PAS in many countries. However, it is difficult to see how such conflicted, one-dimensional information can inform the debate in any meaningful way. As Mitchell and Owens (2004a) comment, “Trying to access empirical data on such a complicated and potentially sensitive activity such as medical decision-making at the end of life is extremely difficult. A questionnaire cannot do justice to the complexity of such decision-making” (p.8). The difficulty of obtaining reliable data in jurisdictions where such practices are illegal also needs to be recognised. For example, despite ensuring the anonymity of responses, self-reporting of illegal actions is likely to be underestimated (Searle, 2006) and will quite possibly contribute to a low response rate to questionnaires (Mitchell & Owens, 2004a).

Therefore, the availability of data from a number of large-scale national studies that have been carried out in the Netherlands since the 1990s has been considered invaluable. These studies have been able to track the frequency and characteristics of euthanasia and PAS in an environment where such practices have been decriminalised since 1984 and legalised since 2002. However, despite mechanisms for societal control of these end-of-life decisions, the prevalence data is still so sensitive to its measurement protocol that it also must be regarded with extreme caution. A study in 1990 utilising both interviews and questionnaires based on death certificates showed that euthanasia accounted for 1.7 % of all deaths and PAS 0.2% (van der Maas, van Deldon, Pijnenborg & Looman, 1991). However, this data was reliant on the reporting rate for such practices that according to Smets et al. (2010) was only 18%. The introduction of a new, more stringent reporting procedure after 1990 resulted in a tripling of reported cases. When these were evaluated in an identical study in 1995 (van der Maas et al., 1996) the incidence of euthanasia had increased to 2.4% but there was little change in the rate of PAS. In 2001 the situation had seemed to stabilise with only a slight increase in euthanasia to 2.6% and PAS remaining constant (Onwuteaka-Philipsen et al., 2003).

However, van der Heide et al. (2007) found a significant reversal of these trends in a follow-up investigation in 2005 to evaluate the effect of the Euthanasia Act that had

legalised what was already an existing practice. Findings showed that 1.7% of deaths were due to euthanasia and 0.1% was the result of PAS, indicating a significant reduction in these interventions following the enactment of the euthanasia law. However, the authors suggest that this may have been due to an increase in the use of other death hastening procedures such as terminal sedation. Indeed, Sheldon (2007) has reported concern within the Netherlands regarding this increasing trend for terminal sedation that removes much of the 'red tape' associated with euthanasia and PAS. The most recent study in 2010 (Onwuteaka-Phillipsen et al., 2012) showed that the frequency of euthanasia had increased again since 2005 to a rate of 2.8% that was comparable to the rates prior to the legalisation of the practice. The rate of PAS remained at a low level while instances of terminal sedation continued to rise.

Although this suggests that both euthanasia and PAS appear to be relatively uncommon social dying processes in the Netherlands, the multitude of issues associated with its measurement render this incidence data virtually useless. Onwuteaka-Phillipsen et al. (2012) claim that the strength of their study, and indeed the other large-scale national studies in the Netherlands, lies in the large representative sample, high response rate and availability of data from the past 20 years. However, they also acknowledge what can be seen as a significant limitation; the information is ultimately reliant on the physician's interpretation. If, as we have seen, there is no consensus as to the meaning of the various terms for the construct under study, then the measurement of it will be fundamentally flawed. This further highlights the importance of research that can go beyond these positivist attempts to capture the intricacies of end-of-life decisions.

The 'slippery slope' and vulnerable groups

Critics of euthanasia often cite the 'slippery slope' argument that holds that the legalisation of assisted suicide and euthanasia will inevitably lead to the acceptance of patients being helped to die at the end-of-life even against their will, particularly those belonging to vulnerable groups. Norwood, Kimsma and Battin (2009) examined what is known metaphorically as the 'hole in the dyke' argument in the Netherlands. Their findings from an intensive qualitative study over 15 months, which focussed particularly on vulnerable

patients at the end-of-life, indicated no evidence of this type of abuse. They based this conclusion on the observation that euthanasia in the Netherlands is more about the process of talk rather than the act. As will be discussed later, this talk is supported by the cultural concept of *overleg* or deliberation, which functions to maintain social bonds and sustain life.

However, it has been claimed that even supporters of assisted suicide and euthanasia in the Netherlands do not advocate a similar system of legalisation in the United States due to the differing system of health care in that country that they believe has the potential to contribute to this 'slippery slope' (Hendin, 1997; Humphry & Clement, 1998). They point to the inequitable distribution of medical care as significantly increasing the dangers of death for profit, particularly for vulnerable groups. This opinion is mirrored by the oft-quoted report of the New York State Task Force on Life and the Law (1994):

The risk of harm is greatest for the many individuals in our society whose autonomy and wellbeing are already compromised by poverty, lack of access to good medical care, advanced age, or membership in a stigmatised social group. The risks of legalising assisted suicide and euthanasia for these individuals, in a health care system and society that cannot effectively protect against the impact of inadequate resources and ingrained social disadvantages, would be extraordinary.

However, Szasz (1999) believes that the idea that universal health care can protect against abuses is an illusion. Although a patient does not have to pay for euthanasia in the Netherlands, he argues that finance will still have a strong impact on health care. Whether or not medical services are paid for by individuals, insurers or the Government, it is clear that the cost effectiveness of euthanasia and PAS to both the patient and society provides a strong incentive to accept this option.

It is important then that the social context and its implications for end-of-life decisions are considered. Wolf (1996) has expressed concern that this has been lacking particularly in the area of gender. Some studies suggest that there is a definite gender trend in assisted suicide

and mercy killing that shows women account for a far higher percentage of the deaths. Although legal constraints in America, prohibiting such practices have made it difficult to elicit information regarding these cases, a unique set of data became available with the high profile suicides assisted by Dr. Jack Kevorkian, a retired pathologist in Michigan. Canetto and Hollenshead (1999-2000) carried out an analysis of seventy-five suicides that Kevorkian acknowledged assisting in between 1990 and 1997. They found that a significant majority (72%) were women, which they claimed was particularly interesting when considered in light of National Statistics on suicide cases where women are a minority (Canetto 1995). This would support the notion that “the gender psychology of assisted suicide is different from the gender psychology of self-inflicted death” (p.182, Canetto & Hollenshead, 1999-2000), and certainly warrants further investigation.

Although acknowledging that these findings may not be typical or representative of all doctor-assisted suicides, Canetto and Hollenshead (1999-2000) discuss a number of possible explanations for this disturbing gender trend. Women live longer than men and are more likely to suffer from chronic illness but have fewer economic and social resources. Their choices for care are limited by these disadvantages and therefore assisted suicide may be seen by them and by others as entirely appropriate. This perception may be reinforced by a cultural bias towards devaluing women’s lives and a societal expectation of feminine self-sacrifice with a lessened sense of entitlement. Canetto and Hollenshead (2002) suggest that if women are only presented with limited options then although a decision to expedite death may indeed be rational and reasonable it does not represent a real ‘choice’ and may indeed become more of a duty.

On the other hand, this concern was not supported by research regarding vulnerable groups in either the Netherlands or Oregon where there has been legalisation of euthanasia and PAS (Battin, van der Heide, Ganzini, van der Wal & Onwuteaka-Philipsen, 2007). In a wide-ranging study that compared the statistics for PAS in Oregon from 1998-2006 and PAS and euthanasia in the Netherlands in 1990, 1995, 2001 and 2005 no evidence was found of a higher rate amongst women in either jurisdiction. The findings showed that as well as being no heightened risk of assisted suicide or euthanasia for women, there was also

no evidence of the economically or socially disadvantaged or other minority groups being targeted. However, in light of indications by Norwood (2009) of the exclusion of some members of society in the Netherlands from the euthanasia discourse it would seem pertinent to question whether these findings are more a reflection of this inequality of access rather than evidence of a lack of abuse of vulnerable groups. Furthermore, the serious methodological flaws associated with prevalence data that were discussed previously need to be taken into account when considering the utility of these findings.

Even if evidence suggests that women are not over-represented in statistics of those ending their life by euthanasia or assisted suicide, Wolf (1996) presents a strong case for a thorough analysis of the role of gender in hastened death. She points to the prominence in the media of cases featuring women wishing to die, against a historical and cultural background that validates women's selflessness, as creating an image of logic and aptness about the women's deaths that should ring alarm bells. In addition to this milieu is the concern that women may seek assisted suicide or euthanasia because of limited access to quality health care leading to insufficient pain-relief and a greater degree of depression. This may be further exacerbated by inadequate financial and social support. Their motivation therefore, may not be death itself but escape from an impossible situation; this idea finds support in gender trends in attempted suicide statistics. The decision by a physician to support a hastened death may be subject to gender bias as well.

Fitzgerald (1999) also calls for a wider analysis of the euthanasia debate and a framework that incorporates the recognition of the broader social context that will inevitably impact on euthanasia decisions. Her concern is that the perspective of many marginalised groups, particularly people with disabilities, has been absent from the debate. Therefore, it is necessary to gain an insight into the daily experiences of people living with disabilities that can possibly challenge notions of autonomy and the conceptualisation of 'lives not worth living'. Fitzgerald further argues that societal stereotypes of disability encourage people with a disability and their families to seek euthanasia as a solution and for doctors to be more likely to accept the request as a rational choice. The historical portrayal of disability

and the traditional role played by medicine and the law in controlling the lives of people with disabilities has the potential, she warns, to be expressed in euthanasia.

The cultural distinctiveness of death also needs to be further investigated in relation to euthanasia and assisted suicide. For example, in the United States it has been suggested that the discourse of the right-to-die may not be as prevalent in non-European/American groups (Canetto & Hollenshead, 2002). Analysis of the ethnicity of those who chose to die by assisted suicide in Oregon showed that 97% were white. Similarly, 96% of those who were assisted to die by Dr. Jack Kevorkian in Michigan were also white (Canetto & Hollenshead, 1999-2000). This is reflected in the membership of the Hemlock Society, a national right-to-die organization in the United States, which is 95% white (Kamakahi, Cossman & Fox, 2001). It would seem reasonable to suggest that there are not only different perceptions of death and dying amongst various groups within a culture but also between different ethnic groups and societies.

Attitudes

Studies carried out in countries where euthanasia and PAS have not been legalised usually involve attempts to measure attitudes towards these end-of-life decisions (Onwuteaka-Phillipsen et al., 2012). The vast majority of this research has been carried out within a humanist paradigm that characterises the traditional Western world-view. Thus, it assumes that a person's thoughts, emotions, behaviour and experiences are a reflection of some inner, unique, definable qualities (essentialism) that we can somehow capture (Burr, 2005). Typically these studies rely on responses to a limited set of questions that seek the opinion of the general public, medical professionals and terminally ill patients.

Although the variable quality of such studies has led to a wide range of results, some general trends can be identified. A review of public opinion surveys regarding euthanasia and PAS in America (Emanuel, 2002) led the author to recommend using the 'Rule of Thirds' in order to gauge a sense of public attitude. The studies indicated that approximately one third of Americans supported euthanasia and PAS, one third opposed these practices, but the final third were influenced in their opinion by the circumstances. Therefore reports

of a two-thirds majority in favour of euthanasia and assisted suicide are somewhat misleading, according to Emanuel. Trends also indicated that a rise in support for these interventions took place in the mid-1970s and has remained relatively stable since then, which is comparable to the situation in the Netherlands. Surveys of public opinion in the United Kingdom and Australia have also consistently suggested that a majority of laypeople favour euthanasia and assisted suicide (Searle, 2009; Sikora & Lewins, 2007).

In New Zealand public opinion surveys purport to show that a majority of the general public support a law change to allow for the 'right to die' under certain circumstances. For example, a survey carried out by a Massey University researcher in 2009 (Gendall, 2010) found that support for euthanasia or assisted suicide was dependent on the issue of pain management. In the case of a painful, incurable disease 69% agreed with a doctor being allowed to end the patient's life if requested. However, if the pain could be medicated the proportion of New Zealander's supporting assisted suicide or euthanasia dropped to 45%, with those in opposition rising from 19% to 39%. Similarly, in the case of complete physical dependency on others in the absence of pain or a terminal disease 44% agreed with the person's right for the termination of life, and 39% disagreed. Although the management of pain is an influential factor in people's attitude to euthanasia and assisted-suicide, the author emphasised that it also needs to be recognised that there are significant groups of the population who are either in favour or opposed regardless of the circumstances.

However, the research findings on attitudes suffers similar limitations as the work on prevalence and a good deal of prudence needs to be exercised when interpreting the results of these studies as there are a number of issues regarding their comparability (McCormack, Clifford & Conroy, 2012). The differences in the formulation of definitions of euthanasia and assisted suicide as well as the participants' own perception of the various terms utilised will undoubtedly impact on participant responses. Furthermore, variability in the actual phrasing of questions will also affect the results. Indeed a study by Gamliel (2012) demonstrated that participants were more willing to support euthanasia if it was presented in a positive frame of 'not prolonging life' rather than the more negatively framed 'ending

life' despite the fact that it was an identical scenario. Therefore, relatively minor changes to the wording of questions in a survey or interview can have a profound effect.

In contrast to the general public, international comparative studies have shown that the attitudes of medical practitioners towards euthanasia and PAS are less favourable (Emanuel, 2002; McCormack, Clifford & Conroy, 2011; Mitchell & Owens, 2004b; Neil, Coady, Thompson & Kuhse, 2007; Searle, 2009). However, despite these findings there also appears to be some ambiguity. For example, although a survey by Searle (2009) found that a majority of UK doctors opposed the legalisation of these practices, the situation within the British Medical Association has been rather uncertain. In 2005, the Association withdrew its opposition to legislation for assistance in dying but reinstated it in 2006 after further consultation with members.

The New Zealand Medical Association also opposes euthanasia and PAS but a study in New Zealand (Mitchell & Owens, 2004a) nevertheless indicated a significant endorsement of these practices by the medical fraternity. Similarly, in a study of the end-of-life decisions of doctors in the State of Victoria, Australia (Neil, Coady, Thompson & Kuhse, 2007) there was also evidence of a highly polarised view within the medical profession. As Searle (2009) highlights, this ambiguity on the issue is a matter of some concern when one considers the important influence played by the support or neutrality of the medical profession in the legalisation of euthanasia and PAS in some countries. Interestingly, results from these studies also appear to indicate that those doctors who are more experienced with treating terminally ill patients show less support for law change but there is also significant disagreement among the medical profession in the conceptualisation and definition of what constitutes euthanasia.

Survey findings in a number of countries have shown that certain socio-demographic characteristics are closely linked to support or opposition to euthanasia and assisted suicide in both lay people and doctors (Emanuel, 2002; Searle, 2009; McCormack, Clifford & Conroy, 2011). Religious beliefs, particularly Catholicism, are strongly associated with opposition to these practices. However, as pointed out by Seale (2009) the concept of

religiosity is somewhat limiting as it may not encompass those who have a strong faith but do not attend religious services. In addition people who are older, those with less educational qualifications, are non-white or disabled are also more likely to oppose euthanasia and PAS. Some studies have also indicated that women have a lower rate of support for hastening death (Canetto and Hollenshead, 1999-2000; Emanuel, 2002). However, this finding contradicts incidence studies that seem to suggest that there may be a higher proportion of women seeking opportunities for this choice (Canetto and Hollenshead, 1999-2000; 2000-2001) and that women represent a significant majority of the membership of Voluntary Euthanasia Societies (Kamakahi, Cossman & Fox, 2001).

Many of the studies that have attempted to measure people's attitudes towards euthanasia and assisted suicide have utilised simple hypothetical questions or vignettes. Rosenfeld (2004) however, points out that asking someone whether they might consider such an end-of-life decision at some point in the future is limited by a number of shortcomings. While this type of research may provide a general picture of public support for such practices, it would be inappropriate to extend these assumptions any further as the reliability (the stability of that attitude over time) and validity (how the attitude conforms to an actual decision) are rather suspect. In fact a number of studies have indicated a large discrepancy between a patient's hypothetical attitude towards considering euthanasia or assisted suicide and a practical desire to hasten death. For example, in a study of 988 terminally ill patients Emanuel, Fairclough and Emanuel (2000) found that although 60% expressed support for euthanasia and assisted suicide in a hypothetical question only 11% seriously considered it for themselves and half this number changed their minds on a follow-up interview.

Rosenfeld (2004) suggests that the inconsistency between the hypothetical support for euthanasia and assisted suicide and the actual desire to hasten one's own death can be attributed to a patient's increasing tolerance to the suffering associated with their illness. This is supported by a study of attitudes to euthanasia and PAS that found that oncology patients who were actually experiencing pain were less likely than other oncology patients and the public to support these practices (Emanuel, Daniels, Fairclough & Clarridge, 1996). These discrepancies are also somewhat troubling when considering the potential of advance

directives that are legal in most countries. A study by Lee, Smith, Fenn and Ganzini (1998) found that patients' treatment decisions often did not match the preferences they had stated earlier. Approximately one third of patients in their study changed their earlier decision regarding life-sustaining medical treatments when they were actually ill, usually accepting medical interventions that they previously expected to reject.

Another issue is the change in attitude of patients towards euthanasia and assisted suicide that can come about with treatment interventions. A study by Breitbart et al. (2010) with patients suffering from advanced AIDS found that successful treatment of depression corresponded with a significant decrease in desire for hastened death. Similarly a study in Oregon (Ganzini et al., 2000) with those patients requesting a prescription for lethal medication under the Death with Dignity Act showed that 46% of patients changed their mind following substantive palliative interventions. However, some patients remained firm in their desire for assisted suicide despite intensive palliative interventions. It is interesting to note that both these studies measured patients' current interest in death hastening rather than a hypothetical future desire (Rosenfeld, 2004).

A number of studies have investigated a wide range of factors affecting the decision to hasten death. Many of these studies have utilised measures of desire for hastened death in an effort to overcome issues of relevance related to the use of hypothetical questions and vignettes. However, as Rosenfeld (2004) comments it is still questionable whether such measures will equate with actual behaviour in seeking euthanasia or assisted suicide. Chochinov et al. (1995) developed a clinician rating scale called the Desire for Death Rating Scale (DDRS) that was administered to 200 terminally ill cancer patients. Results indicated that depression was the strongest factor influencing a desire for hastened death. A more encompassing self-report scale, the Schedule of Attitudes toward Hastened Death (SAHD) was subsequently developed by Rosenfeld and colleagues (Rosenfeld, 2004). On the basis of this measure Breitbart et al. (2000) found that both hopelessness and depression were strong predictors of a desire for hastened death among terminally ill cancer patients. Similarly Rosenfeld et al. (2006), in a larger scale study with patients with advanced AIDS

that utilised both clinician-rated and self-report measures, found that depression and hopelessness corresponded significantly with a desire for hastened death.

Likewise, psychological distress and high care needs have also been shown to be more important to patients than physical symptoms in their desire for hastened death (Emanuel, Fairclough & Emanuel, 2000). The influence of social support was also highlighted in a study by Schroepfer (2008) that investigated the role of social relationships in the decision-making processes of 96 terminally ill people considering hastening their death. The findings showed that a lack of good quality social support or conflictual social support was a significant factor in the decision to hasten death. Moreover, Hendry et al. (2013) in a review of international literature cited psycho-social issues as being amongst the most important reasons for considering assisted dying. These findings however, are contrary to traditionally held ideas regarding the role of pain and suffering in decisions to hasten death. These are also the reasons that most people give for supporting euthanasia and assisted suicide. As Emanuel (2002) comments, “public support conflicts with the actual facts about patient interest in euthanasia and PAS” (p149).

In a similar way to the difficulties experienced in attempting to define euthanasia and measure its incidence and prevalence as well as engaging with issues of context, it is clear that the attitudinal studies discussed in this section also suffer from a wide range of inconsistencies and discrepancies. Although researchers have variously attributed these differences to an array of factors, what they fail to acknowledge is the anti-humanist view that there is no inner ‘essence’ that can be measured. The absence of the concept of an ‘attitude’ lying somewhere within the individual leads to a self that is contradictory and unstable, constantly changing according to circumstances (Burr, 2005). Consequently, attempts to ‘objectively capture’ and measure what I would argue is an illusionary concept are doomed to failure. It is unsurprising then that despite the large body of attitudinal research regarding euthanasia and PAS, we are still no closer to understanding this ‘desire for death’.

Indeed researchers who have utilised more qualitative approaches to the study of euthanasia (Lavery, Boyle, Dickens, Maclean & Singer, 2001; Yi, Mak & Elwyn, 2005) have argued for a greater emphasis to be placed on the social perspective of decisions for hastened death and cautioned about the pitfalls of not appreciating the complexity of the wish for euthanasia and interpreting it at face value. It is also evident from the multitude of problems encountered within the quantitative studies examined thus far in this chapter that a more encompassing framework is required. Therefore, research needs to understand how people make sense of euthanasia by going beyond mainstream positivist methods to examine euthanasia through a qualitative and critical lens.

Representations of a good death

In our efforts to understand end-of-life decisions it would seem eminently sensible to also examine how we depict death itself. In previous research it has often been oversimplified into a qualitative dichotomy that represents the ‘good death’ in binary opposition to a ‘bad death’. Bradbury (1999) uncovered a range of often quite contradictory representations of good deaths that she classified into three types: the ancient sacred good death that over time has changed to a modern medical good death, and the more recent natural good death.

The sacred good death is very much focussed on an afterlife and descriptions emphasise the social nature of the event and the deathbed scene, involving farewells to loved ones, as an essential element. The medicalisation of death and the greater secularisation of society have seen representations of a good death change to a medical model. The focus has shifted to the medical care received and the careful control of death by a physician with the patient preferably in no pain or unconscious. Bradbury (1999) points out that in both the sacred good death and the medical good death the defining issue is control. However, control has shifted from the dying person and their faith to the physician’s control of the physical symptoms of the dying process.

The modern medical representation of a good death is now being challenged by the more recent natural good death that emphasises the retaking of control over dying from the medical profession. However, the various definitions of ‘natural’ rely on one’s own

perspective and therefore frequently change and conflict with one another. Indeed this disagreement about what constitutes 'naturalness' is often in contention in the debate surrounding euthanasia. Bradbury (1999) did not suggest that these theoretical categories should be viewed as a historical linear progression as all three are still drawn upon today to construct an idealised account of a good death.

Walter (1994) also proposed a category of death called neo-modern or post-modern which recognises the type of extended death we are more likely to experience in contemporary times. Thus, although modern medicine may be called upon, it is up to the individual to take control so that they may live well while dying. This control of death by the dying person and the rejection of the passive 'patient' role in the natural good death and neo-modern death is reflected in the philosophy of the anti-medical natural death movement that is also closely aligned with the hospice movement. Hospice and palliative care is based on the belief that death and dying are a 'normal' part of life and revolves around the construct of a good death. It takes a post-modern approach that embraces a plurality of views to what constitutes this good death and undermines the silence surrounding it that was a feature of the modern medical category of death. It highlights what Walter (1994) described as the 'revival of death' and is closely linked to the Western concept of individuality and autonomy.

However, Bradbury (1999) suggests that the autonomy of the dying person may just be politically correct rhetoric and that many contemporary representations of a good death are very prescriptive and as such act to further legitimise the medical model. McNamara (2001) also points out that the ethic of individual choice and the realities of 'doing it my way' can sometimes compromise the ideal good death and have led to a reconstructed notion of a 'good enough death' by health professionals. Furthermore, the ideology of a good death within palliative care/hospice settings can create norms and rules that while providing some stability to the institution can function as a type of social control that excludes some people as well as normalising death in a particular way. Additionally, Long (2004) also comments that the euthanasia debate has shattered the apparent consensus of the ideal good death as proposed by the neo-modern/revivalism category of dying.

Media discourses

The way we perceive death and thus the hastening of death by euthanasia or assisted suicide can be seen as socially constructed and as such will differ between cultures and over time. The meaning attributed to these concepts will also be influenced by the role played by the media. The discourses that prevail in the media are dominant among the ways that we come to understand these phenomena and are linked to power and knowledge. Therefore, it is important that we examine carefully some examples of how death and euthanasia are being constituted.

An analysis of the portrayal of death in magazines in Canada by Clarke (2006) that included topics of euthanasia, suicide and the 'right-to-die movement' found that the prevailing construction was that of control of death. Thus the timing of death was seen as a "result of personal preference" and "individual freedom" and therefore "under control" (p.162). The articles were seen to support the dominant discourses of the medicalisation of death and the focus on individualism and the rights of the individual in North American culture. However, Clarke suggests that these hegemonic discourses are functioning to limit concerns to the role of the medical profession and the right of the individual to choose death, while masking the more salient issues of injustice, inequalities and a lack of control in death experiences on a societal level. This is particularly significant for those groups discussed previously who are disadvantaged by gender, disability, 'race' and/or economic hardship.

Similarly, Hausmann's (2004) investigation into the British media coverage of euthanasia found that press representations had the effect of actually endorsing euthanasia. The discourse of 'voluntary euthanasia' was organised around the positive concept of choice of the individual as opposed to negative social coercion. However, the dominant discourse was that of 'terminal illness', whereby the existence of such an illness alone provided the justification for euthanasia. The responsibility accorded to an individual for taking a life in these circumstances was diminished by being represented as 'tragic'. Conversely, in cases where a terminal illness was not present, the idea of 'criminality' was invoked. Thus, the discourse of terminal illness was portrayed as more important than choice. The author

concluded that euthanasia was highly legitimised when both these discourses came together, that is, when an individual had a terminal illness and had made a choice to hasten death.

Finally, an investigation into the relationship between media portrayals of suffering and support for euthanasia also expressed some concerns that press representations could have a limiting effect on the euthanasia debate (Banerjee & Birenbaum-Carmeli, 2007). An analysis of articles concerning family assisted suicide (FAS) was carried out based on the work of Heidegger who believed that the world could be represented as either ‘orderly’ which allowed for technical responses, or as ‘poetic’ which recognised the world as both complex and chaotic and therefore requiring more contemplative responses. The finding showed that the majority of press reports constructed the suffering involved with FAS as orderly, thus opening the way for a technical resolution such as medical intervention and the legalisation of euthanasia. Through the use of a range of strategies, media reports were able to negate the complexities of FAS and therefore avoid any suggestion that there may not be “a straightforward technical fix to terminal suffering” (p.639).

The pervasive influence of the media into all aspects of our lives cannot be underestimated. It has been assumed (Aris, 1981; Lavi, 2005) that a death-denying attitude characterises our society whereby death is hidden away from everyday experience and considered a socially taboo subject. Therefore, for many people the way they come to understand death and euthanasia will be through the media. However, as Clarke (2006) comments, the knowledge that is conveyed will always be from a particular perspective that will provide limits to our understanding while also supporting the status quo in the established structure and order of society. It is important then that we are mindful of how the discourses identified in these selected studies may be shaping our interpretation of euthanasia. Moreover, it highlights the need for further studies that can contribute to elucidating possible alternative constructions.

Conclusion

The vast majority of information that we now have pertaining to euthanasia has come from studies practicing within the quantitative research paradigm. In the main, they have focused

on attempting to measure various aspects of the phenomenon. However, the complexities and contested meanings that accompany the huge array of terms related to end-of-life decisions have inevitably impacted on this research. The ability to establish the actual occurrence of euthanasia or PAS with any degree of accuracy is effectively undermined by this lack of consensus regarding definitional issues. Indeed, I would argue that the possibility of reaching any such accord is in itself a positivist assumption. Furthermore, research into people's attitudes towards these death-hastening practices is beset by a range of methodological issues and biases and many of the studies unsurprisingly report contradictory findings. Although there is little empirical evidence to support claims associated with the 'slippery slope' or the risk to vulnerable groups in regard to these practices, some studies have highlighted wider social concerns that cannot be ignored. For example, the social disadvantages experienced by people living in poverty, with disabilities, non-European ethnic groups and women must be considered within a wider perspective of euthanasia.

At present, the research into end-of-life decisions has largely adopted a comparatively narrow positivist approach that has become quite limiting and prevented a deeper understanding of this important social issue. However, those studies discussed in this chapter that have begun to consider the broader social context of the way we construct death and euthanasia present a way forward from traditional mainstream research methods. Euthanasia needs to be recognised as a discursively constructed phenomenon; knowledge of it is constructed by people in the day-to-day interactions that comprise social life. Therefore, an approach that focuses on language can expand the parameters of our understanding and offers the potential to gain greater insights into how people make sense of euthanasia.

CHAPTER TWO

Theoretical framework

This chapter presents an overview of the theoretical framework adopted by this study and the issues it presents in order to contextualise the project as it unfolds over the coming chapters. It gives the reader some insight into the development of social constructionism, Foucault's re-theorisation of modern power and the potential that a Foucauldian discourse analysis offers for a different understanding of euthanasia.

Introduction

The application of a social constructionist paradigm to the study of euthanasia can be viewed as a framework that encompasses a critically different theoretical orientation than that of mainstream traditional research. As seen in the previous chapter, the mainstream approach follows a positivist epistemology based on a realist ontology that conceptualises the universe as being made up of structures and materials that are independent of our perceptions and thoughts. Positivism assumes that there is a clear-cut correspondence between the phenomenon of euthanasia as it exists in the world and our perception and understanding of it. Furthermore, it suggests that objective knowledge can be generated by research that is impartial and free of bias with an empiricist approach to data collection that relies on observations of the 'real world' to uncover the 'facts' (Willig, 2001). Positivism is shaped by the mainstream Western world-view that focuses on the individual as a separate entity, independent of the social world it inhabits. It also encourages a type of reductionism whereby social issues are explained in terms of the 'essences' that somehow reside within the individual psyche. The problem with accepting explanations that are based on assumptions of individualism and reductionism as pointed out by Tuffin (2005) is that they fail to consider the wider social and cultural forces at play and in fact work to deflect attention away from issues of politics, power and control in society.

In stark contrast to the time-honoured schemata of empiricism and positivism, this study seeks to step outside what can be considered a limiting framework in order to challenge our taken-for-granted knowledge about euthanasia and the wholesale acceptance of the way

things appear. Thus as Nightingale and Neilands (1997) argue, everyday knowledge is not conceptualised in this study as a direct mirror image of reality that has been objectively reflected but rather as a product of, and dependent on, the historical and cultural milieu. Moreover, the individual and society are perceived as being so intrinsically linked that they are fundamental parts of the whole, one cannot exist without the other. The adoption of the alternative paradigm of social constructionism opens up a whole new range of possibilities and opportunities for our understanding of euthanasia. It offers the potential to engage with alternative research questions that are based on a different set of assumptions. Furthermore, this approach recognises the inherently close relationship between ontology, epistemology and methodology (Nightingale & Neilands, 1997; Tuffin & Howard, 2001). It is important then that this chapter develops an understanding of the ontological and epistemological commitments that underpin this study and inform the methodology for the research.

Social constructionism

Social constructionism arose against a backdrop of postmodernism that challenged the central assumptions of modernism fundamental to the Enlightenment period of the eighteenth century. The Enlightenment period saw a rejection of God and the Church as the only source of truth in favour of science as a mechanism for the individual to make their own rational decisions about reality and truth. Postmodernism on the other hand, dismisses any notion of an absolute truth or indeed that there might be some hidden, underlying structures to the world as posited by structuralists. According to postmodernism, there are no grand narratives through which we can come to understand the world but rather a varied multitude of ways of being in the world that coexist (Burr, 2005). Therefore in adopting this theoretical framework there can be no question of attempting to seek out some fixed fundamental truth about euthanasia or people's perception of the practice.

Social constructionism draws from a wide variety of disciplines but within psychology its emergence can be associated with the so-called 'crisis of confidence' in the discipline between the late 1950s to the mid-1980s (Pancer, 1997). The growing disenchantment with the epistemological assumptions of the empiricist traditions of psychology and its links with positivism provided fertile ground for a new critical approach. However, social

constructionism cannot be adequately characterised by any singular definition but rather should be seen as a set of philosophical guidelines or alternative ways of thinking about the world. It subscribes to a linguistic ontology that recognises the fundamental importance of language and discourse in the active construction of our social reality. The importance of this point cannot be over-emphasised as it is key to an understanding of this alternative theoretical perspective. Social constructionism rejects the notion that there can be meaning outside of language and places language and its use at the centre of research. Therefore, this project is based on the premise that it is through language that the meaning of euthanasia is shaped and constructed. As Tuffin (2005, p. 72) says, “language is actively involved in the construction of our experiences, our subjectivities and our social realities. In other words, constructionist epistemology advances the view that our psychological experience is fundamentally constituted *in and through* discourse”.

The analogy of a range of different family characteristics is often used (Burr, 2005) to describe a social constructionist position. Under this model, social constructionism can be viewed as a collection of different theoretical perspectives that have in common some basic assumptions outlined, initially in psychology, by Gergen (1985). It is these assumptions that lay the foundation for this present study. Foremost amongst them is the premise of maintaining a critical approach to the knowledge in society that appears so obvious and ‘common sense’ that we take it for granted. In critical inquiry, it is important that we challenge societal norms, values, practices and institutions and not unquestioningly accept the status quo of mainstream ideas and beliefs. The task therefore, is to be suspicious of the particular ‘common sense’ ways in which euthanasia has come to be understood in today’s society. Coupled with this is the acknowledgement that this current knowledge about euthanasia is historically and culturally specific. Therefore, what we commonly ‘know’ and accept today in Western society has not always been the same in past times, nor is euthanasia understood in the same way within other cultures. Gergen (1985) referred to these contemporary understandings as ‘social artefacts’ because they have come about, and are a product of, the social interactions and economic arrangements that prevail at that time and in that culture. The changes in our conceptualisation of euthanasia, which will be discussed in more detail in the next chapter, are not a reflection of some transformation of

the phenomenon but rather are contingent on the particular historical period and cultural processes.

Commonly shared versions of knowledge about euthanasia will continue to be sustained not as a function of their validity but depending on all the many interactions between people in everyday life, particularly through the use of language. Therefore, a given form of understanding or knowledge is not only constructed but also maintained by social processes. It is also important to realise that this common knowledge that we take for granted and which will vary from culture to culture and according to the historical period is not an objective representation of reality but rather a construction by people when they engage with one another. Therefore, there will be a variety of possible constructions of euthanasia, each of which will seek to represent the phenomenon in a certain way. However, linked to each of these particular understandings will be an associated form of social action, so certain constructions will support and sustain particular types of social action while excluding others (Gergen, 1985). The implications of this are critical to this study of euthanasia. For instance, constructing euthanasia as a means to a peaceful death in the face of inevitable agony supports actions to change the law related to euthanasia in New Zealand and elsewhere.

Foucault

The French theorist Michel Foucault can be regarded as one of the most influential writers within the rubric of social constructionism. In particular, his radical reconceptualisation of ideas around discourse, knowledge and power are of central importance to this present study. His work can be considered controversial, contradictory and indeed at times quite elusive. It is unsurprising then that Lock and Strong (2010) suggest that it is somewhat of a “moving target” (p.244). Foucault however, embraced inconsistency as being the hallmark of a style of work that was forever questioning, reinventing and reinterpreting itself (Paras, 2006) and was often frustrated at attempts to pigeonhole his work. Therefore, there is no intention here of attempting to typify Foucault or ‘unify’ his work in order to fit into a structured theoretical framework. Rather, the goal is to outline some of the theoretical constructs he has provided and to make use of them to engage in this project.

Discourse/knowledge/power

Foucault's understanding of discourse is pivotal to an explanation of power and the production of knowledge. His concept of discourse moved beyond the realms of language to encompass all aspects of what could be termed a body of knowledge. In this respect Foucault was referring to knowledge as those ways of thinking, speaking and acting that were considered correct or true in a particular culture and time period (McHoul & Grace, 1993). Discourse can be viewed as a way of understanding or interpreting the world through not only language but also social practices that inherently carry meaning (Hall, 2001). For example, it is not just concerned with talk about early or peaceful death but the legal and material means to bring about that death. Discourse does more than just describe a topic, it gives it meaning and brings it into being and according to Foucault, produces knowledge. It defines the way we can think about euthanasia, the way we can talk about it and perhaps more significantly it influences our conduct regarding it. Foucault was interested in discourse not merely as a linguistic device but rather he was concerned with meaningful statements, or ways of understanding, that constructed the objects of our knowledge. He sought to interrogate the rules and practices that allowed certain statements, or ways of understanding, to be possible rather than any others. This he termed "the law of *existence* of statements" (Foucault, 1991a, p.59).

As mentioned earlier there will be a wide range of different discourses surrounding euthanasia each presenting its own perspective. However, some constructions are more likely to prevail in our society today and will be accepted as 'common sense'. It is these versions that Foucault termed knowledge and that are intrinsically linked to power. They provide the potential to act in certain ways while marginalising alternative practices. Power is dependent on these hegemonic 'knowledges'. Burr (2005) points out that power is exercised when we draw on these prevailing discourses to support and validate our actions. Foucault's concept of power then is very different to the traditional notions of power as a possession of the privileged, to be used to dominate and control the weak. Rather this relationship between knowledge and power is perhaps best summed up by Foucault:

We should admit ... that power produces knowledge ... that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations (Foucault, 1977, p.27).

Thus, as McHoull and Grace (1993) highlight, the 'truth' we know is produced by power relations. It is those 'knowledges' that receive the 'stamp of truth' and become 'official' that can operate as tools for normalisation. In other words, their continued repetition assists in the moulding of the population's thoughts and actions so that certain ideas and behaviours become considered as 'right and proper', normal. This study is interested in the various techniques and methods that are invested in these official discourses that contribute to this normalisation while simultaneously excluding alternative possibilities. What is it that can be said or practices that can be undertaken in respect to euthanasia that have achieved this status of 'truth'? And what is marginalised or made abnormal in the process? This focus recognises that relationships of power and knowledge are not stable or fixed, but rather dynamic, constantly moving, reversing and being modified. Prevailing discourses in our society regarding euthanasia will always be subject to resistance from alternative representations that strive to undermine their hegemonic position and their claims to 'truth'. This relationship between power and strategies of resistance is extremely important because resistance is part of the very essence of power and a consequence of its existence (Burr, 2005). Resistance also presents the possibility for change by highlighting previously marginalised discourses that can potentially challenge the legitimacy of our present understanding of euthanasia.

Disciplinary power

Foucault argued that the understanding of disciplinary technologies was essential in order to appreciate the nature of modern power that operates through knowledge and is intrinsically bound up with discourse. This rethinking of power as a productive network was theorised by Foucault to operate through a 'swarming' of disciplinary techniques to be both far reaching and ever present (Rouse, 1994). This came about through a significant transformation in power in the 1600s from a repressive regime of sovereign power that was

characterised by the monarch's right over life and death to a new positive form of power – bio-power. It had as its focus the object of life and the administration of all aspects of that life.

The emergence of this bio-power has been attributed to some key developments that took place early in the seventeenth century that were accompanied by the need to manage people. Central among these was the Industrial Revolution and the rise of capitalism with the corresponding requirement for a constant docile workforce. No longer were human beings dispensable at the whim of the Sovereign as in feudal times; the control of the body and populations became essential for the success of the capitalist economy (Power, 2001). However, the relationship between bio-power and capitalism was, according to Foucault, mutually dependent as one was neither possible nor necessary without the existence of the other (Rabinow, 1984). Bio-power centred on the fostering and regulation of life and oscillated between the human body as an object for manipulation and control and the collective politics of the population. This called for the coming together of power and knowledge to monitor, regulate and transform human life via procedures termed disciplinary technologies. The aim and focus of this disciplinary power was the creation of docile yet productive bodies. The concomitant development of the physical sciences provided the necessary tools for the empirical analysis required for the methods of normalisation that were an essential component of these procedures (Rabinow, 1984; Rabinow & Rose, 1994).

Normalisation brought together all the mundane, infinitely detailed aspects of life into the arena of bio-power. It is at the heart of all the various techniques, knowledges, discourses and practices that surround this new form of power. Foucault viewed the way in which it was applied in our society as being particularly perilous often describing it as a 'strategy without a strategist'. The crucial part of this process was the gathering together of vast amounts of information in order to obtain more accurate records about individuals so that the criteria for normalisation could be both more encompassing and refined, but always on the move. The effect of this was the individualisation and subsequent separation and ranking of individuals. Foucault identified the examination as the procedure whereby

surveillance and normalisation came together to intertwine knowledge and power with the individual as the target (Dreyfus & Rabinow, 1983). An important aspect of normalisation technologies was their role in utilizing the sciences in the ensuing identification and isolation of abnormalities in the social body. The behaviours or characteristics of this abnormality were then seen as determining the 'essence' of the person. Alongside this categorisation and classification was a corresponding undertaking to normalise the anomaly by implementing corrective procedures through such nineteenth century apparatuses as medicine and psychiatry (Rabinow, 1984).

Foucault claimed that disciplinary technologies were able to gain momentum and acceptance because all the while they were being masked by other theories and conceptualisations of power (Dreyfus & Rabinow, 1983). Clinging to the notion of sovereign power and a concept of power as a negative, dominating and repressive force has allowed the emergence of these modern practices of power. As Foucault (1978, p.86) so succinctly states, "power is tolerable only on condition that it mask a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms". The requirement for this power to remain invisible brought the examination to the fore. It is the individual, the object of this power, who takes centre stage. Therefore, unlike sovereign power that seeks to make itself known through exorbitant displays of strength, disciplinary power operates by rendering itself invisible behind the cloak of constant surveillance and visibility of the individual that is at its heart (Dreyfus & Rabinow, 1983).

Foucault's analysis of Jeremy Bentham's plan for the panopticon can be seen as a model for the operation of these disciplinary technologies and methods of normalisation. This structure was conceived in the nineteenth century and consisted of a tall tower positioned centrally in a courtyard. It was completely surrounded by other buildings that consisted of individual 'cells' arranged over a number of levels. Each cell was provided with two windows, one that allowed light in from the outside and one that faced the tower. The tower also had observational windows that allowed all of the cells to be viewed at any time by a 'supervisor'. The occupants of the cells however, were not visible to one another, nor were they able to ascertain when or if they were under surveillance from the tower at any

particular time (Burr, 2005). The brilliance of the panopticon is that the architectural design skilfully ensures that all involved become ensnared in its operation as an apparatus of power. The occupant of the cell can never be certain whether they are being observed or not from the tower so they become self-regulated. The supervisor is also under constant observation from the cells and thus the system also controls him. Foucault saw this as the most insidious aspect of a disciplinary technology (Rabinow, 1984).

Panopticism then is the mechanism for this political rationale that brings together knowledge, power and the subject in the pursuit of social control. It is a new economy of power, both cost effective and efficient, that is integral to our modern society. The ability for on-going close scrutiny of the individual allows for assessment against societal assumptions of normality. It is through the comparatively imperceptible power of these strategies of normalisation that Foucault believed the individual was controlled. As McNay (1994, p.95) points out, “In modern society, the behaviour of individuals is regulated not through overt repression but through a set of standards and values associated with normality which are set into play by a network of ostensibly beneficent and scientific forms of knowledge”.

Subjectivity

It is apparent that Foucault’s ideas around power, and the subject in particular, were continually being shaped and re-theorised throughout his career. Eckermann (1997) comments that this changing conceptualisation of power, particularly in Foucault’s later works has not been given the attention it deserves by many of his critics. Paras (2006) also concurs that many of the critiques of Foucault’s ideas are a result of a lack of understanding around the changeability and trajectory of his work. It has been suggested that Foucault’s initial concerns with knowledge then moved on to examining the intrinsic link between knowledge and power, but in his later work both these concepts took second place to a more pressing concern with the self (Gutting, 1994; Paras, 2006). Indeed, somewhat surprisingly, Foucault (1982) himself has claimed that the aim of his work was not an analysis of power. Rather he saw the modern individual as having been formed by cultural practices that constituted him/her as an object and a subject (Dreyfus & Rabinow, 1982).

His goal he claimed was concerned with isolating the mechanisms of this objectification of the subject.

It is important for this analysis of euthanasia to examine Foucault's idea of how individuals can be made into subjects. He theorised that there are three ways or modes of objectification of the subject (Rabinow, 1984). The first consists of a variety of procedures that result in the dividing of subjects within themselves or from others. Through these 'dividing practices' the subject is separated out, categorised, given an identity and becomes objectified. The individual can then take on the character for example of the sick or the healthy, the terminally ill or the curable. Thus, 'dividing practices' allow power and knowledge to be applied and manipulated to certain groups to achieve their domination and exclusion and/or normalisation. This process is interlinked with the objectification of the subject that also takes place as a consequence of the scientific classification of our methods of study. The 'discipline' of medicine, for example, objectifies the sick subject as a patient.

While these two modes of objectification view humans as being a passive part of the process, it is in what Foucault termed 'subjectification' that we are seen as actively transforming ourselves into subjects. It involves a variety of processes to bring about self-enlightenment often guided by external experts in one guise or another, possibly a doctor or psychiatrist (Foucault, 1982; Rabinow, 1984). For example, the 'euthanasia talk' described by Norwood (2007) is a process required by law and managed by doctors in the Netherlands when considering requests for euthanasia. It is through these consultations, and discussions of meaning with family and their own doctor that terminally ill patients can transform themselves into a subject who is deemed 'suitable' for euthanasia.

Foucault (1978) portrayed these 'technologies of the self' as being linked to Western society's unquestioning acceptance of scientific discourse. The methods of science provided the means for individuals to enter into the realm of knowledge about themselves that enabled them to work on themselves as a project for change. As Dreyfus and Rabinow (1982) point out the process of seeking knowledge about ourselves through self-examination and self-surveillance in order to affect these improved modifications has

become so 'common sense' that we fail to recognise it as an essential part of modern power. Society presents individuals with a multitude of opportunities to subject themselves to readily available disciplinary practices that enable the design and creation of a new version of the self that society deems desirable. The question arises however, as to how society in a particular time and culture shapes this normalised notion that is so sought after.

Although this process of self-formation can be seen as analogous to the technologies of discipline discussed earlier that seek to mould and transform docile bodies, there is a critical difference. In technologies of the self, Foucault's conceptualisation of power shifted significantly so that he saw the subject as an active player in what he termed 'truth games'. These involved the subject invoking their capacity for choice in the on-going project of working on one's own life. It was through this 'care of the self' that Foucault believed the individual had the possibility for freedom (Frank & Jones, 2003). Although the process of subjectification viewed there being no self, or indeed truth, outside of being a subject, it is up to the subject to choose which truth games to play and which technologies of the self to subject themselves to.

Power then is bound up with the production of truth but this should not be seen as an absolute notion but as an effect of hegemonic forms of knowledge, including self-knowledge. However, Foucault's concern with the power/knowledge couplet became focused in his later work on a government/truth pairing (Turner, 1997; Paras, 2006) in which his interest expanded to consider how man was governed by the truth. The importance of this concept of government according to Paras (2006) was its attention to the autonomy of the individual subject. Therefore, rather than the unspecified entity implied by power/knowledge, government included not only the actions of others but also the governing of oneself. Hence, far from Foucault's earliest works that have often been characterised as representing the 'death of the subject', in the notion of government the individual is viewed as central to the formation of his or her own subjectivity.

Governmentality

The 'invention' of a modern form of power that focused on the fostering and regulation of life allowed governmentality to flourish. This term was utilised by Foucault to describe the art of government in developing the ways and means in which to shape and guide the conduct of each and every one of its citizens. Furthermore, it was concerned with how the activities of this practice of government could come to be seen as acceptable to both the practitioners and the citizens. Foucault's unease with the development of governmentality in Western society was with its emphasis on the coupling of both individualising and totalising strategies i.e. the simultaneous concern with each individual as in the objectification of the subject and with all the population (Gordon, 1991). Turner (1997) saw Foucault's treatment of governmentality as further extending his work on power by acting as a bridge between disciplinary technologies and technologies of the self. In acknowledging the transformation of the subject within his work, he utilised the concept of government to explain the complex interaction of the disciplinary techniques of domination and coercion and the technologies of the self in the formation of the subject (Paras, 2006).

The concern of government is closely linked to Foucault's notion of bio-power as a means of regulation and social control of the population through the administrative state. Gordon (1991) interestingly highlights the way in which Foucault's concept of governmentality as bio-politics can bring about a new type of counter-politics. This concern of the government with all aspects of the individual's life can be strategically reversed in order to focus on tactics of resistance. Individuals can utilise those same claims for the regulation of life as the impetus for political demands of their own. This seems particularly evident in the debates around euthanasia. It does not seem unreasonable then to suggest that calls for the right-to-die or calls to uphold the sanctity of life can both be viewed as forms of this political resistance to the governmentality of death.

Although some critics (McNay, 1994) have portrayed Foucault's work on disciplinary power as presenting a picture of an inescapable and all-encompassing force, this is far from what Foucault was suggesting. He was very clear that power could only operate on individuals who had choice of action. It is this dimension of power and governmentality

that is particularly important to conceptualise in this study because the concept of freedom of choice features very strongly in discourses of euthanasia. However, Foucault was very succinct in the way power operated in the conduct of man:

When one defines the exercise of power as a mode of action upon the actions of others ... one includes an important element: freedom. Power is exercised only over free subjects, and only insofar as they are free ... By this we mean individual or collective subjects who are faced with a field of possibilities in which several ways of behaving, several reactions and diverse comportments may be realised. (Foucault, 1982, p.221).

The aspect of this rationality of government that Foucault found particularly disturbing then was the way in which it is based on the notion of a power that takes this very freedom as its object.

Governmentality was essentially a way to imbue what Foucault termed 'economy' into the politics of the state. Economy in this sense refers to the good management of the population, its prosperity and welfare. Foucault was also clear that while he viewed this art of government as having emerged from a carceral society that had in turn come about due to a change from a sovereign regime of power, this did not mean that these previous notions of power had been replaced. Although this complex nexus of power that depended on the knowledge of political economy was paramount, he still referred to a 'sovereignty-discipline-government' triangle that was focused on the population through the application of 'apparatuses of security' (Foucault, 1991b).

A society of security

One of the most important developments of this new way of thinking about government rationality according to Gordon (1991) is the way in which society today focuses on the security of its population. Foucault characterised security as a specific political technique that involved the calculation of both the risks and cost involved in the probabilities of events for the population. An important feature of this security is its interest in *homo*

economicus (economic man) and the ways of ensuring that costs are minimised while an optimal norm is protected. The economic calculations required depend on the notion of freedom of choice for the *homo economicus* of these neo-liberal times. The growing influence of neo-liberal politics in the west has contributed new and challenging ideas to the concept of an art of government. In particular the focus is on the individual as an essential element of the market economy of government.

Neo-liberalism is an ideology that places value on economic markets, efficiency, consumer choice and personal autonomy in order to shift risk from governmental authority to individuals. It depends on a form of power that seeks self-discipline and self-regulation. However, closely linked to an imperative to be in charge of your own destiny is the individual's responsibility to ensure that they minimise the risk they pose as a possible burden to society. The rationality of government is very much focussed on the commodity of an economically productive life. It demands a fiscally prudent approach to the cost of each individual life to society through maximising profitability and minimising the unprofitable. However, at the same time it also needs to economise on its own activities so that it can achieve more but with a lesser show of strength (Gordon, 1991).

It has been suggested (Castel, 1991) that a new framework for administering populations has emerged as part of this governmentality of our post-modern society. This regime, with its focus on risk prevention and management, is concerned with the identification of a variety of factors calculated as contributing to the risk an individual poses to him/herself or society. This requires a new structure of surveillance termed "systematic pre-detection" (p. 288) that depends on the ability to foresee and avert future events that may have adverse consequences. Therefore, an overarching ideology of prevention has surfaced that opens the door to an unlimited multitude of options for intervention. It is powered by a desire to gain control over the often erratic, capricious and unpredictable nature of life itself and the risk that poses to the security of the population. It seems inevitable that this will have implications for our understandings of euthanasia, and thus a focus of this project concerns how neo-liberal ideology and the rationality of government bear on the meaningful constitution of euthanasia and the positions that subjects take up in relation to the practice.

Conclusion

This study should be considered as an act of ‘consciousness-raising’ (Burr, 2005). Its goal is to introduce an element of suspicion to our common sense understanding of euthanasia. There is no intention of advocating any particular discourse over another but rather to make available alternative understandings including those discourses that may be considered as marginal or repressed. It challenges the reader to look beyond the commonly accepted perceptions and social practices that surround euthanasia. In this sense, the project is adopting a Foucauldian reticence in offering any value judgments regarding euthanasia. Although this supposed ‘caginess’ often led to claims that Foucault’s projects had brought about a sense of inertia he argued (Foucault, 1991c) that on the contrary if people are left ‘not knowing which way to turn’ then that in its self is a triumph because it indicates that they are actually looking. It is for this reason that he opposed any attempt to direct or tell people what should be done as it would have the effect of limiting their searching and questioning and function to immobilise them. He claimed that his specific purpose had been to help in disrupting claims to self-evidence and common sense knowledge so that “certain phrases can no longer be spoken so lightly, certain acts no longer – or at least no longer so unhesitatingly – performed” (p.83). The aim of this study then, in line with the epistemological underpinnings of social constructionism, is unashameably political.

This chapter has sought to outline the argument for a research approach that steps outside the confines of mainstream psychology. The decision to utilise a social constructionist framework is based on the perceived potential offered by the different understandings of ontology and epistemology that underpin it. Furthermore, the adoption of a Foucauldian perspective provides a radically different dimension to a consideration of power relations. This theoretical foundation then allows for a new way of looking at euthanasia. The research design will interrogate ‘how people make sense of euthanasia’ through their talk and the possible consequences of this talk in order to highlight the intrinsic connection between meanings of euthanasia and discursive power relationships. It opens up the possibility of challenging the apparent inevitability and naturalness of our present understandings.

CHAPTER THREE

Gesture to genealogy

In the spirit of a genealogy this chapter presents fragments of a Foucauldian ‘history of the present’ that addresses the issue of how euthanasia has emerged as a possible solution to terminal illness. It examines the conditions present at particular periods of time and some specific events that have allowed our present constructions of euthanasia to come about.

Introduction

This chapter will draw on some of the genealogical techniques provided by Foucault to lay the necessary groundwork for this project. In undertaking such a task it is important first of all to gain an understanding of the very different approach that Foucault took to history. Genealogy has often been interpreted as having derived from, or as a successor to archaeology with many similarities but with an added emphasis on the analysis of power (Kendall & Wickham, 1999). The distinction between the two has been seen according to Paras (2006) as a difference in approach that owes much to the influence of Nietzsche.

Foucault’s archaeologies enable an exploration of the history of what has been said and through discourse that which has been brought into being. He was concerned with the conditions that had allowed the emergence of a particular discourse and the events that had made it possible for that discourse to exist as against another. In further elaborating this idea Foucault (1991a) outlined how archaeologies examine the rules of a particular time and culture that identify firstly the possibilities and limits to what can be spoken. Questions then arise of that which is able to be said, what will be retained, used, repeated and circulated and what will be disregarded, repressed and lost? How will these rules define the authority and validity of particular statements as opposed to others? What is the relationship between that which is sayable in this present period and society and the discourses of previous times and other cultures? Who may have access to certain discourses and what are the struggles to gain control of them?

Thus, according to Kendell and Wickham (1999) the emphasis in archaeology is on a 'snapshot' of discursive history whereas genealogy is more concerned with the on-going nature and process of the discourse. Genealogy can be thought of as a way to utilise the method of archaeology by strategically applying it to the concerns of the present and in this respect they can be viewed as complementary to one another. However, a genealogy is explicitly concerned with power relations so it transforms traditional history to what Foucault termed a "micro-physics of power" (Foucault, 1977, p.139). In particular, its focus is on the operation of power on bodies. Dreyfus and Rabinow (1982) comment on the significance of this recognition by Foucault of the central importance of the body in power relationships and as a political instrument in modern society.

A genealogy can be seen as an unsettling methodological device (Gutting, 1994) that has the potential to challenge the very origins and functions of our present day 'knowledge' regarding euthanasia. Although Foucault frequently used this historical technique he termed it a 'history of the present' because rather than attempting to identify a step-by-step process of historical progression, he was instead interested in the multitude of ways in which certain events and understandings may have come about. Thus, unlike traditional histories that trace the causal factors that have led to the inevitable present situation, Foucault focused on the incidental, random and unpredictable nature of history in order to undermine these assumptions of inevitability. His history of the present according to Gutting (1994), demonstrated that institutions and practices and the knowledge upon which they are based have been quite different in the past and it is not particularly obvious or necessary for things to be the way they are today.

However, positivist historians with an interest in historical fact often regard Foucault's genealogies as highly questionable. His focus on a small, selective collection of events in the past, in order to understand the present, often leads to accusations of historical inaccuracy and oversimplification (Midelfort, 1980). Although it is important that Foucault's claims can be seen to reflect historical facts it would seem to be counter intuitive to attempt to utilise orthodox historical criteria in judging these histories of the present. There is much to suggest therefore that some of this criticism is misguided and reflects a

lack of understanding of Foucault's work (Gutting, 1994) and a failure to recognise the importance and value of many of his insightful historical commentaries. Furthermore, his later focus was on what he termed 'problematization' in which the concern was not on a particular time period but rather on the history of a problem and the events relevant to it. As Flynn (1994) comments this could be seen as removing the requirement for a sustained overall historical synopsis that is a condition of a traditional history. The notion of event in this sense was also quite different to the way it was perceived by other historians in that it included both statements and practice.

In this genealogy, I am interested not only in how euthanasia has emerged as a possible solution to the problem of terminal illness but how the subjects are brought into being by this knowledge. I want to investigate what conditions present during a particular period have allowed the emergence of certain discourses and specific ways of doing things rather than any alternatives. Therefore, the focus will be on a small but significant collection of incidents that can help support our understanding of how we have arrived at this present point. It is also important that this genealogy maintains the essential element of Foucauldian scepticism. In acknowledging the obvious contemporary orientation of a history of the present (Dreyfus & Rabinow, 1982) this gesture to genealogy will commence with a reflection on the current situation regarding euthanasia. It will then trace the moral implications of self-destruction through history and consider the more recent effects of medicalisation on society. The contribution of eugenics and the civil rights movement to the present day understandings of euthanasia will also be discussed. Finally, the importance of neo-liberalism and the market economy in our post-modern society will be examined in relation to euthanasia.

The present

Whether individuals have the right to choose when and how to die is a hugely contentious issue in society today. The ethics, legality and morality of euthanasia are hotly debated in many countries around the world. However, this on-going euthanasia debate is characterised (Idol & Kaye, 1999) as having a particularly dichotomous nature where discourses such as personal autonomy and freedom of choice vie for hegemony with

arguments regarding the sanctity of life. There is an associated assumption that you clearly belong to either the ‘for or against’ view, thereby discursively excluding other possible interpretations or positions.

Here in New Zealand, despite continued public discussion about the legalisation of euthanasia and assisted suicide, the intentional termination of any life remains illegal under the 1961 Crimes Act. However, Labour Member of Parliament Maryan Street’s “End of Life Choice Bill” was added to the Parliamentary Member’s Bill ballot in July 2012. But it was withdrawn again in September 2013 until after the election in 2014 due to concerns that it would become a ‘political football’ if debated during election year. The Bill advocates for the right of mentally competent terminally ill patients, or those suffering from an irreversible physical or mental condition that in their perception causes life to be unbearable, to be medically assisted to end their life. It follows on from two previously unsuccessful attempts, by Michael Laws in 1995 and Peter Browne in 2003, at passing legislation to change the law regarding end-of-life practices in New Zealand.

There have also been a number of high profile court cases in New Zealand that have sparked much debate and soul searching about assisting another’s death. Prominent amongst these was the situation of Lesley Martin that was highlighted in the prologue to this thesis, who in 1999 twice attempted to kill her terminally ill mother by administering an overdose of morphine and smothering her with a pillow. Although no charges were laid at the time she later wrote a book about her experiences, “To die like a dog” and was subsequently arrested and charged with attempted murder. Found guilty in 2004 she served 9 months of a 15-month prison sentence and despite two appeals failed to have her conviction overturned.

Lesley Martin rose to some prominence in the New Zealand media as a spokesperson for the ‘right-to-die’ movement. She set up a New Zealand branch of the EXIT organisation in collaboration with Dr. Philip Nitschke, the well-known Australian euthanasia advocate. However, disagreements around the direction the group was taking led her to form the break-away organisation Dignity New Zealand that continues to campaign for the

legalisation of euthanasia. In contrast, there are many opponents to the notion of voluntary euthanasia and while religious beliefs, particularly Catholicism, are strongly associated with such opposition other secular organisations such as the New Zealand Medical Association and Hospice New Zealand have also refused to endorse these practices.

It is important to acknowledge the significance that legislation and the law has in contributing to our contemporary understanding of euthanasia. The law, as well as medicine and religion, have been described as “institutions of normative coercion” (Turner, 1997, p.xiv). The term coercion refers to their function of surveillance over everyday life and their discipline of the individual in as much as actions can be seen to be both produced and limited by them. However, this is not to say that they are coercive in the sense of explicit threats to achieve obedience, it is more insidious than that. This is because we readily accept these normative institutions as having the legitimate moral authority to define individual problems and provide solutions. The framing of laws or indeed the absence of regulation regarding practices of euthanasia can be seen as being very influential in relation to the discourses that constitute chosen death. For example, at present in New Zealand the law lends moral legitimacy to discourses opposing assisted death.

Although to date the attempts at the legalisation of euthanasia or assisted suicide in New Zealand have been unsuccessful, there have been other countries around the world that have passed such legislation. These include the Netherlands, Switzerland, Belgium, Luxemburg and the American States of Oregon, Washington, Montana and Vermont. Belgium legalised voluntary euthanasia in 2002 and in December 2013 became the first country in the world to extend this practice to terminally ill children. Luxemburg passed legislation for euthanasia and assisted suicide in 2008, which was enacted in 2009. Switzerland has had legalised assisted suicide since the 1940s that equally applies to non-Swiss citizens and can also be performed by someone other than a physician. This has paved the way for the high profile *Dignitas* organisation to provide assisted suicide for foreigners, a practice that has been dubbed in the media as ‘suicide tourism’. It is interesting to note that not all assisted suicide is legal under the Swiss penal code; it is considered a crime only if the motive is selfish. Therefore, unlike many other countries where the important issue is intent, for

example with the practice of ‘double effect’, in Switzerland the emphasis is on motive (Nitschke & Stewart, 2005).

The Dutch context is particularly interesting as this is one of the few countries in the world where the practice has been legalised and therefore according to Norwood (2007) has become ‘normalised’ in as much as it is no longer a taboo subject and in fact is widely associated with other end-of-life options. While voluntary euthanasia groups had been operating in both America and Britain since the 1930s this was not the case in the Netherlands. The Dutch Movement for assisted dying originated from within the medical fraternity as a reaction to the dilemmas created by life prolonging technologies.

The gradual nature of the decriminalisation of voluntary euthanasia following a number of court cases in the Netherlands has been credited as being responsible for its successful implementation. Although the termination of life was a felony under the criminal code, in 1984 euthanasia and PAS were sanctioned by the Supreme Court under a doctrine of *force majeure*. Thus, physicians would not be prosecuted when they could show that a conflict between the duty to preserve life and the duty not to allow a patient to suffer necessitated assistance in dying. The grounds for such a defence widened following the Chabot case of 1994 in which a psychiatrist assisted in the suicide of a patient who was suffering unbearable psychological pain. Thus, ‘necessity’ for euthanasia or assisted-suicide was not limited to only patients with a terminal illness or physical suffering (Gorsuch, 2006; Humphry & Clement, 1998; Nitschke & Stewart, 2005).

In 2002 euthanasia and PAS were legalised with the passing of the “Termination of Life on Request and Assisted Suicide (Review Procedures) Act” by the Dutch Senate. Norwood (2009) argues that it is important to locate the legalised euthanasia available in the Netherlands within its own social and cultural context. The Dutch Health System is such that all patients, regardless of financial status, have access to full health care. In addition, palliative care services are very well developed despite a lesser emphasis on hospices than in the U.S.A and U.K. General medical practitioners have a much more significant role at the end-of-life and have usually had a long close relationship with patients and their

families. These factors contrast quite starkly with the medical model in the U.S.A. and other countries.

Furthermore, Norwood (2007) makes a very clear distinction between the actual act of legally sanctioned euthanasia and talk about it, as data shows that only 10% of those requesting euthanasia will actually die by this means. Applying a Foucauldian analysis to an ethnographic study with patients, families and general practitioners in the Netherlands, she identified a discourse based on the Dutch cultural practice called *overleggen* that means to consult, discuss and consider an issue before acting. Thus, the legalisation of euthanasia by the authority of law has led to a discourse of euthanasia talk that functions to bind the Dutch to society at the end of life by engaging the patient, the family and the doctor in meaningful dialogue. As such it can be viewed according to Norwood (2009) as another form of palliative care:

What the Dutch seem to be embracing in their euthanasia discussions is a process of making death orderly. The goal of euthanasia talk, like any good example of *overleg*, is not about the end result. It is not about dying euthanasia deaths, but about living the remainder of your life in proper Dutch ways. Thus it is the process of euthanasia talk, not the final decision made, that creates the order for which Dutch people who participate in this discourse strive (p.112).

However, not everyone can participate in this euthanasia talk, which reflects Foucault's suggestion that not all members of society will have equal access to particular discourses (Foucault, 1991a). There are those first and foremost who by virtue of their religious or moral opposition to euthanasia will be self-excluded. Then there are others who are destined to remain firmly on the sideline of this discourse due to their inability to participate in an acceptable fashion. The complex nature of euthanasia talk in practice means that participants must adhere to a number of unwritten rules. Norwood (2009) explains that those who are experiencing family conflict or neglecting to include family members in the dialogue, are depressed, do not have a specific physical disease, or are simply too 'pushy' and do not use the correct language or behave in a proper Dutch way

may find themselves restricted to the borders of the euthanasia discourse and thus marginalised.

This exclusion has been heavily criticised by Szasz (1999), as he believes that it is an indication of just how little control and autonomy the Dutch actually have on the way they die. The illusion of control, he suggests, lies in the way they can manage the request to die to their doctor to obtain the necessary legal sanction but it is always on his or her terms. Norwood (2009) also observes that contrary to popular rhetoric about an individual's right to choice, euthanasia discussions in the Netherlands are always under the control of the doctor. He or she both manages the conversation and if deemed necessary will stall the euthanasia talk. Norwood suggests that through the apparatus of medicine and law, the State is able to exert social control by this very process of *overleg*. It brings a degree of management to disordered death by promoting social bonding at a time when people often become socially disconnected and lose self-identity. It can thereby offer protection against social death; the processes of dying that lead to disconnection from the social world.

Thus, Norwood (2009) highlights the importance of considering the social in any discussion of legislation. She points out that the American experience with euthanasia and assisted suicide has followed a somewhat different trajectory to that of the Netherlands. The right-to-die movement there evolved as part of patient's rights advocacy and reflects a more contentious relationship between patients and the medical system than that of the Netherlands.

Arguably one of the most influential euthanasia groups in the United States of America has been the Hemlock Society founded by Derek Humphry in 1980. In recent times it has focussed on promoting legislative reform but has also experienced internal conflict that has resulted in numerous splinter groups, mergers with other groups and name changes that could be seen as having led to a lack of cohesion in the support for euthanasia legislation. However, a number of high profile euthanasia cases from Karen Anne Quinlan in the 1970s to Terry Schiavo in 2005 have had the effect of keeping the euthanasia debate alive in the American media. The AIDS epidemic in the 1980's also led to a strong demand for assisted

dying among the gay community. In the absence of legislation some advocates of euthanasia have tried to circumvent the law, for example Humphry published a DIY suicide manual *Final Exit*, while others have openly challenged it with the infamous Dr. Jack Kevorkian assisting in the deaths of what has been estimated as well over one hundred people (Nitschke & Stewart, 2005; Norwood, 2009).

There are at present four states in America, Oregon, Washington, Montana and Vermont where PAS is legal. The 'Death with Dignity' Act was passed in Oregon in 1994 as a result of a Citizen Initiated Referendum however it was subsequently subject to a number of legal challenges and thus was not implemented until 1999. PAS was legalised in Washington in 2008, in Montana in 2009 and in Vermont in 2013. It is interesting to note that in all four of these states euthanasia, where someone else is responsible for administering the lethal dose, is explicitly prohibited. It has been suggested (Nitschke & Stewart, 2005; Norwood, 2009; Rosenfeld, 2004) that this is a reflection of an American culture that strongly emphasises the autonomy of the individual.

In contrast, the Dutch prefer the option of euthanasia, as doctors perceive PAS as having the potential to be more risky and problematic. Indeed, data from the Netherlands indicates that in 18.4% of PAS cases a physician has intervened and performed euthanasia by administering a fatal medication. However, rather surprisingly studies of PAS under the Oregon legislation have reported no such cases (Emanuel, 2002). Mitchell and Owens (2004b) have expressed concern about the absence of active involvement by the physician required by the American legislation as they suggest that such a policy is not always practicable and 'botched' attempts at suicide are under-reported. Furthermore, they put forward the view that the framing of the Oregon Death with Dignity Act may have been more about political expediency than a reflection of public opinion. Thus, the wording of the Act that precludes the active involvement of a physician may have been a more palatable option to ensure support for legalisation of PAS. However, according to Emanuel (2002) the danger is that if complications with PAS do arise, as indicated by data from the Netherlands, it can present a serious dilemma in the absence of complementary euthanasia

legislation. As he points out, “If, in the United States, only PAS will be legalised, what do physicians do when it fails?” (p. 6).

When examining the different approaches that individual countries have adopted in regard to euthanasia it is also important to consider them in light of their own cultural perspectives. This is because, as discussed in the previous chapter, the ‘knowledge’ surrounding euthanasia will be specific to the cultural understandings that are present in a particular country. For example, the Northern Territory of Australia was the first place in the world to have comprehensive ‘right-to-die’ legislation. The Rights of the Terminally Ill Act (ROTI Act) was passed by the Northern Territory parliament on May 25, 1995 and became law on July 1, 1996 but was only in operation for nine months before being repealed on March 25, 1997 by the Australian Federal Parliament. The ROTI Act was considered to have quite stringent guidelines but did allow for both PAS and euthanasia (Kissane, Street & Nitschke, 1998; Nitschke & Stewart, 2005; Street & Kissane, 1999-2000). However, it has been argued (Fitzgerald, 1999) that this legislation failed to consider the perspective of indigenous Australians who make up 22% of that population. The Aboriginal people were not consulted regarding the proposed Bill and it was only after the enactment of the law that their very different cultural point of view was taken into account. Mackinolty (1997) found that the Aboriginal people were almost unanimously opposed to euthanasia and the legalisation of the practice was likely to have led to the unforeseen consequence of an increased reluctance to seek health services. The implications of this for an already highly marginalised group facing serious health issues and inequalities are far-reaching.

In light of the Australian experience it should be seen as significant that in New Zealand there is a dearth of literature surrounding euthanasia and Māori, further highlighting some of the concerning issues that accompany this dichotomous debate. Fitzgerald (1999) points to the importance of seeking out these silent voices in the euthanasia debate if we are to gain a greater understanding of the phenomenon. However, although it is apparent that the traditional Māori perspective on death and dying differs from the Western world-view, it should not be assumed that all Māori continue to believe literally in the ancient myths and

legends of death in our contemporary world. The profound changes that have taken place in respect to urbanisation, technology, family structure and socio-economic status have impacted on the cultural perceptions of death. Nevertheless, Ngata (2005) suggests that it would be reasonable to assume that many Māori continue to identify with and respect the principals and ideologies that underlie the traditional Māori attitudes towards death and dying. The impact of this perspective in relation to our present day understanding of euthanasia in New Zealand has yet to be considered.

The present day struggle to gain acceptance for the practice of euthanasia is taking place within a narrow dualistic focus on the fundamental moral question regarding the individual's right to choose death. However, as we have seen, the law and discourses about choice are differently informed by different social conditions. It is unsurprising therefore that this problematic question should dominate in the West while for some cultures it does not even appear to be on the agenda. It is suggested that the current emphasis on the debate regarding the legalisation of euthanasia within Western society may be more a reflection of a battle for control over the moral domains of life and death. The contemporary dominant framework of medicine and the law is more and more being seen as providing a moral compass that is slowly being wrestled away from our traditional spiritual base. Idol and Kaye (1999) suggest that the nature of the on-going euthanasia debate fails to consider and indeed effectively obscures the power dynamics at work within the competing discourses of the right-to-die and the sanctity-of-life. Furthermore they claim, "the debate positions the interests of the person who is terminally ill as secondary to those institutions that have a stake in the outcome of the debate in terms of ideology and power" (p. 189).

Historical reflections on self-destruction

The "diagnosis of the current situation" (Dreyfus & Rabinow, 1982, p.119) in the previous section has laid the groundwork for a consideration of the historical concepts of suicide and euthanasia and their corresponding moral manifestations. The taking of one's own life has been part of human experience since ancient times but there have been widely varied attitudes through the centuries and amongst different societies. The ancient Egyptian view that life and death were just different forms of existence led to a neutral or ambivalent

approach to the question of self-destruction (Evans & Farberow, 2003). The ancient Greeks held diverse views, and laws and practices differed from city to city. For example, in Thebes self-killing was condemned and the person was denied funeral rites. Likewise in Athens the law required the hand (responsible for the deed) to be cut off and buried separately from the victim's body. However, in some Greek communities magistrates presided over special tribunals that would hear arguments from citizens who wished to kill themselves. Permission could be granted and the poison hemlock supplied if sufficient grounds such as profound physical or mental suffering were established (Evans & Farberow, 2003).

The Greek 'father of medicine', Hippocrates (460 – 377 B.C.) formulated the Hippocratic Oath that is still used today as a guiding principal for medical ethics and professional conduct. It is thought that the sentiments expressed in the oath originated from a group of Greek philosophers called Pythagoreans who condemned self-destruction as advocated by many other Greeks of the time. The oath specifically denounces self-killing and also rendering assistance to someone to kill themselves: "I will neither give a deadly drug to anybody if asked for it, nor I will make a suggestion to this effect" (cited in Evans & Farberow, 2003 p.119). The ramifications of this oath still resonate today with physicians involved with end-of-life issues.

However, many Greek philosophers judged the act of self-killing based on the moral or ethical nuances of the circumstances. Socrates viewed life as belonging to the gods and therefore without their permission taking life was wrong. However, if dying became necessary it was then permissible by the gods and could be considered as noble. Thus, when Socrates was condemned to death by an Athenian court in 399BC for corrupting the minds of the youth of the city he took his own life by drinking hemlock. Socrates pupil Plato (428- 348 BC) also disapproved of self-destruction, recommending that anyone who killed themselves should be punished because of the lack of manliness of the act by burying the deceased in an unmarked grave on the outskirts of the city. In turn, Plato's student Aristotle (384-322 BC) reinforced the illegitimacy of self-killing based on the notion that man belonged not only to the gods but to the state, not to himself (Evans & Farberow,

2003). Thus, his condemnation was widened to incorporate a political rationale that viewed man's allegiance to the state as morally precluding him from taking his own life¹.

The Romans on the other hand, although punishing self-destruction under certain conditions for example by the confiscation of property and denial of a proper burial, expanded the criteria of the law to justify taking one's own life in circumstances of *taedium vitae*. This was a mental state that can variously be described as depression or simply having had enough of life. This criterion however, was not extended to slaves (considered the property of their owners), soldiers, or those accused of a crime (Lieberman, 2003; Szasz, 1999). Later came the Stoic philosophers, disciples of the Greek philosopher Zeno, who articulated a more pragmatic view on self-killing. Although they advocated careful contemplation before the act of self-destruction, they recognised that death was an option to release a person from life's sufferings. Indeed, the Roman Stoic who opted to end his own life could utilise the services of a trained technician to sever his veins. Seneca (4 B.C. – A.D. 65), one of the most famous Stoic philosophers, recommended that as you reached old age you should kill yourself to avoid the inevitable accompanying decay and this should be completed earlier rather than later when you may not be able to finish the act yourself (Evans & Farberow, 2003; Szasz, 1999).

It is important to reflect on the impact of these representations of self-destruction that Lieberman (2003) argues are characterised by a glorification of suicide. For example, the death of Socrates by his own hand and Seneca's self-inflicted death on the orders of the Emperor Nero were seen as heroic events greatly admired by their contemporaries. These deaths were followed throughout Roman history by a long tradition of taking one's own life for honour. Thus, a model of self-destruction for a higher ideal transformed the death into a noble act of sacrifice. There is much to suggest that these narratives continue to play a role in the contemporary moral debate regarding euthanasia.

¹ The gendered language in this section is a reflection of the law of this historical period.

Humphrey and Clement (1998) certainly suggest that the approach of the ancient Greeks and Romans which allowed for self-killing under certain conditions may have influenced the authors of the Bible. The ancient Hebrews recognised the sacredness of life given by God and therefore prohibited the ending of one's own life except under extreme conditions such as defeat in battle or being forced to betray the Jewish faith. However, the Old Testament does not offer a judgement on the rights or wrongs of self-killing but describes a number of instances of self-destruction that are represented as justifiable. For example, the first king of Israel, Saul kills himself to prevent falling into the hands of the Philistines; and Samson, after being betrayed by Delilah, pulls down a Philistine temple upon himself and his enemies. The New Testament also neither specifically condemns nor supports the taking of one's own life and little comment is made on the suicide by hanging of Judas Iscariot after betraying Jesus (Evans & Farberow, 2003).

The Christian Church followed the Platonic view that God gave humans life and as such it belonged to him and could only be taken by him. However, early Christians embraced the idea of dying for God to show their absolute love, for example Saint Ignatius (d.c. A.D. 119) the Bishop of Antioch beseeched his congregation to feed him to the wild beasts so that he could become a true disciple of Jesus. Although the early Church viewed this honourable taking of one's life for God as a noble sacrifice in much the same way as the early Romans, the increasing rate at which Christians sought martyrdom eventually resulted in the Church issuing edicts against the practice (Lieberman, 2003; Szasz, 1999).

Nevertheless, the Church's position on self-killing was formalised by the works of the great theologian Saint Augustine of Hippo in the 5th century. He denounced self-destruction on the grounds that it was an act of murder against oneself in direct violation of the fifth commandment: Thou shalt not kill. It was in defiance of divine authority and punished by denial of both funeral rites and burial in consecrated grounds. Saint Thomas Aquinas (1225-1274) reinforced Augustine's teachings and revived Aristotle's idea that not only did life belong to God but self-killing was also an act against society. This view was used in the Middle-Ages to support many barbaric practices and civil penalties against those who had taken their own life, and their surviving families. Thus, in England all properties were

confiscated and the body was dragged through the streets and buried at night at a crossroads often with a stake driven through the heart to prevent the soul wandering (Evans & Farberow, 2003; Lieberman, 2003). Foucault (1978) comments that it was unsurprising that suicide was characterised as a crime when the power of death, which was perceived as the sole right of the sovereign (whether on earth or in heaven), was appropriated by the individual in this act of self-destruction.

This stance on self-destruction still remains in effect today in the Roman Catholic Church, many traditional Protestant churches and in Judaism but it has been ameliorated by the medical view, accepted also by secular law, that self-killing can be excused on the grounds of insanity, thus avoiding religious penalties. However, there is no doubt that the concepts of suicide and euthanasia and assisted dying are bound together historically and share similar moral arguments. It also seems that euthanasia and assisting dying have been regarded as more acceptable forms of suicide throughout antiquity. This view, according to Norwood (2009), continues today with many advocates of the right-to-die movement attempting to distance the practice of assisted dying from these historic connections to suicide and the corresponding taboos, on the grounds of terminal illness.

In tracing the historical development of moral arguments we are able to gain some insight into Foucault's suggestions about the formation of the self through self-subjection within these ancient ethical frameworks (Turner, 1997). The ethic of self-killing was firstly identified in order for it to become moulded by moral actions. This required the subjection of the self to a recognised moral order, for example the ancient Greeks and Romans subjected themselves to the gods or the state and the early Christians to their Creator and the Church. As a result we have seen that this moral obligation became objectified into ethical discourses and rules of behaviour for different Western societies. However, Turner (1997) further argues that these 'discourses of subjectivity' have the effect of producing identities, for example the chronic sufferer, the old and infirm, and the terminally ill that "become the object and focus of medicalisation and normalisation" (p. xii). It is to these issues that we now turn.

Medicalisation

Lavi (2005) argues that the modern concept of euthanasia can be traced back to death and dying moving from the domain of religion to that of medicine and law. The meaning of the word 'euthanasia' itself has changed radically over the last two hundred years. The term comes from a Greek root meaning 'well-dying' and implies a 'good death' or 'easy death'. In this original sense, the Christian world viewed euthanasia as a death blessed by God. The deathbed at this stage was very much a public event and the province of religion, with behaviour surrounding it governed by a book of rules known as *ars moriendi* or 'the art of dying'.

During the nineteenth century the physician began to usurp the role of the minister as dying became a medical event. Indeed it was perceived as a sign of social status to have a doctor present at the deathbed (Seale, 1998). The physician was now charged with helping the patient achieve this easy death while not hastening it. Thus, by the middle of the nineteenth century the meaning of euthanasia reflected the assistance of the physician in providing a painless death. However, this medicalisation of death was also problematic because medicine was about cure and the physician could not cure dying patients. Therefore, according to Lavi (2005), the option of utilising euthanasia to hasten death "emerged as a possible solution to the problem of dying" (p.6). Subsequent attempts to legalise medical euthanasia had the effect of also taking death and dying into the realm of law and public policy.

The causes of death have also changed, particularly over the last century, with deaths from infectious disease giving way to death from more chronic degenerative conditions such as cancer and heart disease. Thus, the experience of death and dying has been transformed over time by significant advances in medical technologies from a short-term event to one that usually involves a prolonged time of slow decline. Alongside this has been the movement away from dying in the home surrounded by friends and family to dying in a hospital or other medical setting being tended to by health professionals (Lyons & Chamberlain, 2006). It has been suggested that this has led to a death-denying attitude

(Aries, 1981; Lavi, 2005) that characterises our modern society where death is hidden away from everyday experience and considered a socially taboo subject.

Although there is some evidence for this assertion it also needs to be acknowledged that there has been a substantial focus in the last fifty years on the process of dying. The seminal work of Kubler-Ross (1969) that charted the stages of dying led to a greater emphasis on the care of the terminally ill. In the same way, the development of the hospice movement provided a patient centred model that strived for more individual control of the dying process. Therefore, although the hospice movement is portrayed as diametrically opposed to the right-to-die movement, Long (2004) points out that they share similar philosophies of autonomy and the rejection of the medicalisation of dying. The modern hospice movement began under the charismatic leadership of Cicely Saunders in the 1960s in Britain as part of the revival of death awareness and since its inception has spread to over sixty countries worldwide. It was a critical response to what was perceived as the inappropriate clinical treatment of the dying person in mainstream medical settings.

However, McNamara (2001) argues that the professionalisation of palliative care has not only been successful in masking the symptoms of dying but also masks the acceptance of death which was central to the original hospice philosophy. Similarly, Clark and Seymour (1999) discuss how the hospice movement has evolved inevitably “into inflexible, professionalised, rule-bound, bureaucratic institutions” (p. 104) that have aligned themselves with a medicalised culture. This continued medical domination of dying even within the hospice setting have led Clark and Seymour (1999) to suggest that euthanasia may be seen as the logical extension to the physician’s role in end-of-life decisions, and as such can achieve a certain legitimacy. Indeed Martin (2005) has proposed the setting up of ‘Dignity Havens’ in New Zealand as an alternative to hospices that would provide palliative care alongside assisted death if requested.

It is important at this point to emphasise the profound effect of medicalisation on society. Health and medicine are integral to defining ‘normality’, a process that is essential to the disciplinary techniques of bio-power that seek to regulate and transform human life. The

medical 'gaze' encompasses all aspects of our lives, constantly monitoring and regulating our bodies in order to achieve social control of the population. According to Lupton (1997) at no other point in our existence is this medical regime as strict as when we move into frail old age or become terminally ill. The disciplinary technologies articulated by institutions such as medicine and the law, have formed a unique relationship around death and the modern subject. Foucault (1996) argued that medicine was at the centre of the quest for normalisation and by its infiltration of the law had created a 'juridico-medical web' that represented a major structure of power.

However, in contrast to the changed relationship between power and death that accompanied the shift from sovereign power to bio-power, the normalising role of medicine required a different reorientation in its relationship to death. Developments in Western medicine at the turn of the 19th century lead to a change of focus from the promotion of life through the cure of disease to concerns regarding the pathology of death. New light was shed on death by examining the anatomy of the corpse in order to determine the nature of disease and illness. Therefore, rather than our common perception that medicine's sole preoccupation is with the maintenance of life, Tierney (2006) argues that it can be characterised as having a positive relationship with death. Indeed, Foucault (1978) pointed out that although bio-power seeks domination over life, it has not in fact turned away from death because death can be viewed as the limit to this power.

Eugenics, euthanasia and civil rights

The interest in euthanasia and assisted suicide continued to grow in the late nineteenth century as a by-product of Darwin's theories of evolution. The publication of his book "Origin of Species" in 1859 introduced the idea that the evolutionary success of a species was dependent on the 'survival of the fittest' individuals in order to pass on their advantageous genes to the next generation. Social Darwinism sought to extend these biological concepts to issues regarding human society. Thus, there was a sense that the strongest, i.e. the richest and the most powerful, were obviously better adapted to the social milieu of the times and as such should be allowed to flourish at the expense of the weaker members of society.

Social Darwinism was augmented by the principles of eugenics espoused by Galton and expressed in the desire to ‘weed out’ these weaker, less productive members of society in order to enhance the genetic characteristics of the population. These beliefs, based as they were on scientific knowledge of the natural world, found favour internationally as they offered the possibility of providing solutions to a range of social problems. Lavi (2005) draws parallels between the sterilisation programme for the ‘socially defective’ in the United States in the early twentieth century, that was fuelled by these eugenic principles, and the increasing support for euthanasia. Not only did they both require the active involvement of the law in articulating specific criteria to regulate the practice, but euthanasia emerged as a more permanent solution to “the problem of defectives in society” (p.107).

However, this potential resolution of the dilemma of the continued existence of socially unfit members of society was perceived as far too unpalatable to most eugenicists. Therefore, the initial mandate was channelled into a call for the voluntary legalised mercy killing of terminally ill patients with the founding of the Euthanasia Society of America in 1938. Although the relationship that has been drawn between hastening death and improving the gene pool may seem somewhat oblique, Lavi (2005) argues that the practice of euthanasia came to be viewed within a much broader eugenic framework that was increasingly concerned with providing solutions to social suffering for the overall betterment of society. For example in Germany, the initial interest in eugenics-as-euthanasia was based on the concept of humanely removing ‘lives not worth living’ as a service to both the individual and to a burdened society (Szasz, 1999). However, the National Socialist government went on to embrace a return to the biological aspects of eugenics in a euthanasia programme of race purification. It was only following World War II and exposure of these euthanasia practices that there was a widespread public backlash against both the eugenics and euthanasia movement.

Changes in the socio-cultural climate in the West during the 1960s and 1970s that saw increasing secularisation and challenges to traditional authority led to a growing demand

for individual rights, and autonomy. The expansion of the civil rights movement, coupled with the advances in modern medical technology that could prolong the dying process, provided fertile ground for the renewed growth of right-to-die organisations according to Gorsuch (2006). Importantly, this was fuelled by claims to civil liberties rather than an ideology of improving social 'stock'. Indeed, one of the major assertions in the euthanasia argument is that individuals should have the right to self-determination and control over their own dying. However, as Szasz (1999) argues, there is much to suggest that rather than recognising personal autonomy, euthanasia in fact represents an extension of the medicalisation of death. In his view medicine can be seen as having expanded its normalising power to include suicide as a 'treatment' for terminal illness. In charting the historical changes to people's attitudes towards self-destruction he points out: "Suicide began as a sin, became a crime, then became a mental illness, and now some people propose transferring it into the category called 'treatment', provided the 'cure' is under the control of doctors" (p.x).

Neo-liberalism and economics

The significance and importance that we ascribe to the concept of autonomy can be seen as a reflection of 20th-21st century neo-liberalism. Furthermore, the concern with a market economy that is the hallmark of this ideology can also be linked to the increasing interest in the right-to-die movement. As Humphry and Clement (1998) argue, although many people do not want to connect the idea of euthanasia and assisted suicide with cost considerations this 'unspoken argument' is an unavoidable part of the debate. It is not only the rising cost of health care, a significant proportion which is spent on expensive, often futile treatments for the elderly and terminally ill, but the dreadful burden placed on patients families that they believe validate this call for hastened death. Indeed, Humphry and Clement predict it is the economic issues rather than ideas of individual freedom and autonomy that will allow euthanasia and assisted suicide to become acceptable in society. For example, the medical authority of Oregon seems to have accepted cost saving as a justification as when it turns down an application to cover the cost of an expensive new drug, it simultaneously sends out a reminder that the state's assisted suicide program is available at an affordable cost.

Moreover, support for financial gain as part of the practice of assisted suicide and euthanasia also has its proponents. Fung (1993) suggests that by offering insured patients a benefit conversion for agreeing to assisted suicide, thereby avoiding expensive, aggressive treatments, burgeoning health costs can be brought under control and insurance premiums lowered. The rationale for this approach is the seemingly inequitable distribution of limited health resources and the overuse of medical treatments covered by insurance. Therefore, Fung argues that by legalising a ‘dignified death’ and converting health insurance entitlements to a death benefit of approximately 60% of projected health costs of a slow death, not only will it reduce suffering but it will save scarce resources.

The changing face of death over the last century has resulted not only in an extended, expensive dying process but has also led to a rapidly growing aged population. Therefore, the proportion of the population not in the work force, i.e. unproductive labour units; is increasing at such a rate that a successful capitalist economy cannot be sustained. For example, the increase in the aged population over the next 25 years means that 70 million workers in OECD countries will retire to be replaced by just 5 million newcomers (Ministry of Health, 2004). The economic ramifications of this situation cannot be ignored nor should they be underestimated.

In addition, governments can ill afford to be seen to uphold a society that is stymied by regulation and control of the population. Therefore, according to Gordon (1991) the expansion of ideas around personal freedom, responsibility and autonomy has become an “electoral necessity” (p.46). It should not be surprising then that the amalgamation of these factors will inevitably shape the knowledge and practices surrounding the governing of death. However, this neo-liberal approach will have different implications for different sectors of society for example the differential ways in which euthanasia is considered by women, the poor, the disabled and other vulnerable groups has previously been discussed. As Prilleltensky and Fox (1997) point out, “the negative consequences of societal values and norms do not fall equally on all segments of the population” (p.6).

Conclusion

This gesture to genealogy has demonstrated that our common sense understanding of euthanasia has not only changed over time and as a function of the specific cultural setting but is actually a product of that particular period and culture and very much depends on the established social and economic organisation present, as Burr (2005) would suggest. Hegemonic discourses of medicalisation and personal autonomy that prevail in our society today and are accepted as ‘truth’ seek to represent euthanasia as the obvious response of a humane society to terminal illness. They endorse a practice that is widely viewed as the logical extension of a fundamental human right. However, it should be recognised that these discourses also allow for the exercising of power while simultaneously masking that power. This history of the present has attempted to open up that discursive space surrounding euthanasia to at least a modicum of suspicion. It has been designed to nibble around the edges of our complacency; to cause discomfort by questioning how the concept of euthanasia as a solution to terminal illness originated, how it is constructed, how it functions and with what effects and in whose interests?

Although the micro-analytical approach of this gesture to genealogy has, as we have seen, the potential to undermine the assumed inevitability of traditional causal historical accounts it would be naïve not to acknowledge that as Gutting (1994) points out, factors may also be at play at a macro-level which the close genealogical focus may fail to detect. A Foucauldian discourse analysis can be seen as taking a more macro approach as it employs a post-structuralist framework that emphasises the political nature of language. It focuses on the identification of prevailing discourses and the power relationships involved. It also enables an examination of the political implications of the subject positions offered by these discourses. Therefore in undertaking a study of euthanasia, genealogy is but one avenue to pursue and in the following chapters this project will follow other pathways well trekked by Foucault.

CHAPTER FOUR

Method

This chapter endeavours to describe the way in which the research was carried out using a reflexive approach. Therefore, as suggested by Taylor (2001) any problems, concerns or limitations are discussed openly and honestly. In this way, it provides an opportunity not only for the researcher to take responsibility for the study but for others to assess and evaluate it.

Introduction

This research is not limited by the epistemological assumptions of an empirical approach that require the separation of the researcher from the object of study in order to enhance the illusion of objectivity. Instead, from the very outset I wish to openly declare and celebrate my relationship with the topic, the participants and the data itself. The research question, ‘how do people make sense of euthanasia?’ was many years in gestation. It originated from countless discussions and debates around issues of advanced medical technologies and human ethics with my senior Biology students when I was teaching in a secondary school. It grew and evolved as I considered the ways in which students talked about life and death and what it meant to be human.

The secondary school where I taught is at the heart of the small, semi-rural New Zealand provincial town where the study was carried out. It is a close-knit community with a relatively low socio-economic rating. That I had lived and worked in the town for a number of years and was particularly involved in the community through Māori education contributed to my ‘insider’ status. I hasten to add however, that as argued by Taylor (2001) the power differential involved in the research process meant that despite this on-going relationship and rapport with participants I could not regard myself as being on an equal ‘footing’ with them in terms of the study.

The participants who took part in the research must be recognised as an integral part of the story rather than just nameless ‘subjects’. They were for the most part long-term residents

of the community with whom I had both collegial and personal relationships. They came from a wide range of backgrounds and occupations; teachers, nurse, doctor, salesman, farmer, electrician, factory worker, self-employed, superannuates and beneficiaries. They gave freely of their time to answer questions with thoughtful insight and to contribute to the discussions that form the basis of this project. The pivotal role they played towards the goal of attempting to make sense of euthanasia is gratefully acknowledged.

The researcher

It is important within the framework of social constructionism to retain a conscious awareness of the researcher's intrinsic involvement in the social process of the research. Sobrun-Maharaj (2002) points to the necessity of locating the researcher within their own historical and socio-cultural background in order to develop an understanding of how this will impact on the research process. However, despite my support for this approach I also concede that I find myself somewhat reluctant to share my story. This is in part due to the deeply personal nature of the account but perhaps more importantly the concern about what assumptions the reader may draw from these revelations. In spite of this, I believe it represents a vital component of the research method and embodies a spirit of reciprocity to the participants in this study who shared so much of themselves.

I come from a strong Irish Catholic heritage and continue to practice the faith while still finding myself at great odds with Vatican teachings on many issues. When I was 9 years old my paternal grandmother, with whom I had a close relationship, committed suicide in an old people's home. Despite her deeply held religious views she had had enough of living what in many ways had been a very tragic life. At the time of her death in the 1960s suicide, particularly that of an elderly person and a Catholic was cause for secrecy, denial and shame. Although I was aware of the circumstances surrounding her death and also the previous attempts she had made to end her own life, I colluded with the adults for many years by blocking these memories.

In later years I lost both parents, my mother suddenly and unexpectedly and my father in a long drawn out battle with cancer. In common with many adult children, it was particularly

hard to watch a parent slowly and painfully deteriorate to a state where he seemed to hover on the brink of death. It is at these times especially that end-of-life issues come to the fore. His last days and hours seemed characterised by a battle between family requests for effective pain relief and medical concerns about administering too much morphine that would result in ‘tipping him over the edge’.

Throughout the research I was frequently asked what did I think about euthanasia? The answer remains the same, “I don’t know”. This study however, does not seek to address the question of whether people agree or disagree with euthanasia but more importantly how they make sense of it. How my own story may impact on this sense making is uncertain but I fully acknowledge that the values and experiences that I bring to the research will inevitably shape the process and final ‘product’.

Participant recruitment

An informal strategy for recruitment often referred to as ‘snowball sampling’ (Burgess, 1991) was utilised in this study. An already established network of friends and colleagues acted as a pool for possible initial participants and then they suggested other friends who might also be willing to take part. Although concern has been expressed (May, 1997) that such an approach to recruitment may result in the production of partisan accounts that share a certain perspective while failing to engage with alternative viewpoints, this was not found to be an issue in this research. The diversity of the social networks within which the ‘snowballing’ took place made this an unlikely eventuality. However, as this was an issue also highlighted by the Massey University Human Ethics Committee (MUHEC) the researcher ensured that all interviews were carefully monitored as they were conducted and transcribed in order to identify any limitations in the range of discourses presented. A wide range of constructions around death, dying and euthanasia were evident in the data so it was not deemed necessary to access alternative networks.

In the same way, the evolving nature of the research provided the flexibility to respond to the issue of participant numbers. As Baker and Edwards (n.d.) point out in their aptly titled paper, “How many qualitative interviews is enough?” the most definitive answer to this

question from a variety of researchers is that 'it depends'. While they listed a number of criteria upon which to base decisions regarding participant numbers, the most important aspect was the need for the researcher to state clearly how they had dealt with the issue. In this study, the concept of data saturation was utilised as a guiding principal. So mindful that the success of discourse analysis is not dependant on sample size it was initially thought that for the purpose of generating a range of responses, interviews with between 20 and 40 participants would provide sufficient, valid information. Again, the interviews and transcripts were scrutinised as the research proceeded in order to identify data saturation. The criterion applied, as suggested by Potter and Wetherell (1987), was tightly woven around the research question of "how do people make sense of euthanasia?" This could arguably be described as a very subjective process and perhaps not even epistemologically appropriate for qualitative research that eschews such empirical considerations. However, pragmatically speaking the data revealed a stage where I realised that the same range of perspectives was being heard repeatedly. Therefore, it was felt that further interviews would not contribute anything more to the scope of the study.

Bryman (n.d.) comments on the demanding nature of this approach to determining participant numbers as it requires the researcher to engage in sampling, interviewing, transcribing and analysis all at the same time rather than in a singular, linear fashion. However, I would argue that it is the very nature of this reflexive and iterative approach that adds strength to the study. Furthermore, I fully support Jensen's (n.d.) claim that the most salient aspect regarding participant numbers should be "the quality of the analysis and the dignity, care and time taken to analyse interviews, rather than quantity" (p.5).

Research with Māori

The need and desire to include Māori participants in this research was fundamental to a study of euthanasia here in Aotearoa/New Zealand, particularly in light of the dearth of material available and the 'silence' surrounding this topic amongst many indigenous peoples as discussed earlier. In carrying out cross-cultural research, Barbour (2007) points to the importance of a strong familiarity with the cultural context in which the research is taking place. In this project, although identifying as Pākehā, the researcher's past position

as both a teacher of Māori and a mother with Māori children in the community contributed to a successful collaborative relationship. Consultation took place at an early stage of the research process to ensure the acceptability and appropriateness of the research for Māori participants. This involved seeking advice from a local kaumātua with whom there was an existing research partnership and extended to discussions with other kaumātua in the community including the CEO of the local iwi rūnanga (see Appendix A for a letter of support). The recruitment of Māori participants was also enhanced by this on-going rapport with the community and the support of local kaumātua.

However, a potential dilemma arose as to what criteria should be utilised to define Māori identity. This highlights an area of real concern for researchers who strive to understand a Māori perspective in their research. The issue was brought to the fore by one participant who had been recruited via the snowball strategy but felt quite diffident about being included in a Māori focus group. Although her friends and other group members quickly dispelled her concerns and insisted that she did belong, it served as a reminder that Māori are far from an homogenous group and as Durie et al. (1999) point out, “the significance and actual meaning of being Māori at a personal level is not well understood” (p. 11). Concerns of belonging to a category of ‘plastic Māori’ (Tāonui, 2011) that can best be described as Māori who do not speak te reo or have knowledge of their tikanga or whakapapa were particularly relevant in this context.

The conceptualisation of Māori identity by Durie et al, (1999), that takes account of its more dynamic nature, presented a way forward in addressing this issue. Rather than only emphasising a single dimensional view, represented by traditional Māori cultural knowledge or iwi affiliation, it incorporates a wider range of social, economic, and lifestyle factors that necessarily contribute to the reality of Māori identity in the 21st century. Failure to recognise the eclectic, multi-dimensional nature of this identity today by relying on an outdated, stereotypical view has the potential to undermine research like this present study that seeks to make sense of Māori experience. Importantly, the recognition that this framework gives to each individual as being the expert on their own identity is the position with which this present study is aligned. Therefore, rather than impose an inappropriate and

artificial stereotype of what constitutes Māori identity for the purpose of interviews and focus groups, participants in this research were free to choose and self identify.

Data collection

In this study a semi-structured interview schedule was utilised (Appendix B) to discuss issues around death, dying and euthanasia. The questions were informed by the literature review and the genealogy and tested informally on a small group of colleagues and friends. They involved considerations of a 'good death', the desire to hasten death, and the roles played by various individuals and institutions in these end-of-life decisions. However, as the research aspired to be participant-led in as much as it was the participants' voices that I wished to record, there was a great deal of flexibility and open-endedness with the questioning. Participants were free to follow different pathways to mine and tell their own stories in their own way. Responses were sometimes followed up by further probes to seek explanation and elaboration and at times to challenge. This was part of an intuitive approach that following Willig's (2001) suggestion strived to be both reflexive of and responsive to the unfolding research process.

Although it should be noted that there may be some advantages in collecting data from naturalistic sources, particularly in terms of the absence of researcher influence, Potter and Wetherall (1987) argue that the interview nevertheless provides a useful mechanism to study a specific research question. Furthermore, the taboo on death talk, mentioned earlier, would likely make naturalistic sources less accessible. Despite the wealth of on-line material, my focus was not on any particular vested interests therefore the different connotations attached to such data would not serve the purposes of this project.

However, the inevitable power inequality associated with interviews of this nature was still somewhat concerning. Frankenberg (1993) attempted to address this issue by developing what she termed a 'dialogical' approach to interviews whereby she explicitly involved herself in the discussion by sharing her own stories and insights. This technique she claimed, assisted in promoting talk around a sensitive topic and also "served to democratise the research process" (p.31). Although conceding the possible benefits of this method, I

would argue that it also presents a danger of actually escalating the power dynamics of this dual relationship. There is the very real possibility that the researcher's contribution would be seen as having more value and thus shape and confine the conversation.

Furthermore, as already declared I had adopted an unknowing stance in this research with an approach that asked participants to help make sense of euthanasia. Therefore, to take up a position in the discussion would not fairly reflect either the intention or spirit of the study. Thus, on occasions when I was questioned about my own ideas and opinions I tended to use evasive replies in order to extricate myself from the discussion. This retreat was in no way a reflection of any assumptions of interviewer neutrality, quite the contrary. Instead, it represented a respect for the participants and the importance of what they had to say. The main aim of the interviews was to set up a relaxed, informal situation; a conversation or discussion in which participants could freely express their thoughts and experiences without being limited or constrained in what could be said. At the same time, it was also recognised that the researcher's contribution to the discussion would inevitably influence the data elicited.

Individual, pair and group interviews

There were a number of both theoretical and practical considerations in the organisation of participant interviews. The research design was deliberately flexible to allow for individual, pair and group interviews. This was in recognition that each type of interview would generate different data and therefore it was desirable to have access to all these various forms. The data extracts utilised in the discussion of the analysis are identified by the type of interview format for this reason (II – individual interview, JI – joint interview, FG – focus group). Also it was acknowledged that particular interview formations were more appropriate for some participants in different situations, for example some people may have felt vulnerable in a group discussion.

The use of focus groups rather than one-to-one interviews is sometimes suggested (Taylor, 2001) as a way of compensating for the 'unnaturalness' imposed by an interview situation. In general, this view seemed to be supported during the data collection for this study.

Individual interviews, with some exceptions, seemed to elicit more analytically constrained accounts than those that took place in pairs or small focus groups. It was theorised that this was due to the dynamic interaction that took place when other participants were present which contributed to the richness of the pair and group data. The sensitivity of the research topic also needed to be acknowledged when considering the issue of interview organisation. Although it is often assumed that one-to-one interviews may be more appropriate for sensitive topics, focus groups have the advantage of individuals being able to comfortably refrain from answering particular questions. Also group members are often very skilled at offering support to one another when required (Barbour, 2007).

Some researchers (Yelland & Gifford, 1995) have reported that focus group interviews may not be appropriate in cross-cultural research, as they have been devised for Anglo-Celtic populations. However, this study found a real strength in such an approach with Māori participants. Similar to other groups, the interaction between group members elicited and encouraged many insights that may not have come to the fore in the same way with one-to-one interviews. The collective nature of the discussion was also valuable in enhancing participant comfort levels. The researcher's knowledge of the culture and this particular community was also an important asset in conducting these focus groups.

Although the majority of participants in this study were women, it was possible to convene one group of men. The discussion arising from this gender composition was particularly interesting in terms of the thoughtful pauses and silences that seemed to ensue. Despite the researcher being a woman a space appeared to be created where the men could discuss and reflect on a very sensitive topic in a much more in depth way than they had previously experienced:

Mike: I've never wanted to think about this before, that's a bit of a problem for me now [laugh]

Interviewer: No, I don't think I've ever seen the four of you so thoughtful before.

Jimmy: Yeah, I don't want to do this again.

Even though the topic provoked some discomfort, as evidenced in this exchange, this focus group engaged with each other with care and consideration for the valuable opportunity it provided them.

Another factor that was considered in the formation of focus groups was the suggestion by some researchers (Litosseliti, 2003) that it is preferable to recruit participants who share similar characteristics as they are more likely to feel comfortable about sharing their views. This happened naturally in the research as groups formed around friendship and collegial relationships. Also the issue of their knowledge or experience of the topic was generally similar. There was however, a double edge to this familiarity and connectedness of participants in that it posed a particular ethical issue in terms of confidentiality. Barbour (2007) warns that the researcher needs to be mindful that such groups will continue to meet and interact long after the research is complete. This concern was addressed in the initial phase of the meeting between the researcher and potential participants where the confidentiality of the data and the participants' responsibilities in light of this were emphasised.

In order to further promote a 'natural' environment focus groups were kept small (maximum of four participants) which provided more opportunity for participants to talk and interact. It also made it possible to set up the discussion in private homes that provided a relaxing quiet environment. In contrast, the four data collection sessions that were carried out in a workplace setting presented much more of a challenge. The office or meeting room venues were in comparison quite bare and uncomfortable and subject to a number of interruptions. Thus, they provided a different context for participants that as Taylor (2001) suggests has the potential to contribute to different kinds of talk and therefore, in terms of enhancing the opportunity of obtaining diverse data were seen as more of an advantage than a disadvantage. Refreshments were provided for all participants at every venue as a token of appreciation and to enhance the relaxed atmosphere. This was particularly important for

Māori groups as it can be viewed as part of the tikanga surrounding the bringing together of people known as manaakitanga.

The nature of the research topic of euthanasia also presented a special safety issue for focus group members in that there was the potential for participants to disclose information that might be self-incriminatory. This concern was also highlighted by the MUHEC and was dealt with by advising potential participants that if they wished to share information that was possibly incriminating for themselves or others they should take part in an individual interview rather than a pair or focus group. In the same way, the potential risk for group discussions to be somewhat polarising and possibly to become acrimonious was also recognised in the research design. Participants who held views that could be considered highly contentious were invited to choose an individual interview. Despite this, a number of joint interviews and focus groups contained participants with very strong perspectives and widely differing constructions on end-of-life issues. This disagreement was in fact an advantage and as suggested by Barbour (2007) not only was any potential conflict managed and resolved in a very positive fashion within the group but it also provided rich analytical material.

Further safety and ethical issues

The experience of sharing very personal opinions, on what could be viewed by some as a very taboo subject, had the potential to create a highly emotional situation. Although this was discussed at the initial stage with potential participants and carefully monitored throughout interviews and focus groups, it inevitably affected some participants more than others. In one focus group, discussion invoked particularly painful memories for one participant who became quite upset. However, the support and reassurance provided by other group members was invaluable and reinforced Barbour's (2007) claim of the strength of focus groups in such a situation.

A local counselling service was also contacted and familiarised with the nature of the research prior to the commencement of data collection. Information was provided to all participants on how to access these services. Also the effect of the continued exposure of

the researcher to such a sensitive topic throughout the data collection, transcription and analysis phases of the study was considered in the research design. Procedures were put into place to ensure that on-going supervisory support was regularly available.

At the end of interviews and focus groups, time was taken for an informal debriefing session. Participants were encouraged to discuss how they felt about what had taken place, any concerns, thoughts, or observations. This provided a valuable opportunity for participants to comfortably transition from an often deeply emotional and highly charged discussion to more mundane matters. However, there were instances where focus groups and an individual interview had taken place in a workplace situation at the participants' request. This meant that there was very little, if any, time for a debriefing. This was very unsatisfactory and one participant commented at a later date that she felt so "blown away" and deeply moved by the discussion that she was unable to concentrate on work that afternoon. She expressed a personal need to have just been able to sit quietly for an hour or so following the discussion for a time of reflection. In contrast, a highly successful debriefing occurred in one of the Māori focus groups where the discussion culminated in the sharing of a meal and then a closing karakia and whakamutunga. This approach that is a feature of Māori gatherings allows for the seamless movement from issues that are considered tapu to the ordinary (noa) concerns of everyday life through the partaking of food and drink. This I view as an ideal blueprint for effective research debriefing.

This study was reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 10/38.

Procedure

Potential participants who met selection criteria (18 years or over and proficient in English) were firstly contacted by the researcher to introduce the nature of the study either by phone or face-to-face. In some instances where it was deemed more appropriate this recruitment was carried out by a kaumātua who had been fully briefed regarding the research. Although the intention had been to arrange an initial meeting to discuss the study further followed by a second meeting for the interview or focus group, all potential participants expressed a

preference to combine both sessions. However, this gave rise to some ethical concerns regarding the issue of adequate time for a fully informed consent process. In response to this concern, the data collection session was organised into two quite distinct parts.

A convenient time and place was negotiated with potential participants depending on their choice of an individual interview, joint interview or focus group, guided by the provisos discussed previously. There was a full discussion about the research and an explanation of the written information sheet (Appendix C) and consent form (Appendix D and E) as well as a description of the type of questions that the participants might expect during the interview phase. An opportunity was given to ask questions and seek further information and the researcher reiterated the point that no one was under any obligation to accept the invitation to participate. There was then a break in proceedings to allow people time to decide whether they wished to continue or not; all potential participants elected to proceed with the study. The session resumed with all participants being assured of the confidentiality of the research and being asked to fill out a consent form. Those taking part in a joint interview or small group were further requested to sign an undertaking not to disclose anything arising from the discussion. A digital voice recorder was then switched on and the interview and discussion commenced.

The participants

The participants centrality to this project cannot be overemphasised therefore a brief description of each participant and interview situation is provided. The purpose of this is to enable the reader to gain some important contextual information through a more personal perspective of the participants while still preserving their anonymity.

Individual interviews (II)

Rose was a highly educated Pākehā woman in her late fifties who due to personal circumstances was on the Domestic Purposes Benefit. The interview took place in her home.

Kit was a Pākehā woman in her early fifties. Her work in the community as a nurse brought her into close contact with terminally ill patients. She had recently lost her grandmother to cancer. The interview took place in the garden of her home.

Lyn worked in a variety of part time positions including waitressing, childcare and horticultural work. She was Pākehā and in her early forties. The loss of her mother at a comparatively young age some 20 years earlier had greatly affected her. The interview was conducted in the researcher's home.

Rawiri was a young man in his early twenties who identified as Māori. He worked as a truck driver and in horticulture. Although he had a limited experience with death, he had lost a grandmother very suddenly the previous year. The interview was conducted in the researcher's home.

Doc was a semi-retired General Practitioner. He had immigrated to New Zealand from England many years ago and was now in his late sixties. He had a wealth of experience working with terminally ill patients. The interview took place in his surgery.

Joint interviews (JI)

Joy and John were a retired couple in their sixties. They were Pākehā and had recently lost a very close friend in a long drawn out illness. The interview took place in their home.

Rebecca and Mia were mother and daughter in their eighties and fifties respectively and both identified as Pākehā. They had a close relationship with each other and both had been widowed. Rebecca was a devout Catholic but Mia was an atheist despite having been brought up in the faith. The interview took place in Rebecca's home.

Julie and Kaitlin were friends in their late fifties. They were both Pākehā and for the most part struggled to find employment. The interview took place in Julie's home.

Jill and Marian were close friends in their late fifties. They were both well-educated and identified as Pākehā. Jill was a highly respected businesswoman and Marian operated a large-scale family dairy farm. The interview was conducted in the researcher's office.

Focus group interviews (FG)

Men's Group consisted of 4 close friends; Mike was in his mid-fifties and identified as an Indian New Zealander and the other 3, Denis, George and Jimmy were Pākehā and in their

forties. They were all working in a variety of occupations including teacher, factory worker, tradesman and salesman. The group met together for the interview at Mike's home.

Te Rōpū Kuia consisted of Pania who was in her seventies and Nina, Awhina and Carol who were all in their fifties. They identified strongly as Māori and all spoke te reo to a high level. They all were heavily involved in the local Māori community with Nina and Awhina working in education and Carol in religious ministry. As befitted her mana as a respected elder Pania spent much of her time advising and supporting all things Maori in the community. The focus group was convened at Pania's home.

Te Rōpū Wāhine/Tāne consisted of 4 participants: Piripi who was in his seventies, Ani and Mikare who were in their fifties and Pari who was in her forties. They all identified strongly as Maori and all spoke fluent te reo except for Mikare who had very little knowledge of Māori language. They all worked together as teachers and had a good understanding of Māori tikanga and history. The interview took place in a meeting room at the school where they were teaching.

Te Rōpū Wāhine consisted of Tia, Puti and Katarina who were all in their twenties. These participants were not as secure in their Māori identity as in the previous groups possibly because they were not as well versed in te reo or traditional cultural knowledge. This was a particular concern for Katarina initially, as discussed earlier. They all worked as teachers at the school where the interview took place in a meeting room during the lunch break.

In summary, a total of 28 people volunteered to participate in the research: 19 women and 9 men. The ethnicity of the participants included 12 who identified as Māori, 15 as Pākehā and 1 as an Indian New Zealander. Their ages ranged from 24-84 years and the educational, employment and socio-economic backgrounds varied considerably. There were 5 individual interviews carried out, 4 interviews in pairs and 4 small focus groups of 3-4 members. All participants were given a \$20 gift voucher as a small token of appreciation and in recognition of their time commitment to the project. The tapes resulting from the 13 data collection sessions, that each lasted between 30 and 90 minutes in duration, were then transcribed.

Transcription

The transcription of the data was carried out by the researcher because although it can be regarded as a particularly laborious and tedious task it can greatly facilitate the analysis. The continued exposure, firstly through the original interview and then with the repeated playing of the tape, allowed the researcher to become more immersed in the data. The nuances of the discussion, the way things were said, the tone or inflexion or emphasis on certain words all aided in interpretation. This study also utilised short field notes to try to detail meanings apparent during the original interview through personal observations and reflections on the experience. Although this all contributed to the transcription and subsequent analysis it must be recognised that no matter how skilled the researcher may be, it is inevitable that some aspects of the character and meaning of the participants' talk will be lost in the process. Even though all participants were fluent in English, similar to the findings of Umaña-Taylor and Bámaca (2004) in their work with Latina women who were fluent English speakers, there were times when some participants reverted to expressing themselves in Māori. Although not fluent in te reo, the researcher was generally able to translate these particular passages during transcription. However, there were occasions where the concept expressed in Māori had no equivalent English translation and kaumātua assistance was sought to convey the sense of the discourse.

Transcription utilised a very simplified format of transcription conventions based on those developed by Jefferson (1985) for conversational analysis (Wetherall & Potter, 1992) (see Appendix F for Transcription Key). Individual interview participants were offered the chance to review the transcript and make any changes but none prevailed themselves of this opportunity. It was not considered appropriate for pair or group participants to be offered this facility as any potential deletions, additions or alterations by one individual would inexorably affect the meaning of other participants' contributions and the discussion as a whole.

Analysis

The description of the analytical procedure followed in this study needs to be prefaced by an acknowledgement yet again of the researcher's contribution to the data. Furthermore, it

also needs to be recognised that the analysis is not a separate phase of the study but begins during the interviewing period, continues through the transcription and initial coding step, and culminates in what can be considered as the formal analytical stage. However, as Taylor (2001) suggests it can be somewhat difficult to identify a completion point because inevitably some analytical paths will be followed at the expense of others to perhaps be revisited later.

The essence of this analysis then involved getting to know the data by immersing myself in the recordings and the transcripts. This was a long process as it involved returning over and over again to the data to get a sense of what it was about. The research question of “how do people make sense of euthanasia” was used to guide a preliminary step of coding whereby any data not relevant to the topic was discarded. However, as noted by Tuffin and Howard (2001) because the interview schedule was focused around this issue there was very little data redundancy. The second step involved sorting and placing all the retained data into meaningful groupings. In carrying out this step it was important that I refrained from imposing my own categories on the data but rather allowed them to come out of the text (Tuffin & Howard, 2001). The data yielded three categories of construction that were internally coherent; they were *identity*, *reciprocation* and *burden and duty*.

It is in the next stage of analysis that the importance of the theoretical framework in which the research is located became apparent. It involved the identification and explanation of patterns in the data through an intense, iterative process of data immersion and referring back to the theoretical assumptions about discourse, knowledge and power that underpinned the research question. As pointed out by Taylor (2001) the researcher is initially unsure of what the data patterns may look like or even their significance. Thus, it is unsurprising that there were a number of what Potter and Wetherell (1987) call ‘false starts’ where patterns seemed to appear but could not be adequately accounted for within the study’s theoretical constructs or substantiated by the text. However, as suggested by Carabine (2001) as the analysis proceeded the process became more ‘fine-tuned’ so that through repeated close readings of the interview transcripts, listening to the audio-tapes and considering the Foucauldian analytical concepts that guided the research, patterns slowly

emerged that were supported by the data and also able to be explained in an analytically coherent way.

Postscript

While acknowledging that it can be difficult to give a detailed guide on the general process of discourse analysis, Burr (2005) has rightly lamented on the lack of information provided by individual researchers on their own analytical process. Therefore, in the interests of providing more detailed reflection on my own analytical reading this analysis section concludes with a more comprehensive consideration of the 'steps' taken to identify the themes and discourses in this research.

The analytical process, as mentioned previously, began during the interview phase and continued through periods of reflection following each interview. Some interesting features began to emerge at this early stage. For example, I noticed quite a strong preoccupation with the inability of the elderly or dying person to meet certain acceptable standards of 'normal' adult life. Linked to this were concerns that as a consequence of this failure there were double-sided issues around burden and responsibility of care. Noticing this preoccupation, I began to focus on the construction of burden, as a weight to be carried, and responsibility as a social duty, particularly in relation to the moral imperatives associated with living a normal adult life.

The transcription phase, which of necessity is slow and repetitive, allowed time for further contemplation on emergent themes and for searching for wider patterns in the data. At this point it became apparent that the talk around the societal status of the elderly and dying meant that the meaning of human life itself and the concept of a 'life worth living' was at stake. This was also clearly linked to notions of autonomy and independence. It was also at this stage of the analysis that themes around the connection between the individual and society began to emerge, with a focus on attempts to measure the value of each party's contribution to that relationship. These initial patterns were recorded in the researcher's notes but it would be fair to say that at this stage the significance of these 'findings' was

still rather elusive and they were more like a focus of my attention than a systematic 'coding' of emergent themes.

Following on from this was a sustained phase of close reading of the transcripts. This allowed for both a more in depth exploration of some of the emerging patterns and also for a wider investigation of other possibilities. At this stage the process of coding became a dominant technique of the analysis. Although there are a number of software packages available for supporting coding, the necessity of these categories to be underpinned by the Foucauldian concepts that drove the research led me to undertake this phase manually. Utilising a range of different colours, sections of the data that seemed to realise a particular pattern were highlighted. There were often overlaps in the groupings and so the transcripts were photocopied and each section placed into the relevant category. However, there was frequently a need to return to the transcripts for more intense reading that at times led to further additions or deletions from the various categories.

The identification of discourses at work within the themes was also aided by immersing myself in the literature as it often provided a focus for the possible significance of grouping particular patterns of data. For example, the work of Lawton (2000) around experiences of the dying process led to important insights regarding the centrality of a bounded body to concepts of identity. In a similar way, the seminal work of Goffman (1963) provided a conceptual base for the importance of physical appearance to perceptions of identity. The engagement with the literature in this way led to an iterative process of movement between discourses as they manifested in the data and as they manifested in the literature. This worked to refine the analysis by a process of mutual affirmation.

A very important step in the analysis now gained primacy as categories of data were trialed again and again, sometimes yielding a coherent pattern and at other times requiring re-organisation and re-trialing. This process was particularly evident within the theme of reciprocation. Initially there were data groupings that did not appear congruent with this construction or indeed assumptions inherent within a Foucauldian framework. However, after returning to the data and the literature countless times and rearranging and re-trialing

sections of data it became apparent that discourses such as ‘value to society’ and a ‘fair deal’ were accomplishing important work within this theme. Finally, the analytical write-up entailed the presentation to the reader of the three major themes that emerged from the data and identification of the discourses that constructed these themes as patterns of meaning.

Although the various analytical phases that I have discussed here can be considered as having a temporal dimension in as much as they started with interviews and ended with the analysis write-up, it is also important to realise that there was a great deal of overlap between the phases and the overall analytical process was iterative along multiple dimensions: back and forth within the data, the literature, my notes and codes, photocopies and colours. Therefore, it is probably unhelpful to view the phases as steps in any linear sense. Similarly, it is important to note that although the analytical chapters to come are divided into three separate sections or themes with the relevant discourses contained within each, the artificiality of this representation must be acknowledged. I would argue that it is very difficult, and indeed constraining to separate discursive work into essentially arbitrary divisions as seen in the following chapters. However, the need to communicate research findings in such a way that it is easily accessible to the reader brings with it a requirement of compromise. It is through the adoption of this middle ground that we may gain some better understanding of how people make sense of euthanasia.

Conclusion

The method described in this chapter has not followed a straightforward, seamless model but rather represents an attempt to allow the reader to follow the decision-making dilemmas presented by the research process. These were often associated with the perceived problems, concerns and limitations of particular pathways. In spite of this, it should be noted that the decisions made and the routes taken were not always without their own difficulties and challenges that are elaborated on in more detail in the discussion. The important point to make however is that this approach to detailing how the research was carried out allows it to be viewed through a critical lens.

The following chapters will present the findings of the analytical pathways that were followed in the research. They are arranged around the three constructions of euthanasia that were evident in the data; *identity*, *reciprocation* and *burden and duty*, and theoretically linked to the participants' use of discourses to construct their version of euthanasia. The focus on the social and discursive construction of euthanasia is a reflection of the methodology of the study and its epistemological underpinnings. Since discourses are inherently linked to knowledge and power, the identification of different discourses and the effects of their constructions of euthanasia may provide critical insights into ways of making sense of euthanasia and the power relations they support or undermine.

CHAPTER FIVE

Identity

This chapter explores the various discourses that participants drew on to construct identity at the end-of-life. It focuses on the way in which these discourses also function to strip the dying person of his or her identities. The implications of this for life's project of the self are then considered.

Introduction

The concept of social death arose from Durkheim's "Année Sociologique" school in the early twentieth century (Sweeting & Gilhooly, 1997). It has been characterised as a succession of losses that a person experiences as they approach their biological death that culminates in a disconnection from the social world (Seale, 1998). It can include the loss of the ability to work, to participate in social activities, to carry out self-cares and the subsequent losses of identity. It is becoming increasingly common in today's society for social death to occur prior to biological death. However, Searle (1998) suggests that the maintenance of social bonds at the end-of-life is an essential human need. He describes different approaches that have been developed in post-modern times to facilitate this continued social connection. One such tactic is that of euthanasia where the dying person can take control of the timing of death and therefore synchronise both social and biological death.

Another important notion examined in this chapter is the relationship between identity and autonomous selfhood. Lawton (2000) contends that the contemporary Western conceptualisation of the person relies on a physically sealed body that has the ability to act as an independent and autonomous agent. Therefore, she argues that a loss of either or both faculties will have far-reaching consequences for personhood and identity. The consideration of identity at the end-of-life was a focus for participants in their talk around death and dying. They drew on a number of discourses to construct the identity of the dying person in such a way that they seemed to bear little resemblance to the person that they once were. Instead, an unknown entity appeared to have replaced the previously familiar personas of their loved one. This new identity however, was perceived as being somewhat

challenging for a number of reasons and led to suggestions regarding appropriate management strategies.

The suggestion that identity is discursively constructed implicates a sense of identity as an object discursively produced. In as much as identity is formed through its discursive constitution, this chapter treats the notion in much the same way as other constructed objects. Nonetheless, the close relationship between identity constructions, agency and the positions that dying subjects are offered through the talk of participants, complicates such a straightforward reading. While treating identity as an object constituted through discourse, this chapter also considers its implications for subject positioning and agency.

Physical appearance

Physical appearance is an important aspect of claiming identity and the Western World is often characterised as being fixated with what Peterson (1997) refers to as the “cult of the body” (p.200). In the on-going project of constructing identity, the importance of striving for and maintaining this outward signifier of identity through attention to diet, fitness, fashion and even cosmetic surgery in order to mould appearance to a societal ideal cannot be underestimated. The subject positions offered to those who best approximate the socially prescribed standards of physical appearance are of such high status that physical appearance becomes a preoccupation of those aspiring to Western ideals. Therefore, the dilemma posed by a changing, disintegrating and disfigured body profoundly impacts on an individual’s sense of identity.

The dichotomy that exists between physical beauty and the ugliness associated with disease is clearly established in the following extract. Pania creates a contrasting picture that is indicative of this divide as she describes her young nephew’s disease progression:

Pania: He, he was too pretty, too handsome to, to live maybe. Cause he looked like a girl, his features really, really, um was beautiful features, dark, fair, big and eyelashes you know, really curl up. And he had this thing on his ear when he was teething and they caught it and it came up like, like a goitre. Yeah, but it wasn’t

goitre, it was a cancerous growth. And so they took him down to um Christchurch for chemo and they brought him back after. But it didn't help; you didn't want to see that thing. (FG)

The suggestion here is that the boy's beauty has perhaps even surpassed that of an ideal, "too pretty, too handsome", and thus he has been elevated to an almost angelic status that is not compatible with being part of the ordinary world. This sense that somehow he was not meant to live is further enhanced by linking his physical features to ideals of beauty that seem to be intrinsic to the female gender. However, there is a real struggle to clarify what specifically determines the criteria for this beauty as the features are variously described as "dark, fair, big". Nevertheless, the portrayal of eyelashes long enough to "really curl up" clinches the description that epitomises feminine beauty. Therefore, the incongruence of such attractiveness on a male face, albeit a young child, bolsters the account of how things were before the arrival of the "thing". Although it is clear that Pania is aware of the nature of the disfigurement, "it wasn't goitre, it was a cancerous growth", she is reluctant to give voice to its name. Thus, her usage of the very generalised term of "thing" avoids mentioning the harsh reality of the diagnosis and in doing so bringing it into being in the conversation.

This focus on physical appearance as a 'performative' aspect of embodiment reflects the importance that is placed on an attractive physical exterior. Therefore, the growth of a cancerous tumour that blights the young boy's face calls for a turning away from such an unsightly physical entity, "you didn't want to see that thing". The desire to turn away isn't linked to the illness but to the growth – not wanting to see something odd or disfiguring on a "pretty" and "handsome" child. However, as this 'thing' is growing on his face it is unavoidable that your gaze will rest on it when looking at the boy. He is thus marked out and stigmatised by the physical abnormality that is characterised as the coming together of 'Beauty and the Beast'. The 'thing' compromises the otherwise clear image of beauty through which Pania constitutes the subject position that her nephew occupies in relation to the discourse of physical appearance.

It is unsurprising then that research indicates that terminally ill patients report that changes to their physical appearance in particular, as a result of the disease progression, are associated with others viewing them as ‘abnormal’ and ignoring or avoiding them (Lawton, 2000). This lack of acceptance on the grounds of what Goffman (1963) in his seminal work on stigma refers to as “abominations of the body” (p.14) can be attributed to the clearly defined evidence that a substantial difference exists between them and the attributes expected of the ‘normal’ category of person. The implication of this departure from the ‘norm’ is that the physically marred individual is “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p.12). Furthermore, such physical aberrations allow the positioning of the person within this discourse in such a way that it has a profound effect on the construction of their own sense of identity.

Discourses of physical appearance featured prominently in the construction of identity. In the following extract, Mia describes events around the death of her husband’s ex-wife and the mother of his children. In this instance, physical appearance is used to explain how in terminal illness she somehow ceased to be their mother:

*Mia: He hated taking the kids up there every day and she was still alive and she wasn't like their mother any more. She got all blown up with the... what do you ... some hormony stuff that they get, I don't know like, what do you call those steroids and stuff? And, and all bloated and big, fat and she would have **hated** it. She was so particular about how she looked and stuff and she looked awful, you know, and even Kristen who was only, I don't know how old she would have been, twenty, not quite twenty, eighteen, you know and they said, “Doesn't your mother look peaceful?” And she said, “No, no she doesn't, it's not her”. (JI)*

The physical effects of the cancer treatment that have caused the dying woman to become “bloated and big, fat” have also apparently robbed her of her identity as a mother. A crucial aspect of her positioning within her family is at risk. The account of the side effects of steroid treatment is linked to the emotionally laden response of her ex-husband who “hated taking the kids up there every day”. The agony of having to accompany his children and

confront this person who “wasn’t like their mother any more” is overwhelming. The questions that arise of course are that if she is no longer their mother then who is she and why are they visiting? There is certainly a strong suggestion that this is an unwelcome predicament. Furthermore, the fact that “she was still alive” is compounding the situation by blocking their only avenue for escape – her death.

The emotionality evident in this quote is also extended to the dying woman as the strongly negative emotion of hate is utilised again, this time to describe her feelings regarding her appearance. This is not only connected to her identity as a mother but also implicates her identity as a woman. There are compelling societal expectations to uphold a high standard of feminine appearance. As a woman, Mia also recognises this necessity and without question assumes the abhorrence felt by the dying woman in falling well short of these standards, “she would have hated it”. Mia also positions her as not the type of woman who would ‘let herself go’, “she was so particular about how she looked and stuff”. This positioning further supports the notion that in losing the ability to achieve a certain form of feminine beauty that takes time, energy and effort but is so demanded by our society, “she looked awful”, she is also relinquishing her identity as a ‘real’ woman.

Loss of identity both as a mother and as a woman due to the deterioration of physical appearance is characterised as being very evident to those who knew her well. Therefore, although hospice staff may have been unaware of, or chose to ignore, this radically changed physicality and corresponding problematic identity, “Doesn’t your mother look peaceful?” it had certainly not escaped the attention of her daughter. Mia places a lot of importance here in underlining the relatively young age of this close family member in order to emphasise the patently obvious consequences of a failure to meet a societal norm of a pleasing and attractive physical exterior. “Even Kristen” could recognise the unacceptability of her mother’s deviation from this expectation and subsequent loss of identity, “No, no she doesn’t, its not her”.

The importance of sustaining an acceptable physical appearance in order to starve off the loss of identity as a woman that may accompany a slow decline towards death is highlighted in the following extract:

Julie: I don't like to think that the kids are going to come in and see me every day and I'm in agony and I'm withering away and I'm...

Kaitlin: No teeth.

Julie: No teeth [laugh] sunken eyes, well its [unclear.]

Kaitlin: That's my biggest fear, //going into hospital and not having any teeth [laughter].

Julie: //Hair falling out. No hair, having no hair, your hair falling out [laughter].

Kaitlin: Oh, I could live with that I could put a scarf around my hair, but I can't put a scarf round my mouth [laughter.]

Julie: [Laughter] Oh yeah like you know when the families coming to see you today oh help make-up, and then you've got all this red rouge and no, no, no [unclear] no teeth.

Kaitlin: But I mean everyone comes to see you and they're going 'how are you?' you know. (JI)

The pressure to 'keep up appearances' here is unmistakable and extends to some quite specific traits, "sunken eyes", "no teeth" and "no hair". The notion of social surveillance is also clear, as not only "the kids" but "everyone comes to see you". Therefore, positioned as a woman with social obligations for a pleasing appearance, it is imperative that you attempt to repair or cover up those failing features that may be undermining your identity. However, this attempt at concealment is not altogether successful, "I could put a scarf around my hair, but I can't put a scarf around my mouth". The laughter that is so evident in this extract underlines the preposterous situation that the dying woman is facing. The use of make-up, an essential element of maintaining the feminine façade, is also somewhat challenging. There is an acknowledgement that even this most potent technology in a woman's repertoire may still be insufficient in hiding the signs of the physical disintegration on a dying face. The resulting outcome of "all this red rouge and no ... teeth"

only further highlights how far they have diverged from society's perception of the ideal female identity.

Discourses constructing physical appearance after death were also important for the construction of identity. There was a real concern for some participants that they should die with an intact body:

Marian: I wouldn't want to die in a car accident, that's one way I would hate to die.

Jill: Yeah, me too.

Marian: All hurt and broken and cut and I've been in two car accidents now and I really would not like to die in a car accident. (JI)

Jimmy: And tidy, I don't want it to be something messy with a, you know when they're putting you together in a box. All the family can't see you, all the kids. They might not want to anyway but... (FG)

In Western secular society, death is understood as final. The individualism that characterises this culture perceives the body as being the “private domain of the individual person” (Kleiman, 1988, p.11). This conceptualisation offers some insight into a pre-occupation with the body's condition at death. The obvious signs of violence implied in death by car accident, “hurt and broken and cut”, represent an affront to your most intimate personal possession. There is a desire for consistency and orderliness in this exterior vessel even beyond death. The need to retain some form of bodily integrity can be linked to a sense of responsibility to ensure appearances are maintained, particularly as surveillance continues and indeed is an integral part of post-death rituals. Therefore, if death is “something messy” it will inhibit the ability of family and friends to gaze upon your body in that final farewell, “All the family can't see you, all the kids”. As Haddow (2005) points out “The newly-dead body remains a powerful representation of the self – a person's features and characteristics are imprinted on their corporeal identity” (p.108-109).

In a similar way, Māori perceptions of embodiment also place an emphasis on an intact body at death. However, Webb and Shaw (2011) argue that rather than this being due to any individualistic concepts regarding the body, it can be attributed to understandings of

Māori identity that are associated with the wider views regarding whānau and whakapapa. This more holistic construction of identity recognises that the body represents a link between past ancestors and the present generation of whānau. Therefore, drawing upon discourses that value bodily integrity and the acceptable appearance of the tupapaku (deceased) are vital.

This section has examined the importance of discourses of the body and its physical appearance to constructions of identity. There is an important continuity between the demands for an acceptable physical appearance not only during life, but also at the end-of-life and even after death. Claims to identity are linked to the ability to maintain and uphold at all times a standard of appearance that falls within ‘normal’ societal expectations. The failure to achieve this level of acceptability threatens the very foundations of an individual’s identities. The gendered nature of many of the discourses in this section also highlighted how particularly integral physical appearance is for constructions of feminine identity.

Leaky bodies

We now turn to discourses constructing other ways that the body is seen as betraying us at the end-of-life and in the process undermining identity. Seale (1998) argues that particularly in the West it is through our bodies that we are able to fashion an individual sense of self-identity. However, according to Lawton (2000) if that body becomes unbounded or loses certain aspects of bodily autonomy then selfhood is threatened. In the following extract, the corporeal inability to wash oneself and take care of other intimate needs is seen as the catalyst for ending a life. Mia has expressed the opinion that she would have no qualms in agreeing with euthanasia in certain situations. However, her mother, Rebecca is vehemently opposed to this view and this has led to the following exchange:

Rebecca: ...And I suppose you’d get rid of me pretty quick. I’ve had enough of this.

Mia: No, but if, if it got to the point where I knew you weren’t getting any better if you were in really bad pain, if you were just sick of all the rubbish, cause it must be

*quite painful getting washed by someone else and **all** that kind of stuff, not necessary painful but embarrassing. It's just not you it's not like you. I would, I'd (.) put the pillow over. (JI)*

The inevitability of having to rely on others to perform the most basic personal necessities of self-care is seen as analogous to pain. Although the emotional pain of the embarrassment involved is qualified to differentiate it from a physical pain, it is still evident that the humiliation is deeply disturbing, “it must be quite painful getting washed by someone else and **all** that kind of stuff, not necessarily painful but embarrassing”. The intensely private nature of such activities and the apparent shame attached to them is reflected in Mia’s inability to actually name the intimate cares involved, instead she resorts to the phrase, “and **all** that kind of stuff”. This has the effect of simultaneously being able to glide over these ‘dirty’ activities euphemistically while at the same time clearly emphasising the personal degradation involved in someone else undertaking the multitude of tasks involved.

The implications of these unacceptable yet necessary “invasions of intimacy” (Seale, 1998, p.149) clearly result in a loss of identity, “It’s just not you, it’s not like you”. This is similar to the earlier extract where Mia talks about a deteriorating physical appearance as having the effect of stripping a mother of her recognisable features. In this case, it is the inability to manage simple hygienic requirements autonomously that contribute to the separation of identity from that familiar maternal figure. This subsequently leads to an obligation in Mia’s eyes to extinguish the life, not of her mother, but of an unrecognisable entity, “I would, I’d (.) put the pillow over”.

Failure to attend to one’s personal cleanliness and in particular to go to the toilet unaided presents some real challenges to the Western conceptualisation of a fully autonomous self. The contrast between an ideal of independence and the helplessness associated with being unable to control or cope with these basic bodily functions is highlighted in the following extract:

Kit: My grandmother died recently, or a year ago, she was um a fiercely independent 94 year old woman...., and she wasn't able to function and she couldn't go to the toilet and it was just the most terrible thing. (II)

The “fiercely independent 94 year old woman” is an image that we as a society admire and aspire to emulate in our own old age. Therefore, the disparity that is created between this heroic figure and someone who cannot perform the simple function of toileting is truly shocking, “it was just the most terrible thing”. The deplorable incapacity to take control of the discharging of bodily wastes in an acceptable fashion is seen in the next extract as quite difficult even to talk about:

Jill: ...Larry's Mum, I was um helping her go to the, you know, when she was on the toilet and she looked up at me and she said, “Oh Jill, I just, I just want to, I just want to go” and she said, “It shouldn't be like this” and I just said you know, “Come on Jackie, I'm family, I'm your daughter-in-law, I'd do anything for you” but it's just ...

Marian: It's not right. (JI)

The social taboos associated with human urination and defecation are undoubtedly very strong. It is unsurprising then that Jill struggles to find the appropriate words to describe the situation she finds herself in with her mother-in-law, “I was um helping her go to the, you know”. Although the familial ties that bind them together are emphasised, “I'm family, I'm your daughter-in-law”, there is the jointly held assumption that not even a family member should be called upon to perform these duties, “It shouldn't be like this”; “I'd do anything for you, but it's just...” Marian supports this view with a clear declaration of the inappropriate and unacceptable state of affairs, “It's not right”.

The process of aging can bear many similarities to the experience of dying (Seale, 1998) in terms of the losses associated with the inability to maintain fundamental bodily tasks. This severely impacts on both self-identity and others perceptions of the embodied individual. These discourses around the daily routines and requirements of personal hygiene and

toileting very much reflect a normative conceptualisation of life that privileges individual autonomy and control. Expectations of autonomy are undermined by the failure of the aging or dying body to conform to these criteria. The apparent deviancy from these standards results in the production of a deficit identity where the individual is defined in terms of their lack of independence.

Lawton (2000) argues that an essential element of personhood is agency that requires the ability to act for one's self. Therefore, if the capacity for performing these corporeal functions unaided is lost, the individual is positioned as lacking the characteristics of a "full person" (p. 142). This was seen in the following extract where there was a regression of identity to that of an infant as a direct consequence of performative deficits in autonomous self-care:

Ani: I'd hate for my family to have to look after me and bath me and change me and all of that. I'd like to go early before that stage.

Piripi:: I would rather my family have quality...

Pari: That's right.

Ani: ...Time than have to babysit and look after me and...

Pari: Wiping my dribble or anything like that, Nah. (FG)

There is a definite sense here that the status of a full adult identity has been lost by virtue of the necessity for others to carry out tasks akin to the care of a baby. The need to bath and change someone, wipe their dribble and indeed to "babysit" them is viewed with some abhorrence by these participants. As Lawton (2000) comments, it is only when these taken for granted activities that are reliant on bodily autonomy are lost that their centrality to the Western concept of person and self are brought into focus. Furthermore, related to this necessity for an autonomous, independent individual is the requirement to maintain a physically bounded body, one that does not 'leak' in the context of social relationships, as a fundamental aspect of personhood.

The leaky bodies sometimes associated with the decay of terminal illness emit specific smells and odours that are greeted with a sense of revulsion:

Nina: When Mary was dialysing I went up to pick her up and she had someone sitting next to her and he was asleep but the bowel motions were coming up the back of his clothes, right up his back and I just thought, and it, and it smelt, it really smelt when you walked into the room and I felt, really felt sorry for him. Lucky he was asleep, he didn't see my face cause naturally I screwed it up with the smell. And then to see it oozing which he couldn't help, out and he was only about 28 and he died about three months later. And that's, but that's what happened you know luckily for us I suppose whatever happened to her she hid it or it didn't happen, I don't know, we never ever struck it with her. (FG)

The unbounded body of this young man betrays him by the uncontrolled leakage of human wastes as he sleeps, thus challenging the Western concept of a sealed, contained individual. The importance of being able to resist being positioned in this potentially damaging discourse by hiding these aspects of the dying process and shielding others from the disintegration of the body's boundaries is clear in this extract. Nina recounts how 'lucky' her family was that "whatever happened to her," her sister Mary "hid it or it didn't happen". In contrast, a failure to contain these bodily emissions and associated putrid smells are reflected in the faces around you:

Carol: My brother died with um kidney problems, dialysis, four years or something and um, and in the end he was um, it was oozing out of his skin, the smell was not very pleasant, and the thing he hates about being like how he was and he said, "The looks on your faces" and he said, "The looks on your faces is" he said, "I don't want to see that," you know on our faces and "What do you mean?" And he said, "The looks on your faces is um 'Oh, this poor bastard'". That's, these are, these are his own words, "Oh, that poor bastard he has to go through all this".

The 'docile' body of Foucault's bio-power has eschewed the individual's attempts at discipline and control. The stench that accompanies this unboundedness is further evidence of how far the dying person has strayed from the criteria of a 'normal', functioning human being. However, according to Lawton (2000) the significance of these odours is specific to our contemporary Western culture. Technological developments have enabled us to 'hide' the scent of bodily functions with everything from water closets to deodorant, including room deodorisers. In previous historical periods and different societies, such smells were accepted as part of everyday life. The necessity to conceal these bodily functions from public sensibilities has gone hand in hand with the development of a 'civilised' society and a Western ideal of individualism and personhood. This has led to claims (Lawton, 2000) that the hospice has become a place to sequester away not those who are dying but especially those individuals whose bodies decay and rot in the process, in order to mask these facets of death that as a society we find so unpalatable.

In the above extract, the dying brother is able to read on the faces of his loved ones the full extent of his disintegration, "The looks on your faces is um 'Oh, this poor bastard'". It is this stark evaluation of his impossible situation from those around him that is of greatest concern, "The thing he hates about being like how he was and he said, 'The looks on your faces' and he said... 'I don't want to see that'". His reluctance to witness the inevitable assessment of him from their surveillance is understandable as it can only reinforce his own sense of a diminished self. It is apparent to both himself and his family that he can no longer claim membership to the category of a person by virtue of his leaky, smelly body. The consequences of this loss of self-identity are unmistakable:

Carol: He decided that he didn't want any more and he said, "It doesn't matter how many times they wash me I could smell my body dying" and he said, "I don't want it". (FG)

There is a separation here of the body from the self, in other words a disembodiment. Although his caregivers wash him repeatedly it has no effect on the body and the smells it emits as it dies. This partitioning of the body from self allows him to distance himself from

both the odour and the dying. However, it is clear that the severance is still insufficient and a more permanent solution is necessary. In this instance, the decision involved ceasing dialysis and thus hastening death.

Identity at the end-of-life is assailed by both the inability to control and contain bodily fluids and to provide self-care. In a similar way to how a deteriorating physical appearance due to the ravishes of the dying process undermines identity, the loss of autonomy over basic corporeal functions leads to a further debasement of personhood. The desire to avoid the corresponding losses of identity can lead to the notion of a dichotomy between the body that is betraying us and the self or mind. This was evident in the previous extract and was seen as an on-going dilemma for participants in the research.

Mind/Body Dichotomy

The question of whether we have a body or are a body (Turner, 1996) has long been a pre-occupation of philosophers. The dualism of mind/body that is associated with contemporary Western thought has its origins in the work of the seventeenth century French philosopher René Descartes. The mind was viewed as being “responsible for conscious thought, and conscious thought was the very essence of human existence. *Cogito, ergo sum* – I am thinking, therefore I exist” (Martin, 1998, p. 271). However, the mind was regarded as quite separate to the physical body, it was seen as an ethereal, non-corporeal entity that, depending on your belief system, was synonymous with the soul and could continue to exist after the death of the mortal body.

The ambiguity that participants expressed regarding the various effects and consequences of the disintegration of the body versus the mind lends support to the enduring nature of this ‘Cartesian dualism’:

Jill: One of my aunties, her mind was as sharp as a tack, absolutely sharp, she was 82 and, but she was crippled with arthritis, ... And she made a conscious decision to end her life and she said, “I’m sick of it, I’ve got no quality of life... So she chose, so

her quality of life was based, for her it was based on the fact that physically she had become so impaired that everything had to be done for her and she didn't like that.

Marian: No, I wouldn't like that Jill. Would you like that? I would not like that.

Jill: No, but I'd rather have my mind. Oh, I don't know //it's so hard.

Marian: // Well at least she had her mind to make the decision. (JI)

There is a clear division here between a highly functioning mind and an ailing, twisted, dysfunctional body. The metaphor “as sharp as a tack” leaves us in no doubt of her aunt’s well-honed mental faculties. The inclusion of her age, “82” also adds emphasis to the admirable capabilities of this octogenarian mind. In sharp contrast, it is her body that has completely betrayed her so that, “physically she had become so impaired that everything had to be done for her”. Although the distaste that this loss of bodily autonomy evokes for Marian is abundantly clear, “I would not like that” there is some compensation to be found in the fact that “at least she had her mind”. However, the quandary that this predicament presents for Jill is palpable,” No, but I’d rather have my mind. Oh, I don’t know, it’s so hard”.

The Cartesian discourse constructing a mind/body dichotomy illustrated by this extract has complex and far reaching implications for constructions of identity and indeed for notions of what it means to be a living human being. As mentioned, discourses that have been discussed previously in this chapter have highlighted the significance of physical appearance and an autonomous, bounded body for the construction of identity. However, in the following extracts there is a real emphasis on the importance of the rationality of mental processes in order to maintain identity:

Pania: I don't want anything that will send me around the bend and I need to have my faculties about me, I don't want to go with the fairies...it sends you cuckoo, I'm not

here, you know it's somebody else, I'm not here, I'm away with the fairies...I want to be down to earth. (FG)

Jimmy: Sometimes it's not even drugs, it's just the mental processes aren't working as they should and they don't, you know, they, they're almost, they're not themselves anymore, they're someone else. (FG)

Pania recognises the very real possibility that a terminal condition may precipitate the necessity to take mind-altering drugs. However, her profound desire to remain in the 'here and now' and thus retain her identity is unmistakable. The text is rich in mixed metaphors that have the effect of connecting irrationality with a loss of self-identity. Therefore, the various scenarios of being sent "cuckoo" or sent "around the bend" or "being away with the fairies" all result in Pania somehow being 'missing in action'. Further compounding her disappearance is the emergence of another entity that has, in her absence, had the audacity to take on her identity, "it's somebody else, I'm not here".

The debate around the mind/body issue is at the very heart of how we perceive ourselves in terms of the relationship between the physicality of body and brain and the thinking, feeling, conscious mind. As Martin (1998) suggests there is a long held presumption that it is the conscious mind that sets us apart from less developed animals, or indeed being conceived as nothing more than a machine. In a similar fashion to Pania, Jimmy's concern with any malfunction of "the mental processes", drug induced or not, is linked to the idea that it is the mind that distinguishes you as a unique individual and thus bestows identity. Therefore, in many instances when it was perceived that the mind had 'gone' or was severely impaired, participants often positioned the person in terms of a vegetable or an inanimate object:

Kaitlin: Well, I mean they, yes, they must, they must be able to say that there is no hope for that person, it's going to remain a vegetable, you know I mean once again you've just got a body just wasting away there, the heart's beating but there's

absolutely, it's just been kept alive by machines well you know I mean as hard as it is, I mean but... (JI)

The vegetable metaphor used here by Kaitlin evokes a failure of mental functioning. The contrast set up between this loss of mind and the “wasting” body is further emphasised by employing a key indicator of minimisation (just) to undermine the value of the body, “just got a body, just wasting away”. This depersonalisation of the terminally ill subject is further supported by the substitution of an object for the person, “it’s going to remain a vegetable”. The emphasis on the body, and its parts, worthless as it may be, reinforces the factual nature of the medical account of a machine-aided organ beating in a wasting body while simultaneously drawing attention to the lack of human traits displayed. It is little wonder then that in these circumstances Kaitlin perceives that there is “no hope for that person”.

Loss of humanity however, was not always restricted to those who were unable to reach a required standard of mental functioning but at times also extended to those who had lost control of their body:

*Joy: Um and it's the worse, the um becoming, being a vegetable and having **no** control, maybe having (.) no, being alert in your mind but having no control over your body whatsoever, that you have to rely on machines and people to do everything for you, knowing that would never, ever change. I wouldn't want to be just (.) just a log lying there. (JI)*

Although there is some hesitation and perhaps uncertainty about the various merits of retaining a mind as opposed to maintaining command of the physical body, Joy again positions the person as a vegetable. The implication is that the situation is worse because “being alert in your mind,” means that you are only too painfully aware of the catastrophic failure to control your body, “having **no** control”. Furthermore, you are also able to appreciate fully the magnitude of your circumstances, “knowing that would never, ever change”. It is at this point that all vestiges of personhood seem to have disappeared as the

analogy of “just a log” is utilised to paint a vivid picture of a totally useless, inanimate object. The desire to avoid this fate is clear:

Rawiri: You know like, if you're, if I was a vegetable I'd rather be dead, I don't care how old I was. If I was, if all I could do was just lay there, be fed through a tube, I am dead. That's how I see it. (II)

Death is seen here as a far preferable option to that of being positioned as a vegetable, “I'd rather be dead”. Moreover, the vegetable status is perceived as symptomatic of death, “I am dead”. The separation of the body from the mind or self sets up a dilemma regarding the meaning of identity and the definition of life itself. In the following section, the problematic nature of distinguishing between life and death is considered.

Alive but not living

The struggle that participants had in making sense of what constituted a living, human person was very evident in a number of the discussions. In many instances, the talk closely mirrored the concept of a ‘non-person’ (Haddow, 2005) where although alive the terminally ill patient was perceived by those around them as having no meaningful existence or identity.

Kaitlin: He was just, he was just a vegetable... Mm and um years, he just lay there, years and years and he never ever woke up, never ever woke up.

Julie: No, cause he's, cause there was nothing to wake him up, it's only a heart beating, it's a, it's a muscle, listen to me, it's a muscle, I mean it's a heart and a muscle is a heart though when you've got emotions and you've got memories and you've got everything but when there's nothing there, it's just a muscle that's just pumping. (JI)

The idea of a ‘social death’ is quite apparent in this extract as the reference to the heart as “just a muscle” seems to evacuate the social from the body. The heart that is often closely

associated with emotions such as love is down-graded in this instance to nothing more than a collection of contracting fibres, “it’s just a muscle that’s just pumping”. This is equated to nothingness while in stark contrast if you retain your emotions and memories, “you’ve got everything”. This construction of personhood is very much based on the notion of a rational, feeling, social being. Therefore, the loss of the capacity for awareness and some form of interpersonal relationship brings about a separation of the material body from that of a recognisable, rational, social unity of a ‘full person’.

The complexity involved in the continued existence of the perceived ‘non-person’ is compounded by an ambiguity regarding the cessation of life. This is hardly surprising given that the medical definition of death has also changed significantly in the last 60 years. The traditional notion of an absence of a heart-beat as an indication of death has been superseded by the medical criteria of brain stem death. However, the uncertainty surrounding the continued existence of the person who is kept alive by machines is apparent:

Joy: Well I suppose it’s the same as the ones in the hospitals on those, the life support machines and there comes a time when the switch has got to be turned off. It must, I would hate to have to make that decision. I don’t know how that would sit with me. Even knowing that there was nothing, that that person wasn’t really there, but are they not there? I don’t know... (JI)

The demarcation line between the person being still present or having already ‘gone’, leaving nothing more than a vacant body, is a source of some anxiety for Joy. The enormity of having to make a decision regarding this status reflects a concern with what it means to be alive. This predicament has come about partly as a consequence of the more recent categorisation of death. As Haddow (2005) comments it has resulted in an “ambiguous entity” (p.94) that still breathes, has a heart that beats, and feels warm to the touch. In other words, it somehow fails to meet a ‘common sense’ view of a dead person.

However, a marked difference is seen in the following extract where there is a very definite sense of what constitutes life:

*Marian: My Uncle Martin lived like that for **ten** years, **ten** years... he'd had no life for ten years... And his children got very upset and when my Dad died, they came to his funeral and my cousin Joan she said to me "Well at least Marian, you've got a funeral, you can say goodbye to your Dad. Our Dad's been dead for so long but we, we haven't been able to say goodbye to him yet". (JI)*

In this instance, although Uncle Martin fails to meet the medical criteria of death to all intents and purposes, his family is adamant in his positioning; he has "had no life for **ten** years" and "has been dead" for this time. The loss of both bodily autonomy and the ability for rational thought due to the effects of Alzheimer's in this case is seen as unequivocal evidence of the loss of the person. Lawton (2000) suggests that in a similar way to the dying person, such an entity can be viewed as the ultimate "body-object" (p.113). Her research also supports the notion seen here that the dying person is frequently viewed as having already 'gone' before the point of biological death is reached. There is some resentment then that others can properly mark the departure of their loved one, "Well at least Marian, you've got a funeral, you can say goodbye to your Dad" while they are left in an on-going state of limbo, "Our Dad's been dead for so long but we, we haven't been able to say goodbye to him yet".

One of the effects of the prolonged existence of this unrecognisable entity is that family and friends often have mixed reactions to visiting:

Marian: But I think it's very hard like Auntie Nell she went religiously, visited Martin 2 or 3 times a week... And um I think it slowly killed something in her too, but she's quite a, you know positive lady. But it was just you know Martin didn't know, he didn't know her. And I think the kids stopped going cause they just couldn't accept that their Dad was, didn't know them. I think they crumble...Their little hearts crumble...It's no longer their Dad. (JI)

Although Martin's wife visited him frequently "2 or 3 times a week", there are definite under tones of an obligatory religious pilgrimage rather than an eagerly awaited, enjoyable reunion with her husband. This text has many parallels with an earlier extract where the physical appearance of a loved mother was viewed as so horrendous that a real hatred was expressed at having to expose her children to such an experience. In a similar fashion, the suggestion here is that this long-term fruitless visiting of someone who "didn't know her" has had a devastating and permanent effect on Auntie Nell, "it slowly killed something in her too". The consequences for Martin's children continuing to visit are also seen as clearly detrimental to their wellbeing. The metaphor of the heart is utilised in this instance to portray something both fragile and laden with feeling. Therefore, the impossible, emotionally fraught situation they find themselves in is perceived as the catalyst for it to disintegrate into fragments, "Their little hearts crumble". However, in an act of self-preservation the children have been able to sidestep their filial obligation to visit on the grounds that "It's no longer their Dad".

The many identities that are part of the social life of a person e.g. father, husband, friend are seemingly collapsed into one that is the identity constituted through the process of dying. However, in cases where this identity is both unknowing and unrecognisable the interlude between social death and the subsequent biological demise is perceived as very troubling for many participants:

Mia: Then I think about Jan who, who hung on and on. It was awful. It was three weeks, you know that she was in that limbo of, of almost...Oh it was terrible for the kids, they'd, they'd said goodbye, they knew she was going, they'd you know, and they kept going up to the hospital everyday//

Rebecca: //And she was still there...

*Mia: And everyday. Oh, it was awful. It was awful. But that wasn't that wasn't nice, she should have died ...The kids were ready for her to go, it was just prolonging **that***

agony for the kids as well, you know. They, it was, it was over and yet it went on for at least another fortnight. (JI)

There is an unspoken expectation that this dying entity should not have been able to linger especially when it is evident that others are “ready for her to go”. In other words, there is a responsibility attached to the role of a terminally ill subject to physically die in a timely fashion rather than to “hang on and on”. There is also a clear recognition in this extract of a sequential two-part nature to death, “it was, it was over and yet it went on for at least another fortnight”. The desire expressed here to close this temporal gap between social and biological death is very strong.

Yet for some, although recognising that there has already been a loss of personhood, the conclusiveness of physical death represents an irrevocable severing of a bond:

Jill: And I remember my Mum saying when her mother died she'd had a bit of dementia but you know she'd held it together pretty well and she was in an old folk's home and Mum said, “she was”, she'd been in a coma for a few days, and she said, “we wanted her to die but when she died there's this finite line”. And I didn't understand what she meant till she died, that while they're breathing, they're still there, they're still warm, they're still living, they're still, you know they're still a part of you. When they die that's it. They're still part of you but it's, there's a finality there.

The wish to bring physical death forward to more closely match the timing of the demise of the social self, “we wanted her to die”, is tempered by the knowledge that this loss of the material self represents a point of no return, “When they die that's it”. This view of the finality of death for human existence can be attributed to a modern, secular Western discourse of death that is characterised by the extinction of the individual.

Dead yet still living

However, it was evident from the transcripts that drawing on this discourse of the finality of death was not universal and a number of participants held the belief that they would continue to “live on” after death in a variety of ways:

Joy: Whereas John doesn't believe in anything I'm quite happy to believe that I'm, my soul or whatever is going to go on or I will live on in the kids anyway, so um, I don't have a fear of it (death). (JI)

Joy's concept of the essence of the person is not dependent on the presence of a living body or a functioning mind, but rather reflects a more dualistic view that the self or soul as a separate entity can ensure a continuation of existence in some form or other. Nevertheless, it can be seen that Joy is ‘hedging her bets’ somewhat with the suggestion that if her “soul or whatever” doesn't go on there will at least be a genetic continuation through her children. There is clearly a commitment to achieving some form of immortality in order to avert any notion of fear that may be associated with death, “I don't have a fear of it”.

Interestingly, some participants drew a comparison between cultural discourses of death for Māori and Pākehā that reflected a difference in understandings of end of life. As Seale (1998) points out, in societies that have a tradition of respecting and worshiping ancestors a social identity will often remain long after the body has gone. Therefore, in marked difference to the previous section, there was seen to be a responsibility by Māori to maintain the social relationship with the spirit (wairua) despite the fact that the body had ceased to function:

Mikare: See without being thing in anyway, you look at the way that Māori deal with death, it says everything... my English part of me it says “oh, here you are, put them in the ground, you know, leave them alone.” But we don't do that with a tupapaku, we're with it the entire time.

Ani:...we would never...

Mikare: We don't leave.

Ani: ...Leave our loved ones. So that's a, yeah, a different experience again. (FG)

Mikare prefaces his explanation of this difference with both an acknowledgment of his own joint English and Māori heritage and a vague attempt at defending himself against any possible claims of cultural insensitivity, “without being thing in any way”. Then, he goes on to give an account that clearly positions the “way that Māori deal with death” as the ideal model to emulate. The practice of keeping the body (tupapaku) company in order to keep it warm and comfortable is in recognition of the continued presence of the wairua and the need to assist it lovingly on its journey to the ‘afterlife’. As discussed earlier the importance of the requirement for both an intact body and the need to “never...leave our loved ones” can be attributed to the way in which the deceased represents a link between the living and the dead, “Although it is the end of a physical link with a genealogical defined tribal member, the spiritual link goes on forever” (Ngata, 2005, p.33).

It is unsurprising then that during the funeral (tangihanga) the coffin is left open to allow mourners to look upon the face of the deceased and perhaps kiss (hongī) or caress the body. Greetings and speeches are frequently addressed to the deceased person as if they can hear and are aware, with the expectation that these will be communicated to others who have already passed on to the spirit world. Even after burial, concerns remain that the wairua may still be present inhabiting its normal abode. Thus, the practice of ‘tramping the house’ (takahi whare) is carried out by a tohunga, kaumātua or minister in order to remove the tapu and release the spirit to continue its journey. This Māori world-view of the continuing presence of the wairua long after biological death has taken place is further exemplified in the custom of kawē mate which takes place often many months after a death. The wairua of the deceased is taken on a physical journey around the country to many marae where there may be a genealogical connection. The deceased is viewed as continuing to fulfill an essential role on the marae and the on-going influence of their wairua, even after death, is acknowledged by the living (Olivieri, n.d.).

In contrast, Mikare portrays a Pākehā approach as being devoid of any bond with the physical presence of the tupapaku, “put them in the ground, you know, leave them alone”. There is a strong implication and assumption that Pākehā have no recognition of any entity remaining with the body beyond death. This cross-cultural perception could be seen to be supported by earlier extracts that indicated that in some cases, even though biological death had not yet occurred, participants had already mourned the loss of the person they once knew.

However, despite this, there was still a desire on the part of many participants for some sort of positive presence to continue long after the demise of the physical body. Alongside this aspiration was the need for this presence to be a true reflection of the ‘real’ self rather than that of a dying, dysfunctional remnant:

Jimmy: I just sort of think if they can see all what's happening around them and they see people you know cancer, or whatever else you know arthritis, they can't walk, they've gotta get mobility chairs, the next stage from that is they've gotta get taken everywhere, their own self-respect I guess is what they are looking at. Maybe they want their family to see them as they are now, you know how when people die, you remember them as you last saw them. Someone whose fully functional maybe they're thinking of their family, they're gonna remember me as someone who was fully functional rather than someone who was bedridden and had to put up with that for weeks, months, years. I don't know, hard one. (FG)

Jimmy is responding here to a question regarding why some people may advocate for the right to choose to die. He is approaching this dilemma from a point of view that focuses on how the family may perceive and ultimately remember the dying person. Therefore, the loss of autonomy and agency as a consequence of requiring “mobility chairs” and having to “get taken everywhere” or being “bedridden” is equated with a loss of your “own self-respect”. If, as suggested by Foucault, we are continually engaged throughout life in a project of reflexive self-formation then the prospect of having it undermined and debased at this very end point of our life is surely something to avoid at all costs. The possibility then

of being able to circumvent these unwanted, lasting memories and die “fully functional” is seen as having some merit.

The need to be remembered not as a singular dying identity but rather in terms of the multiple achievements and identities that have previously characterised your life is very strong. In the following extract, Jill talks about her experience with her mother-in-law in commenting on reasons why people may want to hasten death:

*Jill: No, I, well, I just think that's one reason that the quality of their life that they remember what their life is like. Well she's in the middle stages of dementia and she understands what she's done and who she's **been** and the kind of person she **was**.*

Marian: Who she's turning in to. (JI)

There is a strong focus here on the past tense with a three-part list, “what she’s done and who she’s **been** and the kind of person she **was**” that highlights the stark difference between what has gone before and this present quality of life. The social death of Jill’s mother-in-law is a *fait accompli* that even “she understands”. However, pending biological death she has apparently morphed into a new identity, “Who she’s turning into”. It is this identity at the end-of-life that has seemingly become so problematic to the task of creating a version of the ideal self that will live on beyond our corporeal existence. The decisions that the subject makes at this critical time, in regard to which technologies of the self to embrace as part of this project of building a lasting monument, will have far reaching consequences.

What to do?

A new problematic identity has been forged by practices that have focused on the body as an object. These discourses constructing identity have classified and isolated the dying person in much the same way as Foucault has described the dividing practices in his first mode of objectification of the subject. It has led to the creation of a distinct group characterised by a shocking, unidentifiable entity. However, the very ‘essence’ of this

categorisation i.e. 'terminally ill' also implies the impossibility of being able to rectify their aberrant identity:

Kaitlin: ...and of course you'd go to her and you used to say "oh, you're looking so much better" you know it's like she was never going to get better and um you're just fooling yourself if you, and, and I mean she knew that she wasn't um going to get better. (JI)

Kaitlin is clear that despite engaging in the social niceties required when visiting the sick, "oh, you're looking so much better", it is a farce that the visitor and the dying person both recognize, "you're just fooling yourself" as there is no way back to full health. No hope of a return to 'normal' human life remains because "she was never going to get better". There is a real dilemma then as although the terminal identity has moved so very far from the established 'norm', the implementation of any corrective procedures in order to facilitate normalisation is doomed to fail.

Participants frequently linked the question of 'what to do?' about this anomalous identity to our responsibility for the humane treatment of animals:

Jill: And it's like they wheel them in, these old darlings on stretchers, you know, and they've pushed food in one end and clean up the mess at the other and they have, Larry would say they're past their use by date, you know, it's so sad.

Marian: We don't treat our animals like that, we // do not treat our animals like that.

Jill:// We would get rid of our animals.

Marian: We do not treat my cows like that.

Jill: Yeah, I don't think, I think a majority of people if they saw a picture of themselves like that and that was to be the way that they ended their life they wouldn't want that.

Marian: Oh, put a bullet in them. No, put a bullet in them thank-you, that's what I do to my cows. (JI)

Jill's description of "them" reinforces the undifferentiated grouping and objectification of the subject inherent in the formation of anomalous end-of-life identity, but she is able to moderate the harshness of this collective terminology by the tender use of the phrase "these old darlings". However, she continues to emphasise their lack of worthwhile functioning with the view that sustenance is somehow wasted in a one-way journey of no purpose. This is further supported by her reference to Larry's consumer claim that "they're past their use by date". The risk posed by retaining these 'out of date consumables' is implicit within the metaphor – they present a danger to the health and well-being of society. Furthermore, Jill expresses a concern that was highlighted in the previous section, regarding the final image that this identity portrays of our life's project. The potential for this "picture of themselves" to be the defining memory of their existence is perceived as something that "the majority of people...wouldn't want". The problem then of what to do about this category of deviation from the norm of productive human life is readily characterised as analogous to our humane approach to animals: "We don't treat our animals like that"; "We would get rid of our animals"; "Put a bullet in them".

Despite, or perhaps because of, our "deep seated need to distinguish humans from the 'lower animals'" (Martin, 1998, p.267) it is this appeal to our humanity that is particularly poignant:

*Mia: But I think you reach a point where you know. It's like with the dog, we just, you know had Chris's dog put down and it was **time**. You knew, it was time that he went, his quality of life was compromised, hers was too, having to deal with him, all those*

little things. And you went in and you gave him a big cuddle and a pat and he was fine, well he wasn't, but he was fine.

Rebecca: Just went to sleep.

*Mia: And you pushed this button, you know push the plunger and the lights just went out. That's all it was, you know. That's the way it should be and that's what I thought at the time. I was just watching thinking "this should be available to people". You know the quality was there, the respect was there, um you know the love was there.
(JI)*

The reference to a temporal dimension in the creation of this dying identity, "you reach a point" closely matches the earlier concern with a "use by date". There is a sense that an intangible yet culturally shared understanding of a line has been crossed whereby "you knew that it was time that he went". The kindness of this approach is highlighted by the description of the procedure that emphasises its quiet simplicity, "that's all it was you know". The consequences of pushing "the plunger" are also couched in terms of gentle metaphors of death, "just went to sleep", "the lights just went out". Having set the scene for an ideal departure from this life, there is a strong claim that this should also be the 'solution' for people who have been divided off into this problematic, terminally ill identity, "this should be available to people". This is further supported by reference to the attributes of "quality", "respect" and "love" that evoke such positive connotations that they function to preclude any possible argument. Thus, the terminally ill subject who has been assessed and classified as diverging too far from the 'norm' of human life needs to be managed in a way commensurate with our 'humanity' to animals.

Conclusion

The discourses identified in this chapter of physical appearance, bounded bodies, individual autonomy and a dichotomy of body and mind, were drawn on by participants in order to actively construct identity at the end-of-life. It is through these culturally available resources that they sought to make sense of the issues around dying and euthanasia.

However, the particular understandings of identity evident in this analysis present a number of interesting facets to the challenging question of what it means to be human and how this might impact on end-of-life decisions.

The centrality of physical appearance to identity seen in this analysis was perhaps a reflection of the relative simplicity of utilising such criteria to form judgments regarding the 'normality' of the individual. Assessment in this case is dependent on a quick and easy visual surveillance. In a similar way the unbounded body betrays itself with undeniable signs that affront the senses and provide irrevocable evidence of the person's fall from the category of a 'civilised' member of society. The debasement of identity that resulted from the inability to control bodily wastes or provide self-cares such as toileting and washing oneself or indeed being able to independently move and exercise agency was strongly associated with a societal expectation of individual responsibility and autonomy.

The accompanying dualistic focus on the mind led participants to view a loss of rationality as contributing to the disintegration of the last bastions of identity with the resulting onset of social death. However, the singular residue of identity that was left behind posed a real dilemma for life's enterprise of the self. The desire to be ultimately immortalised in a fashion that both reflected and respected all lost identities was threatened by the dying entity.

Burr's (2005) analogy of how identities are crafted by discourse to form a fabric perhaps best sums up the findings of this chapter. The many 'threads' that constitute identity seen in this analysis are intertwined in the production of the fabric of personal identity. Therefore, when these threads start to unravel at the end-of-life the fabric is pulled apart and begins to disintegrate, there is no longer any shape or form or recognisable features. Identity is reduced to some meaningless pieces of cotton on the cutting room floor. It is the intervening time before these threads, the last traces of the fabric, are swept away by biological death that poses the biggest threat to the Western conceptualisation of human life.

CHAPTER SIX

Reciprocation

This chapter examines how reciprocation is constructed through discourses realised in the data. In particular, it looks at a ‘life worth living’ in terms of both its past and present value to society and its future potential. This is weighed against a consideration of societal obligations to its members. The precise measurement of the intricate balance of reciprocal payments between the individual and society is seen to be somewhat problematic. However, the assessment of reciprocation arrived at, will undoubtedly have far reaching implications for the practice of euthanasia.

Introduction

The analysis of participants’ talk about euthanasia highlighted a concern with the idea of a mutual relationship between the individual and society. They saw this relationship as an interdependent association based on an interchange of resources that offered advantages to both parties. Therefore, discourses that constructed reciprocation were often drawn upon when trying to make sense of end-of-life decisions. It has been claimed that reciprocation is the foundation stone of human culture (Cialdini, 2009). The notion of ‘give and take’ is found in all societies and is often considered the cement that holds together our social structures. Indeed, an evolutionary approach goes so far as to attribute our evolution as humans to the system of reciprocity (Leaky & Lewin, 1978). This theory suggests that it was through learning the highly adaptive skill of sharing resources that our early ancestors were able to progress and advance their social evolution. From this came the growth of mechanisms for exchanging goods and services and the division of labour that allowed for the development of efficient societies based on the norm of reciprocation.

In the context of this knowledge production, we are therefore seen as being destined to forge a social contract with society as a consequence of our humanness. Humans are bound together through a system of inter-reliance such that there is a strong expectation that an individual will always contribute to the advantage of society as a cost for enjoying the benefits that ensue from societal membership. The concepts of indebtedness and obligation

characterise the norm of reciprocity and govern this social contract. Reciprocation can be viewed as representing a technology of social organisation and thus not only has it become an important feature of our socialisation, but it is a powerful force in the regulation of human behaviour in modern society. As the next sections of this chapter will illustrate, the construction of reciprocation was very evident as participants drew on the following discourses in making sense of euthanasia.

Potential and value to society

There is an assumption that Western societies face a unique situation in regard to euthanasia, simply because of the advancing medical technologies that can prolong the life of the elderly and terminally ill. However, according to Glascock (1990) this is a fallacy. Hardwig (1997) points out that in many so-called primitive societies it was accepted that when you reached the end of your usefulness and became a burden to society you had a duty to die. This was culturally supported and assistance to commit suicide was often provided. Humphry and Clement (1998) cite the historical example of Japanese and Inuit elders who were highly respected in their cultures while they continued to contribute. However, once they became a liability to the community they were abandoned or helped to die.

Similarly, in a study of nonindustrial societies where some forms of death hastening were occurring, analysis indicated that the decision to hasten death was usually made by adult children in consultation with the elderly person. It took place as the elderly moved from a distinct category of intact normal old age to become decrepit and thus unproductive and a burden to the community; “already dead” (Glascock, 1990, p.47). This reference echoes similar concerns with the social dimension of death discussed in the previous chapter. Although still alive, these individuals are distinguished as failing to achieve any sort of meaningful existence and consequently are considered as no longer living.

Participants drew comparisons between the similarities of present day concerns regarding euthanasia and the ways in which previous societies had approached this issue. In the

following extract Mia describes the ‘duty to die’ that she saw as characteristic of previous societies:

Mia: It used to be in the very, very old days, you know, like cave men days and that when the old lady, her teeth were gone and that was the worst thing wasn't it, your teeth? Cause you couldn't eat any more, so you became a burden, you weren't a functional member of society, weren't contributing. You actually became a burden like a child, but a child has potential to grow and contribute whereas an old person like that doesn't and won't. (JI)

The vivid description of the aged, toothless cave woman unable to eat highlights one of the fundamental biological necessities of life. It sets the scene for a shared understanding of the ramifications of this deficiency in terms of her unlikely survival in the natural world. As she will undoubtedly become weak and sick from lack of nourishment she represents a liability to other members of the group. She becomes a burden by virtue of being incapable of contributing or operating as a “functional member of society.” There is a corresponding assumption that her inability to fulfil the expectations of her contract with society also voids society’s contractual obligations for her care and support.

There is also a comparison with a young child in this extract that acknowledges the similar burden that both the very old and very young present to society. However, the defining difference lies in potential or lack of it. The untapped potential that resides in a child, “a child has the potential to grow and contribute” contrasts strongly with an “an old person like that” who is not only devoid of all potential but has no possibility of it ever being regained. Thus, the young and the elderly are cast to the extreme opposite ends on a continuum of prospective usefulness and value to society.

Analogous to the concerns with the possible benefits that an individual may or may not bring to society, participants viewed children who were born without the capacity for normal development as belonging to the same category as the very old through their inability to conform to the norm of reciprocity:

Kaitlin: I mean why do they keep, why do they keep (.) when children are born absolutely physically, mentally disabled why do they keep them alive? You know, I mean...

Julie: Why doesn't euthanasia happen then? When they are brain, they've been so damaged that their whole life they're gonna have to have medical, I mean millions of dollars spent on them for they can't do anything, they can't, yeah, they can't do anything, they're just satisfying (.) I mean even the parents must get exhausted because they can't do anything, they're just there. Why don't they euthanise? (JI)

It is clear that the child's absolute physical and mental disability precludes them from being bestowed with the status of having potential. Furthermore, their "damaged" state represents a huge economic cost to society, "millions of dollars spent on them". They have no hope of ever repaying this debt because "they can't do anything". Although there is a fleeting suggestion that the disabled child may possibly provide some 'satisfaction' to parents, even that proposition is quickly dispelled, "even the parents must get exhausted". The undoubted failure of this type of child to be able to realise their potential in terms of societal expectations negates the wisdom of investing time and effort in their upbringing. Therefore, the appropriate societal response is clearly illustrated with the use of rhetorical questions: "Why do they keep them alive?" "Why don't they euthanise?"

The importance of being able to play a useful role in society now or in the future is clearly recognised in these extracts. The ability to discharge this responsibility is then utilised as a criterion for establishing a distinction between suicide and euthanasia. The defining point again revolves around the issue of potential:

Mia: Euthanasia I see as being perfectly legitimate... but I think suicide I'm, I'm not happy with suicide, I, I can't see that as being right...That, that's a waste, that's a real waste because there's still potential there, you know there is potential even though, deep as the hole might be, or black as they might be feeling there is, there is a possibility of them coming out of it and living normal lives and being part of society

and stuff again. With euthanasia I feel that you, you've gone past all that, you're beyond that, there is no point of return. (JI)

Although, as discussed previously, suicide and euthanasia share an underlying conceptual basis there is often seen a need to separate out these two forms of death hastening. In this extract, suicide is perceived as robbing society of the individual's possible future contribution. While there is still the prospect of redeeming their life, of being able to extricate themselves from the 'deep, black hole' then there is hope that they can resume a "normal life" that by definition is seen as being "part of society and stuff". Although the "stuff" is a very general description it still manages to convey the concept of playing a useful role in the everyday concerns of society. It is also interesting to note that in line with the hegemonic medical discourse there is a preconceived notion that the suicide is attributable to depression. Therefore, it is assumed that it would not be a rational choice to take your own life and in doing so deprive society. Suicide is portrayed as a shameful waste of an important resource i.e. the individual's life that rightly belongs to society. As such it is not to be tolerated, "I can't see that as being right".

Euthanasia, on the other hand, is seen as "perfectly legitimate" because the life involved no longer has any value to society. It is clear that it has gone long past any hope of usefulness; it has reached a stage where there is "no point of return". Therefore, the removal of such a life does not represent any meaningful loss to society. On the contrary, it can be viewed as beneficial because it eliminates any societal obligation for the continued support of what has become a worthless asset. The suggestion aired earlier that euthanasia may indeed represent a form of altruistic suicide as defined by Durkheim (Evans & Farberow, 2003) certainly seems a reasonable proposition. A person whose integration into community life is no longer of any benefit could be seen as performing the ultimate altruistic act by requesting euthanasia.

The 'yardstick' used to determine a 'life worth living' centres upon the sense of potential imbued within that life in relation to its value to society. Therefore, it is seen as important to maintain a life while it can continue to contribute to society but once that 'tipping point'

has been reached it becomes expendable. This is made very clear in the following exchange between Mike and Jimmy:

Mike: If they can find a good quality of life they should keep going, absolutely.

Jimmy: Yeah why not? They're still a benefit to society overall...If you're not a benefit to society any more why have you round? (FG)

There is a link drawn here between the evaluation of “quality of life” and a person still being a “benefit to society overall.” A shared relationship exists whereby quality of life and benefit to society are mutually dependent. A good quality of life ensures that one can be of service to society, while continuing to perform a functional role in society also contributes to one’s sense of well-being. Therefore, the loss of these coupled attributes leads to a life that no longer serves any meaningful or useful purpose either to the individual or to society. Thus, it seems quite logical to pose the question, “Why have you round?” Indeed, the expendability of a life that has no possibility of meeting the requirements of a social contract based on the maxim of reciprocation ‘goes without saying’ in the following extract:

Jill: If that person is never going to be a fit normal human being, um yeah... (JI)

The characterisation of “a fit normal human being” is very much a reflection of the desired end product of the machinery of bio-power. Normalisation requires the identification and subsequent management of those not conforming to the ideal standard. This standard, as we have seen, is based on the criteria of potential and value to society. However, despite having established the parameters for a judgment of a ‘life worth living’, participants often grappled with actually assessing a life against these norms. In judging the standard that needed to be met there were references to the multiple difficulties involved in such a decision:

*Mia: It's very hard, cause again where is that line? I don't know where that line is.
(JI)*

The frustration at being unable to clearly identify the position of “the line” is evident. There seems to be no objective measures available to quantify when that marker has been reached. The ever-changing and highly contested nature of the norms associated with a ‘life worth living’ renders this goalpost as somewhat elusive. However, the ability to adequately measure a life in terms of meeting the criteria of potential and value to society is central to discussions about euthanasia.

A fair deal

In the previous section, the ability for an individual to contribute positively to society now or in the future was seen as a measure of their life’s worth. In the absence of being able to attain this perceived standard there was no apparent benefit in that life continuing. However, in the context of being asked, “could you ever envision a ‘duty to die?’” participants claimed a reprieve from forfeiting life by drawing upon a discourse reflecting the Kiwi ideology of ‘a fair deal’ that demands the just and even treatment of all parties. This cultural expectation is perhaps a reflection of New Zealand’s colonial past whereby early pioneers emigrated to escape perceived inequitable treatment in English society. Although the norm of reciprocity requires individuals to meet the obligations expected by society there is also a corresponding responsibility for society to repay this debt. Therefore, if old age or illness impinges on the value ascribed to that person’s societal contribution there is still a sense of entitlement to society’s care and protection:

Denis: Yeah, you know I think we've got a duty to look after them, I mean they've probably paid their taxes // all their lives.

Mike: //Paid their taxes all these years, yeah, absolutely.

Jimmy: They've paid their debt to society by living and doing that, their taxes and they've paid for other people now...

Mike: It's their turn. (FG)

It is very clear in this extract that having fulfilled the obligations expected of a full member of society, “they’ve paid their debt to society”, there is an expectation of ‘pay back’; for society to observe its “duty to look after them”. Although there seems to be an implicit assumption that such individuals are no longer ‘productive’ members of society, there is a rejection of the previous concept of ‘survival of the contributing’ in favour of the notion of enforcing the terms of our social contract. It is of particular interest that the description of societal indebtedness is focused on the individual’s previous financial contribution in the form of taxes. This is unsurprising given the importance of *homo economicus* in these neo-liberal times (Gordon, 1991). The recognition by participants of the essential part played by the taxation system in upholding the economic structures of society is evident. Therefore, the significance of having met not only their own fiscal responsibility but also having contributed to the support of others must be duly acknowledged by society and acted upon, “It’s their turn now”.

However, it was equally clear that this ‘stay of execution’ was not available to those who were seen as having never contributed to society through employment and therefore taxation. The social contract of reciprocation demands that individuals supply their labour to the society they are born into through economically productive work. Furthermore, they are required to forego a proportion of the fruits of that labour (tax) for the greater good of society. Cialdini (2009) points to the distaste and derision applied to those individuals who fail to comply with the obligations expected by society. This is graphically illustrated in the following extract:

*Jimmy: If we're gonna say they're no use to us and they're costing us too much then let's get these **bums** off their backside and working and actually committing, um contributing to society.*

Mike: Because that's what we did.

Jimmy: You've got your 15 to (.) what fifty year olds, you know some of them never working, they're just a drain on society. At least these other guys, most of them have contributed, a lot of them now have never contributed anything, they've just bludged the whole time, let's get rid of them first and then we'll worry about the others. (FG)

The contrast set up here between an older generation who have worked all their life and those individuals of working age who are unemployed effectively highlights the inequity of utilising the previous criteria regarding life's value. A judgment based solely on the debilitating effects of old age and infirmity on the ability to contribute to society now or in the future fails to take into account the measure of a lifetime's work. Instead, the perceptions of being "no use to us" and "costing us too much" are now applied to those "never working." The violation of the norm of reciprocity whereby these individuals take the benefits associated with societal membership without giving back to society by entering into the paid workforce leads to negative labelling and stereotyping: "**bums**", "never contributed anything", "just a drain on society", "just bludged the whole time". This is understandable as these individuals are identified as having defied a rule that is at the very core of human existence.

Therefore, if the necessity for removing individuals from society arises as characterised by the interviewer's question regarding a 'duty to die', it is suggested that there needs to be a more wide ranging assessment of life's value. This would appear from these extracts to involve a ledger or balance sheet whereby debits and credits could be weighed up in a more accurate accounting system. It would more clearly acknowledge the value added to society over a lifetime rather than just relying on the present or future value of an individual life. As Katarina succinctly puts it, a basic human right is earned by virtue of your contribution to society through work:

*Katarina: But I mean if you've worked, the thing is if you've worked your **whole entire** life you kind of have a right to live out your old age. (FG)*

Kaumātua reciprocity

The extracts in the previous section outline a rationale for not embracing euthanasia for the sick and elderly who despite their current lack of productivity have nevertheless worked throughout their lifetime. However, a very different perspective was gleaned from participants discussing these issues within Māori society. Rather than viewing Māori elderly as being ‘past their use by date’, kaumātua were instead seen as important assets to society. As Durie (1999) points out “A reciprocal relationship exists in Māori society between kaumātua and community. A positive, if demanding, role is complemented by an assurance of care and respect” (p.105). Kaumātua fulfil essential roles within their whānau, hapu and iwi by virtue of their age and cultural competency. The presence of this older generation ensures guidance and leadership that is imperative for upholding the mana of the people. Even the frail elderly who are perhaps unable to continue a more active kaumātua role are still considered as taonga or treasures that can add value to society (Durie, 1999).

Within Māoridom a loss of the elderly represents a major threat to the effective functioning of society. It is unsurprising then that there is a strong reciprocal obligation for their care and support and the concept of euthanasia for the sick and elderly is rarely discussed (G. Knowles, personal communication, June 24, 2011). However, unlike the previous section where the obligation to look after these vulnerable individuals was primarily based on an assessment of their prior contribution to society, this responsibility is very much focused on the current value of the kaumātua to the community. Furthermore, the family or whānau is considered to be at the very heart of Māori society with each member intrinsically linked in such a way that the sickness or dying of one individual will invariably affect the whānau group as a whole (Ngata 2005). This is particularly evident when the family member concerned is of kaumātua status. The traditional assumption of care within Māori families ensures both the availability of resources and commitment to meet these obligations of reciprocity:

Mikaere: See and I think even further back, pre-European, cause they were whānau orientated, so therefore they carried you, if you were māuiui they carried you, you were sick they looked after you cause it was a whānau unit //...

Ani: // It was whānau time.

*Mikaere: It wasn't just a **family** it was a **whānau** unit and so therefore the old people they weren't a burden, they were our old people [laugh]. And you looked after them **totally**. (FG)*

Mikaere is at pains here to explain the depth of these whānau ties and the interdependence of each family member. He struggles to find an equivalent English word to convey the true sense of whānau, “It wasn’t just a **family** it was a **whānau** unit”. The significance of the whānau to the survival of Māori society cannot be underestimated. The imperative to care for the sick and elderly was an essential element for the continued wellbeing of a societal structure based on whānau, hapu and iwi. Therefore, the suggestion that the elderly may represent a burden was considered laughable. There could be no other possibility of action other than, “you looked after them **totally**”.

Although in many cases Māori have continued to recognise what Durie (1999) terms “intergenerational reciprocity” (p.102) it needs to be acknowledged that there have been profound changes to family organisation over time:

Mikaere: And I think it comes down to the thing like without, to put a term on it is urbanisation. Because our whānau was spread far and wide. We used to be within throwing distance of each other, almost living on the back door step. Now...

As Mikaere rightly identifies, Māori have been dispersed from their traditional collective whānau base (Ngata, 2005; Olivieri, n.d.). Although he is somewhat reticent in naming the mechanism of this cultural dilution, it is clear that post-colonial economic development has been an important factor in bringing about these changes. The consequences of colonisation have undoubtedly impacted on the ability of Māori to observe these customary practices. However, there is yet another challenge on the horizon for this reciprocal arrangement between kaumātua and the next generation. Demographic changes indicate a rapidly expanding population of Māori elderly but as Durie (1999) argues it is questionable

whether a significant proportion of these individuals will have the appropriate cultural skills to undertake the role of kaumātua. Many will have had little contact with their marae, will not speak te reo nor have an understanding of tikanga. He warns that the inability to fulfil the kaumātua role in Māori society may lead to a further loss of the reciprocal support and care from whānau.

The associated devaluing of the current worth of these elderly to Māori society will result in the necessity to fall back on to a consideration of the individual's previous contribution to that society. However, as discussed, it is unlikely that they will have had a close relationship at all with their own culture and thus, would be perceived as not having participated in any meaningful way. A monetary assessment of lifetime worth as suggested in previous extracts is also unlikely to result in a positive judgment. Māori are consistently over represented in unemployment statistics, our prison system, as beneficiaries and in low-income jobs (Walker, 1989) so the ability to contribute to society through taxes will have been severely limited. According to these criteria Māori sick and elderly will be judged as having little value in the past, present or future to either Māori or Pākehā society. The implications of this assessment within this construction of reciprocation will have important consequences for Māori.

Religious reciprocity

A religious discourse was drawn upon in the construction of reciprocation by those not advocating euthanasia but rather insisting that individuals and society have a responsibility to maintain life until it reaches its natural conclusion. In much the same way as seen in the previous sections, there is recognition of the importance of a mutual relationship. However, there is a wider conceptualisation of the notion that incorporates and gives greater emphasis to a third party, God. Therefore the rationale for allowing a drawn out and sometimes painful death is related to the benefits that are perceived as being gained by the individual and the wider family. In the following extract the pain and suffering endured in the dying process is seen as a catalyst for bringing the family together:

Pania: That's true. In our, in our hahi (religion) the same. As long as um there's a breath of life in a person continue to help their sickness...

Carol: And it strengthens the family

Pania: Yes.

Carol: To go through the pain and suffering

Pania: Yes. (FG)

The strengthening of family ties is attributed to the shared experience of the “pain and suffering” by the dying person and their family. The role of religion is clear in ensuring that the sick are continually cared for until the very end. There is also no room left for doubt regarding the timing of this end as it is eloquently described using religious symbolism that is often connected to the Spirit of God – “as long as there is a breath of life”. The notion of *quid pro quo* is very evident in that not only will significant benefits ensue from the distress and anguish of a painful dying process in this life but as the following extract demonstrates, there is the expectation of payback in the next life also:

Rebecca: If God wants you to have pain and that well (.) you will. We've always sort of believed if you die in great pain like that you go straight to heaven anyway cause you have suffered on earth. (JI)

There is a sense here that the decision whether to experience pain or not is out of our hands. It is God who will decide for each individual the way of their death, “If God wants you to have pain and that well (.) you will”. However, the burden of dying “in great pain” will be rewarded by a direct and swift entry to heaven, “you go straight to heaven anyway”. The pain and torment that the faithful believe may be visited on a less than worthy soul in purgatory is counterbalanced by the suffering already endured on earth. Therefore, even though dying may be an agonising process for the mortal body, euthanasia is not an option

endorsed by this discourse of religious reciprocity. It is the immortal soul that will clearly reap the benefits of the individual dying a 'natural death' through preferential entry to the next world.

Within this discourse, reciprocation is constructed as extending into the question of ownership of one's life. If it is clear that God is the owner of that life as proposed by the great Christian theologians, Augustine and Aquinas (Evans & Farberow, 2003; Lieberman, 2003), then a generally accepted notion of morality would suggest that the timing and manner of its end should only be decided by him/her. However, if the life can be shown to belong to the individual, then any decision to hasten death could be construed as rightfully theirs based on that same ethical principal. There is a lot at stake within this argument as it has far-reaching implications for the rights and responsibilities of the sick and elderly. It is also at the very core of many belief systems. The following exchange between an elderly mother who is a committed Catholic and her now atheist daughter reflects the fundamental importance of how people are positioned within this discourse for decisions regarding euthanasia:

Mia: It's, it's you, it's your body, it's your decision, ok...

Rebecca: I don't think you're much of a Catholic are you?

Mia: No.

*Rebecca: Well you're **not** much of a Catholic.*

Mia: No.

Rebecca: But that, that's not, not the Catholic way of thinking at all.

Mia: No

Rebecca: It's wrong, because it's not your life, It's God's life isn't it?

Mia: Mm. Well, not to me, that's, that's what I think. That's your... (JI)

As evidenced in Mia's words, "it's your body, it's your decision", the assertion that the person has ownership of their own body is a strong and frequently cited discourse in moral debates around such bio-ethical issues (Lewis, 2005). This is because ownership provides an almost unassailable right to make decisions about our 'possessions'. However, Rebecca is quick to challenge this assessment of title to the body. It is clear that in her eyes it represents the very antithesis of a Catholic viewpoint, "that's not, not the Catholic way of thinking at all". In voicing her contrasting, heretic paradigm Mia's status as a Catholic is greatly undermined, "Well you're **not** much of a Catholic". She is therefore effectively side-lined in the subsequent religious appraisal of the morality of euthanasia, "It's wrong, because it's not your life. It's God's life isn't it?"

Rendering ownership of the body to God through virtue of the fact that he/she has gifted life to the individual opens up a multitude of future obligations. The rule of reciprocity demands that the person repays this ultimate gift by following the dictates of God's will as interpreted here by the Catholic Church. Therefore, not only is the individual required to live that life according to the edicts of the Church but also to die within this moral framework that specifically excludes recourse to euthanasia. According to religious theology, this faithfulness is in turn rewarded by God through guaranteed entry into 'heaven' once that life has ended.

Conclusion

The pervasiveness of discourses that constructed reciprocation in trying to make sense of euthanasia is testament to the enormous power wielded by this societal norm that is ingrained into us from birth as we are socialised into human society. The requirement for a perceived equal exchange of resources between the individual and society is of paramount importance. The obligation to contribute in a positive way to society, usually through paid employment or providing other valued services is repaid by a societal duty of care for its

members. Even our relationship with God is perceived as being based on a reciprocal contract or covenant. In return for being gifted a life, believers bow to the will of God and follow his laws in expectation of receiving support not only in this world but also eternal life in the next.

However, as in any social contract it is by its very nature open to a wide range of understandings and interpretations by the various parties concerned. As we have seen, the assessment of an individual's contribution to society is fraught with difficulties and ambiguities. In the same way the obligation of society to its most vulnerable members is contentious to say the least, based as it is on a measurement of 'life's worth'. It is unsurprising then that the terms of this reciprocal relationship are very much at stake in the euthanasia debate. Decisions of life and death are governed by the way in which people draw on these discourses that construct reciprocation as an object and the differing subject positions they offer.

CHAPTER SEVEN

Duty and Burden

This chapter explores the dual concepts of duty and burden and their relationship to constructions of euthanasia. The length of time involved in the dying process is a critical dimension that strongly influences our sense of responsibility, while simultaneously impacting on the conceptualisation of burden. The duty to care, support and protect the next generation was seen to be the over-riding concern of the elderly and/or dying. In contrast, their own needs were characterised as representing a burden that had the potential to subvert neo-liberal aspirations of autonomy and independence.

Introduction

Duty and responsibility interlinked with burden were important constructions in making sense of euthanasia. The discourses that formed these objects worked in close co-articulation with those that shaped reciprocity, discussed in the previous analytical chapter. As we have seen, the recognised need to contribute in a meaningful way and add value to society was an important factor in reciprocation. It was only in fulfilling these expectations that the individual's social contract with society could be validated and society's reciprocal obligation for the care and support of its members therefore be activated. However, the corresponding cultural and spiritual complexities that arose from endeavouring to navigate through the terms of this contract were extremely problematic in relation to determining a 'life's worth'.

In a similar way, participants attempting to make sense of euthanasia by drawing on the inter-woven discourses that constructed burden and duty were often challenged by the double-edged nature of these concepts. The sense of duty to care for one's family was part of, and yet simultaneously set against, the notion of refraining from being a burden. The uncertainty created by the resulting ambiguity was further compounded by neo-liberal desires for autonomy and independence. The multitude of competing responsibilities that

accompany these connected discourses can be seen to impact on participants' perceptions of end-of-life decisions.

Death's dilemma

During discussions about death and euthanasia, concerns about the timing and actual mode of death in terms of the perceived 'ideal death' were often aired. These revolved around a dichotomy of quick and painless versus a long drawn out suffering and the respective implications of these ways to die. In particular, participants were seen to assess the various merits and disadvantages of these 'options' by considering the effect the manner of passing would have not only on themselves but also on others:

Jill: I think my ideal death would be I'd get up one day, it's a great day and um I collapse during the day and that's it, have a massive heart attack or else I go to bed, go to sleep and never wake up.

Marian: Interesting because my Dad did die like that and it was a huge shock for everybody but it was so amazing for him because he got up in the morning, he'd watched his favourite rugby game the night before, he'd had his Bluff oysters, got up to the loo, said "oh, I'll think I'll get dressed" and sat on the bed and died. That was it, no warning, and um, but brilliant way to die.

Jill: I think, I think the kind of the way of dying that you and I would choose for ourselves it would be good for the person dying but // it wouldn't be, not for the family. (JI)

The picture portrayed here of the quintessential 'kiwi bloke's' death is indeed nothing short of "amazing" and "brilliant". We are left in no doubt that to die suddenly and without warning at home after viewing "his favourite rugby game" and consuming the much sought after delicacy of "Bluff oysters" is certainly the best way to go from the perspective of such an individual. Jill also reinforces the notion that to die during "a great day" or in your sleep is the preferred alternative for the person dying. However, there is an acknowledgement that it would present an unwelcome upset to others left behind, "it was a huge shock for

everybody”. A clear division is drawn between the benefits ensuing for the person dying and the detrimental effects of an unexpected death on those left behind.

In a similar way, not only the shock of a sudden death but also the lack of planning and the failure to organise one’s social responsibilities was seen as being somewhat problematic for remaining family members:

John: ...I'd rather just go, snuff it. I appreciate that probably then leaves a problem for the rest of the family because if I guess one thing if you did you know you were going to die then at least you would have a chance to prepare and maybe tidy up a few loose ends but whether you can ever tidy up everything I don't know, probably not, yeah. (JI)

While very clear in his preferred way to die, “I’d rather just go, snuff it”, it is also evident that John has a concern with ‘tidying up loose ends’ that is very much connected to a sense of duty to family. Although this is a rather oblique metaphorical reference to ensuring that both a life’s work and death are dutifully completed without any risk of unravelling, it is apparent that a failure to take care of these issues is perceived as presenting a possible burden to the living, “leaves a problem for the rest of the family”. Notwithstanding John’s reluctance to commit to ever being able to “tidy up everything” his personal preference for a certain style of death is weighed up against duty and responsibility to family.

The length of time involved in the dying process was also seen as an important consideration. Despite the apparent advantages for those left behind of a more extended terminal phase, the time spent waiting for death and subsequently grieving was cause for concern. Therefore, when prompted with a question regarding an ideal, good death, Pania and Katarina were very clear about the importance of ensuring a rapid process:

Pania: Quick.

Katarina: Yeah, quick.... Definitely not drawn out, yeah it would definitely have to be quick... if you do feel like you're going to be a burden and there is no way out ,...you want a quick death, your family to get over it. (FG)

Although time can allow the space to prepare for the coming loss and also to put life's affairs in order, it also represents an essential commodity in today's society, therefore, any perceived waste of this resource needs to be minimised. The capitalist conception of time efficiency is very much related to its monetary value and has led to the growth of whole industries focused on time saving, for example fast-food, fast-cars, fast-cash. It is understandable then that death should also be viewed through this lens, "definitely not drawn out, yeah it would definitely have to be quick". There is also the implication that time itself would pose an added burden on those involved with the dying, "if you do feel like you're going to be a burden and there is no way out...you want a quick death." Indeed, the inability to be able to influence the temporal nature of the dying process can lead to a number of financial ramifications.

The realities of taking responsibility for the care of a sick or dying family member requires a number of practical adjustments that certainly will impact on the economic situation of the caregivers:

Tia: I guess it could be a financial thing if like the family has to stop work to look after someone or like has to, they have to move in with them or...

Katarina: I mean that's part of that, that being a burden isn't it?

Tia: Yeah.

Katarina: You know, you feel like you're stopping other people from living their lives so they can watch you die. (FG)

The need to give up paid employment to provide the required care is an important consideration. This is particularly significant if the time factor involved is prolonged, as the on-going effects on the family of a lost wage are likely to be substantial. As a consequence this may also result in the need to relinquish the family home and “move in with them”. There is a definite perception that all aspects of the caregivers’ lives, including their financial aspirations, are being put on hold during this ‘death watch’, “you feel like you’re stopping other people from living their lives”. Therefore, although a lengthened period of terminal illness or old age that often includes sickness and frailty have come to be the expected norm in the modern world, the economic implications associated with this extended life span are of considerable concern.

The elderly in particular are acutely aware of their potentially dwindling resources:

Jill: And older people // worry about using up all their money...

Marian: // They do worry about money.

Jill: ...and thinking there will be none left for the family. (JI)

The associated monetary cost of chronic health conditions and long-term care needs results in a high level of anxiety for “older people”. This worry is induced not only by fears of being unable to meet the financial responsibility of their own needs but also a feeling of apprehension at the thought of dying without being able to provide posthumous financial support for their family. A long old age and/or a protracted dying process pose a credible risk to the economic sustainability of all involved. It is a situation that is best characterised by the adage ‘time is money’.

In the same way, having a period to grieve also poses a threat to the productive use of time; therefore as Katrina says the ideal is for, “your family to get over it”. This is in stark contrast to previous historical periods where for example among the English upper class at least 12 months was allowed for the mourning process, accompanied by strict statutes and etiquette that governed individuals’ behaviour and even the clothing that could be worn by the grieving family (Bradbury, 1999). Cultural practices regarding death and grieving

amongst Māori also differ vastly from the contemporary Western perspective of an appropriate time dimension. The mourning processes associated with tangihanga for example have been poorly understood and catered for when drawing up workplace bereavement laws in terms of time allocation and the constitution of ‘legitimate’ whānau members. As a result, Māori are too often placed in an unenviable position of having to juggle employment and fiscal responsibilities with whānau and iwi expectations of appropriate death and mourning rituals (Ngata, 2005). Modern Western society decrees that grief and mourning should be set aside as quickly as possible to enable the timely resumption of essential societal duties.

Time is also a key factor in the measurement of the “death journey”. As the following extract indicates, such travel may involve more than the dying person and therefore its length is of crucial importance:

*Awhinia: I watched one of my sisters go, and that was the **hardest** thing for me to do was to watch her, see her go through this journey of death ... I watched her and I went through this journey with her. (FG)*

The metaphor of a journey is commonly used to portray a long and tedious process often inter-spaced with difficult terrain requiring careful and sometimes painful negotiation. Awhina initially describes herself as a bystander watching her sister take this final journey and is clearly deeply affected by this experience, “that was the **hardest** thing for me to do”. However, she then goes on to explain that, “I went through this journey with her”. Having to accompany family members on this “death journey” undoubtedly presents a huge burden both in time and emotions spent. There is a definite sense that this tortuous travel is as unwelcome as it is unavoidable. Therefore, the ability to be able to mitigate the length and time taken for this ultimate trip can only be viewed as beneficial for all concerned.

There is a real struggle to come to terms with a version of death that can be considered ideal to all parties involved; the dying individual, family and society. Although a quick passing may be seen on the one hand as an appealing option, there are a sufficient number

of caveats to ensure a lack of consensus on the matter. The complicated nexus of duty and burden creates a dilemma for participants in choosing the best ‘way to go’. However, in the following sections of this chapter the analysis will attempt to unravel the connections between these discourses that can appear on the one hand complementary and yet at the same time contradictory.

Intergenerational responsibility

The sense of responsibility or duty to the next generation was a common theme in discourses drawn upon during participant interviews and focus groups. If, as we have seen, a social contract binds the individual and society together in an on-going relationship of reciprocity then the connection between family members can be perceived as an even stronger bond. In particular, the feeling of obligation to provide for children and grandchildren in the wake of your passing and into the future was a pressing need:

Awhina: If possible I'd actually like to know before time if I was, if it was possible that I was dying, that's me personally. That way yeah I could set my family up, my mokos, my kids (.) yeah... duty to me would be to make sure that when I go my family is set up, there's things in place, money's there to pay for my funeral and my burial, not depending on my kids to bury me, there's things in place. There's too many a times we've been caught, I've seen my, my aunties, uncles, nanny, Mum being caught, caught out and the processes that we have had to go through to try and get everything on track um, it's horrific.....That, that's what I see as our duty as the living now to make sure that our family ain't gonna suffer when we go. (FG)

As in the previous section the advantage of having prior knowledge and time available before death allows for important planning and organisation to take place. The focus of this preparatory activity is very much the next generations, “I could set my family up, my mokos, my kids”. Although the children are adults with their own families, there is still a sense of responsibility to safeguard them, particularly from financial burdens. This is especially significant as the costs are associated with the death of the parent/grandparent, “money’s there to pay for my funeral and my burial, not depending on my kids to bury me,

there's things in place". Therefore, the ability to retain not only economic independence but also the role of provider to the next generations, even after death, is perceived as a duty.

In this above extract, Awhina makes it clear that she has had a wide range of experience of situations where no provision had been made for those left behind, "I've seen my, my aunties, uncles, nanny, Mum being caught". While describing the consequences of this lack of planning as "horrific" she also emphasises the unexpected nature of this predicament, "There's too many times we've been caught...caught out". Indeed, there is very much a sense of failure or even wrongdoing in being financially unprepared in this way and thus, "caught out". It is unsurprising then that this duty to anticipate the costs of dying that may fall on the shoulders of the next generations has been exploited by the insurance industry. The multitude of funeral and burial plans now available that are specifically targeted at the older generation are testimony to the hegemony of this discourse. It is also a reflection, as discussed in an earlier chapter, of the risk prevention ideology of our post-modern society.

The responsibility felt by parents to continue to plan for the future of their adult children and grandchildren after they have gone is duly acknowledged by the younger generation. However, in accepting the parental need to fulfil this duty the children also have to come to terms with the inevitability of their own parents' death:

*Mikaere: See I was really lucky because my Mum, I **hated** talking about it, bout various things, her dying and my Dad dying and stuff like this, is still alive touch wood or God willing, but they've done exactly that, they've done exactly that. They've bought their plot, she knows what prayers she's having [laugh] she's set it all up, she's set it all up you know and, and it's all done.... The wills are all sorted, everything's all done ...So we've been really lucky in that fact. When she was talking about it, **it hurt like hell.** (FG)*

Mikaere emphasises how "really lucky" he and his siblings have been at the forethought and planning that has gone into all aspects of his parents' passing. The funeral service, the burial, and the inheritance have all been taken care of and therefore both the emotional and

financial burden have been removed from his generation. He is equally clear though, that having to discuss these organisational details with his mother has been very difficult, “I **hated** talking about it...**it hurt like hell**”. The prospect of the close bond between himself and his parents being severed by their demise is understandably exceedingly hard for Mikaere to accept. Even talking about the eventuality engenders a feeling of superstition or of ‘tempting fate’, “is still alive touch wood, or God willing”. However, it is this very bond that places on the parents a sense of obligation to maintain their responsibility to the next generation even in death.

This duty of care also extends to attempting to protect the younger generation from full awareness of the extent of the suffering of the older generation:

Pari : I know with my Mum who has emphysema um and you know there's lots, there's asthma on top of that and you know there's just a whole contributing 75 years of, of, lots of things, alcohol included, that have led up to this tiny woman who I know is suffering within herself but because she doesn't want that burden to go on to us she pretends lots you know. (FG)

Although it is apparent that Pari has a clear understanding of the health issues that are besieging her elderly mother, “emphysema...asthma...alcohol” there is still the perceived need for her mother to “pretend lots”. The failure of this pretence however, is all too obvious as there is no doubt that Pari is fully aware not only of the cumulative causation of the current situation but also its devastating effects, “this tiny woman who I know is suffering within herself”. Even though there is an implication that the suffering is internal and not easily visible to the surveillance of those around her, Pari’s close filial bond gives warrant to her perspicacity. Furthermore, she acknowledges the logic and reasoning behind her mother’s charade as representing a desire to protect her children from also being burdened with this suffering, “doesn’t want that burden to go on us”. There is an acceptance of the common sense nature of this attempt to take responsibility for the emotional wellbeing of the next generation.

In a similar way, the older generation is seen as continuing in the role of protector even at a time when they are most in need of support themselves. The imperative not to communicate pain in any way or indeed to go to great lengths to conceal it is very strong:

Tia: Yeah, yeah well like my Koro's cancer, it wasn't really until the last few days we really saw how bad it must have been for him. But up until then he could have been in pain everyday but // he's just not telling us, yeah.

Pania: // He would have hid it too. Especially our old, old grandmas and grandparents they kind of //tend to try and hide it

Tia:// Just hard it up.

Pania: Yeah, they, they'll you know just like, I guess like boys, they'll go cry in their room. They might not cry in front of you but they'll go away and cry and it's the same with our, our parents or the older people.

Tia: Mm.

*Pania: They try and put a brave face on when you're there but when you leave...
[laugh] (FG)*

There is a realisation only in “the last few days” that the cancer affecting Tia’s grandfather has likely been causing a great deal of pain over a protracted length of time. The considerable suffering that he has stoically endured finally becomes apparent, “we really saw how bad it must have been for him”. However, the reluctance to share this anguish with his family, “he’s just not telling us” comes as no surprise to Pania. She describes this unwillingness to talk about the pain as a consequence of the perceived need of the older generation to shield the young from the knowledge of these painful experiences. The methods employed to accomplish this ‘cover up’ are variously described as “just hard it up”; “just like, I guess like boys”; “put a brave face on”. Although the courageous quality

of these endeavours is clear, we are left in no doubt as to the extent of the unspoken vulnerability and despair of the dying elderly, “but when you leave...[laugh]”.

Despite the depth of the agony, the duty to protect younger family members from the harsh realities of dying is even stronger. Closely connected to this responsibility is the desire to manage the project of one’s self in the final phase of life. As discussed previously, Foucault made it clear that in technologies of the self the individual is always free to choose which disciplinary practices to subject themselves to and the role they wish to assume in such ‘truth games’. The desire to maintain the image of strength and protection for the next generation, particularly during the dying process, requires subjectification to prevailing discourses of heroic suffering. The family can be seen as colluding in the preservation of this version of the socially desirable dying self by also refusing to acknowledge the distress of a painful death:

Pania: People in pain you can’t do nothing much except to hide your real feelings to be strong for them and to let them go.

In a similar fashion, there is a complementary conspiracy to mask “real feelings” and to display a measure of strength to aid the dying process. The strong duty felt by the older generation to shelter their family from the burdens associated with their dying is shared by the next generation. They also seek to reassure their dying parents and grandparents that somehow ‘everything will be alright’ in the face of the inescapability of death. This intergenerational sense of responsibility is undoubtedly a strong discourse drawn upon by participants in their attempts to find an ‘acceptable’ pathway through the blurred boundaries between duty and burden.

Burden

Dying patients commonly employ the metaphor of burden to describe themselves as they become progressively weaker and more dependent on others. There is a loss of self in the shift from one’s perception of being a subject to that of an object – a burden. This can be further reinforced by the objectification of the terminally ill by those involved with their

care (Lawton, 2000). The trepidation that participants expressed regarding the possibility of becoming a burden to others in their old age or while dying was very clear:

Jill:// And so I think that that is a big thing. And, and people that get so ill that they don't, the big thing is they don't want to be a burden on their families, that comes through um people that I've had stuff to do with they say, "I don't want to be a burden, I'm a burden". (JI)

In many instances, these discourses constructing burden were at the very heart of discussions around euthanasia. In part, this was related to the responsibility felt towards the next generation as seen in the previous section. There was a real concern that any burden arising from the care needs of an elderly or dying parent should not become a liability for the children:

Carol: That's what you mean you don't want to be a burden//

Pania: //No.

Carol: To anybody else.

Pania: No...

Carol: You don't really want your kids to do it either.

Pania: Yeah, you've done it for them, now they want to do it for me but they, they have to sacrifice the care of their kids to deal with me and I don't like that... I don't want them to neglect their kids. (FG)

The prospect of being a burden to “anybody else” is seen as being quite intolerable. While this initially seems to refer to people outside the family circle, any suggestion that your children should take on this responsibility is also perceived as undesirable, “You don't

really want your kids to do it either”. However, there is an acknowledgement that children will invoke the rule of reciprocity in their desire to care for their parents, “you’ve done it for them, now they want to do it for me”. Although the feeling of obligation to return the loving care received as a child is understandable it is seen here as unacceptable on the grounds that it will subsequently seriously impair the care of grandchildren, “I don’t want them to neglect their kids”. Therefore, parental care is regarded as a special category of service that does not require reciprocation in the usual way. Instead, the responsibility is to pay this debt forward to the following generation.

In line with the correct order of care posited in the above extract, there is an exception made to the desire not to be a burden to anyone. In the following exchange although dependency and being “a burden” is seen as undesirable, it is at the same time somehow deemed suitable to be dependent on and accept care from a mother:

Nina: Well you don't want to be //dependent.

Pania: // to burden, to be a burden to anyone, except a mother. (FG)

As we have seen, the perceived natural order of intergenerational interaction is for the older generation to nurture their descendants. In addition, the role of mother particularly is strongly linked to expectations of selflessness. Indeed, children can be seen as an integral part of a mother’s life project:

Pania: My goal and my achievements was to do with my kids...I had something to work towards. (FG)

Therefore, it is unsurprising that there is an acceptance of the notion that mothers should take on the care of sick or dying offspring. It can be viewed as a ‘common sense’ solution to the management of a burden. Mothers not only have a duty to the next generation but by taking responsibility for the terminal care of a child, albeit an adult, it also provides a means of accomplishing their life’s work. Furthermore, prevailing discourses of

motherhood and women in general strongly suggest that they are particularly well suited to a caring role (Burr, 2005; Canetto & Hollenshead, 2000-2001).

The caring feminine gender stereotype has been seen as playing an important part in the original development of the hospice movement. According to Walter (1994), the hospice movement arose as a direct resistance to the growing implementation of 'male' technological solutions to the dying process. Therefore, the care received within a hospice setting was essentially feminine. However, Lawton (2000) points out that conflict is now arising as hospice services are progressively becoming more integrated into mainstream health institutions. The accompanying requirements for financial accountability and efficiency are seen as elements of the masculine structure that hospices originally rejected. Consequently, she argues that in the UK there is an uneasy relationship between the goals of hospice staff and the objectives of NHS (National Health Service) management due to this 'masculine/feminine' tension.

The sense that women by virtue of their intrinsic femininity are far better equipped to fulfil the role of caregiver as portrayed by this gender stereotype is clearly exemplified in the following two extracts that discuss the care of an elderly and dying mother and father-in-law respectively:

Kaitlin: And so she ended up coming down here to the beach to live with my older brother... and she became more of a, I think a burden to Graham.

*Julie: Well I don't think Graham could have coped anyhow, cause none of them do.
(JI)*

Marian: And I think having four boys in that family actually made his quality of care probably not as good as it could have been.

Jill: Mm, cause women tend to be the carers. (JI)

There is recognition in the first extract that the elderly mother living with her son represents a burden. However, the inability to cope with the demands of the care required is not restricted to Graham alone. Julie's assertion that "none of them do" marks out the entire male sex as being at fault. There is an acceptance that male helplessness in the face of such a heavy responsibility is in fact 'normal'. Marian reinforces this view in the next extract by attributing the substandard quality of care for her dying father-in-law to him only having sons. There is an obvious inference that if he had instead had daughters there could have been an expectation of a superiority of care. It is clearly right and appropriate then that "women tend to be the carers".

Brotchie and Hills (1991) also point out that the word 'carer' is not a neutral term; on the contrary, it implies an obligation to accept the responsibility of providing care. There is seen to be little choice in the matter as to refuse the role is tantamount to not caring. Families in particular can feel a great deal of moral pressure to take on this position. However, it is clear that caring for an elderly or dying relative presents a huge burden to the family:

Jimmy: Cause it's not just the person whose lying in the bed whose got a lack of quality of life, it's all the people caring for them. You're at home, and you're in a state where you can't look after yourself, someone's gonna commit to looking after you and it's usually family members.

Denis: Yeah, it puts a lot of stress on them ah?

Jimmy: Lot of stress. Not, not just that person who's looking after them but their family as well. You know it takes a lot of time out of your own family. (FG)

"A lack of quality of life" is used here as an indicator of the far-reaching consequences of dealing with such a burden. Not only is the quality of life of the bed-ridden patient compromised but the burden that their care places on others is also seen as impacting on their own quality of life. The "stress" involved with this burden sends out ripples that affect

even more family members, “not just that person who’s looking after them but their family as well”. However, as discussed, there are perceived as being very few alternatives for either the family or the patient regarding who takes responsibility for the care, “someone’s gonna commit to looking after you and its usually family members”. Therefore, it is understandable that one of the main reasons terminally ill patients give for wishing to be admitted to a hospice is to release their family from the burden of their care (Lawton, 2000). It allows for the only possibility, short of death itself, of circumventing the seemingly obligatory familial duty of care and thus can ease the burden on their ‘nearest and dearest’.

Autonomy and independence

Integral to the discourses constructing burden was the struggle to maintain independence and autonomy. As discussed previously, these concepts are fundamental to the Western notion of a ‘normal’ complete and intact individual. Therefore, participants strongly resisted the possibility of being positioned as a burden because it was associated with the loss of their rights as a fully independent and autonomous self. There was an acknowledgment of the real reluctance and difficulty of having to come to terms with such a newly fashioned identity:

Pania: Yeah, I mean it’s bad enough saying, “I’m getting hoha” [laugh] And the kids will say, “Oh no”. Because I think I, I’ll, I’ll be hard, I’ll be hard. I’ll be a hard person to, to...

Carol: To look after.

Awhina: Be maro

[Laughter]

Pania: Yeah, I feel, because I’ll make it difficult for them because I don’t want them to see me the way I am and not be able to do for myself. (FG)

Pania recognizes the unfairness of being difficult and unreasonable to those involved with her care, “I mean its bad enough saying, ‘I’m getting hoha’”. However, she fully admits that she expects to be extremely “hard” to deal with if placed in this untenable position. The group laughter endorses their understanding of this complex situation. The norm of reciprocity would indicate that the service of care should be repaid by gratitude at the very least. On the contrary, in these particular circumstances the dependent but unwilling recipient is more likely to demonstrate resentment at the care that is unable to be reciprocated. In addition, Pania explains the reasoning for such a belligerent response as being connected to her loss of independence, “I don’t want them to see me the way I am and not be able to do for myself”. The evident distaste at having her sense of autonomous-self violated is compounded by the new objectified identity being on open display to her children.

However, the understandably disagreeable reaction to the need to relinquish independence and autonomy can have unfortunate repercussions:

*Marian: Chris’s father ended up with dementia and they said his brain was slowly dying. He became **nasty**, really, really, really nasty, and got to the point where he wouldn’t **let** people help him or he would criticise the hell out of people helping him. So that people ended up not **wanting** to be around him because he was just becoming really horrible. ..but he wouldn’t, wasn’t capable of looking after himself. (JI)*

Although it is apparent to those around him that Chris’s father is not “capable of looking after himself”, he is angered by any attempts at intervention. The unwillingness to accept help ranges from abuse and criticism to an outright refusal to “**let** people help him”. The impasse that is created results in a strong antipathy by family members so that, “people ended up not **wanting** to be around him” and consequently a lack of suitable care for a dying individual. The inability to care for oneself with the corresponding need to have someone else “help” you represents a fatal blow to the most basic sense of autonomy. In doing so, it lays the foundations for one’s transformation into a burden, an identity that is closely linked to dependence. It is unsurprising then that individuals would seek to repel

help in order to maintain their independence; thereby deferring their positioning as a burden for as long as possible.

While the requirement to depend on others undoubtedly creates a burden, the contrasting position of independence is seen as something to aspire to and take pride in:

Tia: And everyone else around you has to (.) you know do everything for you. I'd find that probably the worst part.

Puti: Same.

Interviewer: Why do you find that so difficult?

Tia: I don't know, it's just, I think being a burden on other people is my main issue.

*Katarina: I think cause I mean especially now days people are more independent too. I mean I've always been relatively independent and don't **want** to be a burden on anyone else, don't **want** to rely on anyone else to, you know, expect them to take care of **me**. (FG)*

Again, the difficulty of giving over the care of oneself to others is categorised as “probably the worst part” of dying. There is an intrinsic suggestion that this act will constitute a burden, and as such represents the “main issue”. The significance and importance that is ascribed to the concept of independence can be seen as characteristic of 21st century neo-liberalism that values personal autonomy and responsibility or in terms of Foucault’s bio-power, the need for self-regulation and self-care. Katarina’s desire to care for herself, not to rely on anyone else and above all not to burden others is very much part of this paradigm. There is also a corresponding assumption that “now days people are more independent”. Therefore, the contrasting notion of dependency and burden is perceived to be of a far greater concern in the post-modern world.

This however, poses a particularly difficult dilemma for Māori participants as they are situated with one foot in Te Ao Māori and the other in Te Ao Hurihuri, the changing world of the Pākehā:

Pari: And I think the whānau was a lot tighter //as well...

Mikare: //Tighter yeah.

*Pari: ...back in the day where they, they had no problem with taking on someone's māuiuitanga, but these days you know because we're all sort of living our own lives we are sort of looking at our own individual families now and saying for **you** we don't want you to carry us anymore and you know that should be our choice, not the iwi choice, but our choice not to burden you even though that we know that the whānau whānui would take on the responsibility of us that's //not what we want anymore.*

Ani: //It's the burden. (FG)

As Pari indicates there is a fundamental shift of emphasis here from past times as discussed in the last chapter, where there was an all-encompassing duty of care by the whānau that was in no way considered a burden, to a new dawn of individual responsibility, “we’re all sort of living our own lives”; “We don’t want you to carry us anymore”. Although Pari acknowledges that the wider family would still provide the care required, “we know that the whānau whānui would take on the responsibility of us”, there is a very clear indication that this would be unwelcome in these neo-liberal times, “not what we want anymore”. There is also a desire to break away from traditional social structures that were based on collective decision making to a society characterised by individual responsibility and choice, “that should be our choice, not the iwi choice, but our choice”.

However, despite these claims that are very much indicative of our contemporary capitalist world, in many cases Māori have continued to identify with and respect the cultural norm

of whānau care of the sick and dying. The huge impact of this responsibility in the face of profound changes to family structure and economic imperatives precipitates their entanglement in a catch -22 situation. As Pari reiterates:

Pari: But the burden of responsibility is just too much these days, you know it's just, that's not, what for me personally what I wanted for my family, for my children, for their, for their children, for my brothers to take on, I just don't want it. I don't think it's fair on them. (FG)

The neo-liberal priorities of autonomy and self-care are pitted against cultural concepts of familial responsibility for the care of the sick and elderly. However, the burden of fulfilling these traditional obligations in a post-modern world is seen as “too much”. It is not only undesirable, “not...what I wanted” but also unjustified, “I don't think it's fair on them”. Furthermore, it is not only the consideration of the intolerable burden that the cultural responsibility places on the family that is at stake, but also the implications for the dying individual of accepting this care. As discussed, the desire for full autonomy is challenged by the very act of relinquishing one's own care to others. This is made very clear in the following extract:

Nina: I, I don't want to be dependent on anybody.

Pania: No, I don't either.

Nina: I value my independence, full independence. (FG)

The dichotomy created between ideas of dependence and independence is such that we are left in no doubt of the privileged standing accorded to the position of “full independence”. These changing notions of autonomy can be seen as vital to constructions of burden and duty. While a traditional Māori world-view suggests that the individual should be perceived as having limited autonomy (Smith, 1981), the modern Western concept of a self-caring,

independent entity is testing this belief. The problem that this conundrum poses for decisions regarding end-of-life care is particularly significant then for Māori.

Conclusion

Duty and burden can be seen as essential elements contributing to the complexity that surrounds the euthanasia debate. Participants struggled to come to terms with the varying paradigms and related expectations inherent within these constructions. The duty to care and support family members, particularly the younger generation, was paramount but was seen as being undermined by any reciprocal care obligations to the elderly or sick. Discourses constructing duty were very much portrayed as 'a one way street'. Any attempts to apply this sense of responsibility to the needs of the older generation in an extended old age that might include chronic illness and/or a long term terminal phase were constructed as a burden.

There was a corresponding strong sense of duty not to become a burden. The positioning as an object that would indisputably be the source of a heavy responsibility to family members was to be avoided at all costs. The necessity of this imperative was reinforced by its links to the demands of a post-modern world. The requirements for autonomy and independence have become the 'holy grail' of our neo-liberal society. However, in making sense of euthanasia, participants drew upon discourses of burden represented by notions of dependence and reliance on someone else. As such, they epitomised the very antithesis of the desired version of the modern self. It is this highly valued societal norm of self-determination that has undoubtedly impacted significantly on constructions of euthanasia.

CHAPTER EIGHT

Discussion

This chapter attempts to draw together the many threads of the research. It reflects again on the perceived inadequacies of previous mainstream research and reiterates the importance of the present study. Issues of methodology, strengths and limitations are discussed and suggestions for future research put forward. The contribution made by the genealogy and the discourse analysis of participants talk in making sense of euthanasia is then critically examined.

Introduction

This study has set out to address the issue of how people make sense of euthanasia. Although not seeking to engage with the value-laden debate surrounding the 'right-to-die', it is acknowledged that the researcher's own background and experiences will have undoubtedly impacted on the construction of 'answers' to the research question. Furthermore, the adoption of a critical psychological approach is never a neutral enterprise (Prilleltensky & Fox, 1997) as it attempts to step outside the status quo in order to take a stand against individualism, inequality and social injustice. As such, it encompasses its own set of values and ideology in the pursuit of political and social action.

The critical analysis of traditional, positivist research on euthanasia in this study has highlighted the limitations of a narrow quantitative research approach that has been besieged by multiple issues of methodology, severely undermining the utility of the data. In addition, the constraints placed on our understanding of euthanasia by failing to consider the social or discursive context of end-of-life decisions were all too apparent. Attempts to break down this complex phenomenon into simpler components in the mistaken belief that somehow the process will lead to a better understanding, results in explanations that are firmly focused on the individual. This 'social reductionism' (Hayes, 1995) leads to individualistic conceptualisations that not only fail to take into account aspects of power and control but function to divert attention away from other possible explanations and a consideration of wider social issues.

Furthermore, it is argued (Prilleltensky & Fox, 1997) that a traditional, mainstream research approach can act to support the dominant institutions, assumptions and values of a post-modern capitalist society and in doing so mask issues of disparity, discrimination and oppression. Therefore, a critically different approach to the present study was justified not only by the perceived failings of previous studies undertaken within a positivist paradigm to elucidate the phenomenon of euthanasia, but by the desire to identify social injustice and thus effect change. A study based on the foundations of social constructionism and framed by the theoretical insights of a Foucauldian approach was seen to offer the greatest potential for redressing injustice in our understanding of euthanasia and to challenge the power structures that reinforce the unacceptable status quo of Western society.

Reflections on methodological approach

The discourse analytical approach adopted in this study sought to identify how euthanasia was being discursively constructed and the possible opportunities and limitations posed by these shared ways of understanding the issue and the various subjectivities offered by them. The decision to adopt this pathway, as we have seen, was informed by both the perceived limitations of traditional, mainstream research and the potential to increase our understanding of the phenomenon by examining it from a different perspective. Although, according to Burr (2005), discourse analysis does not qualify technically as a methodology because it involves principles and guidelines rather than a prescription on how to proceed, there were still a number of procedural decisions and steps taken that, as alluded to in Chapter Four, need to be revisited and are now reflected on in this section.

For example, the relationship between the researcher and participants differed significantly from the expectations of an empirical study. There was no attempt to separate myself as researcher from the participants to fulfil some vain notion of achieving objectivity. Rather, the relationships I had previously forged within my community were critical to both the recruitment and interview phase. The informality of the 'snowball sampling' in the small community enhanced the uptake of the research while the establishment of a strong rapport based on previous associations and interactions enabled discourse to flow. It was this more personal perspective I would argue that elicited the in-depth conversations and discussions

about how people make sense of euthanasia seen in the analysis. Furthermore, the unstructured approach to the interviews allowed people to tell their own stories and voice their ideas and concerns without being limited or restricted thus allowing the participant voice to be heard in the research. This was particularly salient for Māori participants who provided a seldom-opened window into our understanding of euthanasia in Aotearoa/New Zealand.

Despite the advantages of a close relationship, it needs to be acknowledged that differences around discourses of expertise will position the researcher and participants differently regardless of how much a researcher aspires to an equal relationship. Although some researchers (O'Connor, 1997) have attempted to disrupt this imbalance through the use of reciprocity for example, returning interview transcripts and collaborating on data analysis, others (Marks, 1993; Parker & Burman, 1993) suggest that such attempts will still not achieve a real change in the power relationship and fail to undermine the 'warranting voice' of the researcher. Similarly, in contemplating the possible use of reflexive devices in the present study such as dialogue boxes, poems and artwork I was also mindful of Gill's (1995) criticism that such devices can be used to defend one's own argument against rebuttal. Therefore, I decided on an approach of reiterating wherever possible that my close involvement with the participants and the research discussions would inevitably impact on the data generated. Moreover, the interpretation and analysis of the data would be influenced by my own experiences and world-view.

Another aspect of the methodology that needs to be considered is how the composition of the interview, in terms of individual, pair or group, influenced the data (Taylor, 2001). As mentioned in Chapter Four, there was a variation in the talk elicited in these different contexts. The powerful societal discourses drawn on to discuss end-of-life issues seen in the analysis were more apparent in joint interviews and focus groups than individual interviews. It needs to be recognised that once these discourses are employed they become 'common sense' and are easy to go along with because not only do they seem sensible but they are also part of making smooth social discussion. Although it would seem easier to raise resistances to such discourses in an individual interview or even voice contradictory

or opposing discourses, this was not found to be the case. Participants in individual interviews drew on similar discourses but there was a reticence to expand on their accounts, possibly due to the more formal, constrained format induced by this one-on-one interview situation.

Although the great advantage of face-to-face interviews over other methods of information gathering such as surveys is the richness of data that they can solicit (Davis-Berman, 2011), it was in the transcription of this talk that difficulties arose in trying to convey the real sense of the experience. For example, I struggled to capture the raw emotion expressed by an elderly man (Piripi) talking about his childhood memories of the death of his father, or the loving disagreement in the interactions between a mother and daughter (Rebecca and Mia). The problem of attempting to put into words or transcription notation the full impact of pauses and silences or the significance of the rough humour and laughter in many of the transcripts was an on-going concern. As Barbour (2007) points out, “So enshrined are transcripts in the process of qualitative research that we rarely question their value or the ways in which they are produced” (p.80). A possible way forward for future studies would be to include images and even video clips in a multi-modal approach (Reavey, 2011) to enhance the transcript data and subsequent analysis and discussion. However, these too would suffer from Gill’s (1995) critique that they could serve primarily to ‘defend’ the analysis, rather than to represent it. This approach could also restrict participants in their talk and would undoubtedly raise significant issues regarding confidentiality and anonymity. Therefore, the dilemma this issue posed for the researcher still remains.

Limitations of the study are also related to the methodological approach adopted. In rejecting the notion that discourse analysis can have any claim to absolute truth, it must also be acknowledged that there will be other readings of the data that are equally valid. This particular version, as previously emphasised, has inevitably been shaped by my own ideals and experiences and also the socio-cultural values of the present historical period. In addition, the analytical insights offered in this study are necessarily limited to the discourses provided by the 28 participants and therefore cannot be generalised to other

people or situations. As Power (2001) points out, “Discourse analyses are written in order to become rewritten” (p.65).

Although the scope of the project did not allow further analyses, the study is nonetheless limited by ‘what is not there’. For example, institutional discourses and the power dynamics within such institutions as the Church, the law and medicine would allow for the consideration of euthanasia within a wider social network. Despite variation in the data, the participants of this study were in the main quite homogenous in terms of age and life stage. Therefore, it would be important for future research to interview other groups of people to investigate how discourses may differ for example, from younger people with no children. The bicultural context of Aotearoa/New Zealand must also be recognised by researchers in this field of study. The value of gaining greater insights into a Māori world-view and perspective on euthanasia cannot be over emphasised.

The recent extension of the euthanasia laws in Belgium to include children (Belgium, 2014) highlights the importance of carrying out further research to include their voices in making sense of euthanasia. Also studies of the discursive construction of euthanasia by terminally ill patients would be useful in furthering our understanding of the phenomenon. Indeed, Kubler-Ross’s (1969) seminal work on death and dying was based on the premise that talking to the dying can teach us the most about death. Other avenues for future research would be the analyses of the inter-net and social media sites to better understand how euthanasia is being constructed on-line. However, despite limitations and the potential for a range of other studies to complement these findings, it is to a consideration of the value of the present research that we now turn.

Genealogy

The gesture to genealogy was considered an integral part of the present study as it provided an historical and cultural perspective on the many transformations of understanding, practices and power relations of euthanasia. It emphasised the importance of resisting the ‘taken-for-granted’ idea that euthanasia may represent an ‘obvious’ response to a problematic dying process. Instead, inspired by Foucault’s mastery of suspicion, we need to

critically examine euthanasia and the 'apparatuses' that surround it and be open to the possibility of alternative ways of viewing the phenomenon. In particular, we need to be cautious of the power that can operate through such 'inevitable' concepts and practices. Indeed, there were a number of unsettling issues highlighted by the analysis.

Although euthanasia is ostensibly a humane response to the need to end the suffering of frail old age or terminal illness I would argue that it is also a procedure bound up with power. Control over death was seen to be a fundamental aspect of the phenomenon of euthanasia. The early Greeks and Romans approached death from a variety of standpoints but there was an underlying commonality in determining the ethics of ownership and command of life and consequently the ending of that life. Therefore, although possession and control of life and death was seen to reside with the gods, in certain circumstances that right could be abrogated to the individual to enable them to perform an act of self-destruction that was both heroic and pleasing to the gods, but still under their moral authority. However, this freedom was not extended to those individuals who were perceived as having no claim of tenure to any aspect of their own living or dying for example, slaves, soldiers and criminals.

Similarly, Christianity embraced the notion that the individual life belonged to God alone, therefore disallowing the ending of one's own life. The Church, as an institution, formalised the prohibition on self-killing and even in today's more secular society fights to maintain and protect this control. Discourses of religious reciprocity identified in the analysis were supportive of God retaining the right to decide issues of the time and mode of death. Aligned with the control wielded by the Church, society also has a vested interest in the life and death of its citizens. Aristotle introduced the notion of state ownership of life that was later reinforced by the Church in the teachings of St Thomas Aquinas. However, it is through bio-power that control over life and death assumes its greatest focus. The shift to a power that is concerned with managing and optimising life has a corresponding requirement to manage and assert control over life's exit (Foucault, 1978). Any attempt to wrestle control away is prejudicial to the power of an administration of life.

The medicalisation of death can be viewed as providing the disciplinary technologies required to retain control through the apparatus of medicine. McDorman (2005) claims that bio-power, through the institution of medicine retains control over the body by limiting individual rights in choosing the way to die. Attempts to 'normalise' this concern with the body through for example medical and legal discourses that disallow and abnormalise the desire to seek death represent in his opinion, a dangerous escalation of bio-power. Therefore, he suggests that the right-to-die movement is offering up resistance to these dominant discourses and he characterises the current euthanasia debate as a power struggle between the individual and the state regarding control over the body and death. On the face of it, it certainly seems that the growing demand for the legalisation of euthanasia is an indication of attempts to wrestle the power back from the state, to break free of the repressive chains of a juridico-medical system that denies an individual the right to determine their own dying destiny.

However, there is much in the genealogical analysis of euthanasia in the study to suggest that this is a far more complex situation. Even if governments pass legislation in favour of euthanasia, it is unlikely to result in a change to the balance of power regarding the control of death. As Salem (1999) points out, legalising the right-to-die will not demedicalise death as the proponents of the right-to-die movement claim but rather "medicalise suicide" (p.30). It does not offer a resistance to the power of the state in controlling death but actually expands the role of medicine in the dying process and in doing so limits the autonomy of the individual. Certainly, there are indications (Norwood, 2009; Szasz, 1999) that despite legalisation of euthanasia in the Netherlands, control has not been handed to the dying individual at all but remains firmly in the hands of the state through the apparatus of medicine. Tierney (2006) also concurs that while euthanasia and PAS require the approval of a medical authority, legalisation of the right-to-die does not present any challenge to governmentality. Instead, legislation can allow the hollow perception of individual freedom of choice in dying but at the same time uphold control as residing with the medical apparatus of the state: "This goal of gaining control over death will likely be unfulfilled as the legalisation, rationalisation and medicalisation of suicide will render it a safe practice within the administrative parameters of the juridico-medical order" (p. 631).

Furthermore, I would question whether renewed calls for the right-to-die might instead represent an even more insidious pathway for the state not only to retain control of death but also to achieve the economic objectives of our neo-liberal society. As we have seen in the genealogy, the twin concepts of social Darwinism and eugenics were the antecedents of calls to allow the practice of euthanasia as a solution to both individual suffering and the problems of society. It also needs to be remembered that according to Foucault, the state's concern with the health of the population was related to its objective to increase productivity of the workforce. Therefore, medicine is an important instrument in distinguishing between those individuals who are treatable and those who are unable to be cured (the elderly and terminally ill) who are potentially detrimental to a capitalist society.

In addition, the socio-cultural period of the late 20th century and early 21st century saw the people railing against a state that was seen as presenting an impediment to the fulfilment of Western ideals of individualism and personal autonomy. Demands for control over one's own body including such things as sexuality, abortion and euthanasia are responses to the perceived domineering influence over the individual of the societal institutions of the Church, medicine and the law. Rather ironically, a growing neo-liberal society also requires individual responsibility, not through any notions of freedom for the populace, but as a way of ensuring the productive, economic contribution of each of its members. It demands that there is a careful consideration and calculation of the risk that citizens may pose to the financial security of the state. It is clear that the extended dying process characteristic of our modern world, the growing elderly population, and the unprecedented demand on limited health resources are presenting a substantial risk to this economic imperative.

However, any attempts by neo-liberal governmentality to regulate or control the population in a manner that mitigates this risk must be covert. It is essential that the power inherent in such a crucial task and its mechanisms are hidden from view. Therefore, it must involve techniques that enable economic risk reduction by providing an avenue to remove those individuals who are no longer productive, and yet simultaneously be perceived as promoting individual autonomy. Euthanasia as a disciplinary technology has the potential

to maintain control of life and death firmly in the grasp of the state under the guise of a humane positive act that recognises the personal freedom of each citizen.

The increasing calls for the legalisation of the right-to-die are unlikely to deliver the promised freedom of choice of our own dying, rather they will result in the escalation of governmental power. Euthanasia can be seen as emblematic of neo-liberalism that is intrinsically linked to an art of government that is always seeking to mould all aspects of the lives of the people. As Foucault (1991b) points out, it requires the population to be acted on to ensure its own welfare and for its own economic good through techniques that need to gain approval and acceptance and indeed come to be seen as ‘common sense’. Therefore, I strongly suggest that we need to question whether in making sense of euthanasia now we are looking at the manifestation of “a more devious and discreet form of power” (Foucault, 1978, p.11).

Discursive analysis

Power, according to Foucault, does not ‘belong’ to any particular group or institution, but rather is dependent on the discourses that historically, culturally and socially are taken as ‘common sense’ and accepted as ‘knowledge’ and ‘truth’. Therefore, prevailing discourses of euthanasia are intrinsically bound up with power. They bring with them special rights and responsibilities and open up possibilities to act in certain ways. The analysis identified three categories of construction: *identity*, *reciprocation*, and *burden and duty* that were used by participants to discursively constitute their versions of euthanasia and were pivotal to understandings of decisions around hastening death.

Identity at the end-of-life was a significant determinant to understandings of what constituted a living human being. The focus on physical appearance as a particularly important aspect of identity reinforced the primacy given to the visual realm in our everyday lives, what Rose (2007) refers to as the ‘ocular centralism’ of modernity and post-modernity. The deterioration of physical appearance linked to sickness and dying stripped the person of their identities to such an extent that they were unable to be recognised. It is unsurprising then that there was not only a reluctance to gaze on the physical

manifestations of the dying body but the terminally ill patient was similarly unwilling to look at those around her/him because of the reaction that was evident on their faces to the bodily abnormalities. The negative affect elicited by such visual information played a central role in determining the importance of physical appearance to constructions of identity.

The loss of identities that resulted from a disintegrating physicality was particularly salient for women. A high standard of physical appearance is equated with a measure of femininity and womanhood that is greatly prized by society. The constant social surveillance during illness, where visual 'readings' are the most easily available tool for assessment, places an undue burden on sick and dying women to maintain societal expectations of beauty. This is recognised and supported by initiatives such as 'look good - feel better' that teach beauty techniques to women with cancer to help manage appearance. Although such a project can be viewed as a positive public service that helps restore and enhance self-esteem, it also acts to reinforce the importance of physical appearance to notions of feminine identity. It would be interesting to question why there is not a similar programme offered to men undergoing cancer treatment.

The importance of maintaining physical appearance even after death was also apparent in the data. This was linked in Western society to individualistic concerns with bodily ownership and being able to ensure an acceptable representation of the self under the intense gaze of post-death surveillance. The desire to be remembered by a final bodily image that was not only intact, but represented the corporeal identity of the living self in a favourable light was very strong. This was especially significant when the dying process itself had physically undermined identity. Similarly, in Māori society there was a need to ensure as far as possible that the tupapaku (deceased), the link between present and past whānau members, retained its physical integrity. Indeed, it is suggested (Webb & Shaw, 2011) that such cultural understandings of embodiment are an important factor for Māori in organ donation and transplantation.

Identity was also threatened at the end-of-life by an unbounded body or loss of bodily autonomy. In conjunction with the deterioration of physical appearance, the failure of an aging or dying body to conform to the normalised Western concept of an individual as a fully autonomous, sealed vessel contributed to the emergence of a new deficit identity that was both unfamiliar and problematic. However, it also needs to be acknowledged that the concern regarding the ability to maintain a bounded body is a masculinised version of the individual that is generalised to the population. Female bodies are 'othered' and portrayed as leaky and messy (Shildrick, 1997). Therefore, I would suggest that an unbounded body presents greater implications for men than women whose bodies are expected to leak at various times during their lives.

Furthermore, although identity was seen to be undermined by a leaky body, this finding needs to be considered in terms of culture and socio-economic status. The discourses drawn upon by participants, portraying disgust and revulsion at the loss of control over basic bodily functions, were very indicative of Westernised, middle-class notions of the individual. Indeed, Lawton (2000) alludes to the historical and cultural specificity of such distaste for bodily secretions. It is reasonable to suggest that people living in more impoverished circumstances or in a closer communal way, including in Western society, are much more accustomed to the sights and smells of leaky and/or sick bodies. They would also be more familiar with engaging in other people's personal hygiene just because there may be many people across generations living in one house, sharing bedrooms and bathrooms. Therefore, issues of intimate bodily secretions and associated odours may not be such an affront to them because they are more used to it as a 'normal' part of daily life. In contrast, people living in a small nuclear family unit or in a more affluent situation may be able to distance themselves from such experiences by virtue of having multiple bedrooms and bathrooms. They are also more likely to be able to afford professional care for the sick, thereby ensuring that they are clean for presentation to family and friends.

Hospice care that has been shaped by a Western perspective may therefore cater more for the needs of white, middle-class clients. This is supported by international studies that have shown that economically disadvantaged ethnic minority groups are less likely to utilise

hospice care than whites (Greiner, Perera & Ahiuwalia, 2003; Ngo-Metzger, Phillips & McCarthy, 2008). Similarly, a study in New Zealand (Bray & Goodyear-Smith, 2013) also found that Māori, Pacifica and Asian populations were under-represented as hospice users. Although there are undoubtedly a multitude of barriers to accessing hospice care for these sectors of society, there also needs to be some consideration given to a possible alternative explanation. If, as Lawton (2000) argues, hospices have primarily become institutions that enable the unbounded, dying body to be hidden away, then these groups may simply not have the same need for these services.

The uncertainty expressed by participants around the different consequences for identity of a loss of bodily containment and agency versus the loss of mental faculties is a reflection of an on-going Cartesian dualism between the mind and body. The question of what sets us apart as human beings and defines our humanity was found to be both complex and troublesome. However, it was clear that when individuals failed to meet established norms of either acceptable physical or mental functioning they were also seen as relinquishing claims to personhood. This was reinforced by the use of references to vegetables and inanimate objects to describe the anomaly. The resulting 'non-person' represented an enigma to concepts of what it means to be a living human being. The dilemma of being alive but not living added urgency to the desire to close the gap between social death and biological death. As Prado (2003) points out, although we need to be biologically alive in order to live our life, that in itself is not enough. Thus, the many identities that were forged through living life as against merely being alive were subsumed by a singular dying entity.

This new identity represented a significant challenge to Western ideals of autonomy and independence. The intrinsic value accorded to a life that is lived autonomously, simultaneously diminishes lives that require dependence on others. Therefore, such individuals were positioned as an object – a burden. Participants indicated their strong desire to resist becoming a burden or liability particularly to the next generation. Discourses around intergenerational burden and responsibility generally presumed an orderliness of death whereby it was taken for granted that the older generation would become sick and die

first. Therefore, it needs to be considered if raising the topic of euthanasia itself constructs death in a particular way that may not be assumed in other discussions of death and dying.

In becoming a burden individuals not only lose their rights to autonomous self-hood but also pose a major risk to the objectives of neo-liberalism. The requirement for a self-caring, productive population is at the core of this Western ideology and is thus threatened by these non-functional members of society. The potential for these individuals to utilise societal resources without any reciprocal compensation and their inability to meaningfully contribute to the economy devalues them as assets. Constructions of reciprocity were very much centred on life's value to society with attempts to measure 'a life worth living'. Certainly, it is this concept that often forms the basis of arguments in the euthanasia debate. However, from a neo-liberal perspective if an individual is perceived as a drain on society then their removal can be considered beneficial.

In spite of this, the discourse of a 'fair deal' seen in the data advocated a fuller assessment of life's worth. Based on the norm of reciprocity that characterises the social contract between the individual and society it argued that if you had worked all your life and paid taxes then you were entitled to access to health resources. However, we need to consider if this sort of discourse would be apparent in societies with different forms of health care. For example, in New Zealand we have a public health service that is funded by taxes therefore the link between paying taxes and receiving health care is quite obvious. In contrast, if healthcare was all privately funded, as is the case in some countries, the discourse may not have been formed in the same way. This is because individuals who paid health insurance throughout their working lives would receive health care in their old age while those who were not 'fit' economically within this system and couldn't afford premiums would not have access and so couldn't be a drain on these resources. The important point is that we need to reflect on how economic and political structures including health care systems shape the ways in which 'fair deals' are discussed and norms of reciprocity are turned into ideology.

The constructions of reciprocity and duty and burden identified in the analysis also had particular implications for Māori. The commonly held assumption of altruistic respect and care for elders in Māori society that is viewed with some admiration by Pākehā, was seen to be linked to their perceived value as cultural reservoirs. However, the growing population of elderly Māori is unlikely to be able to continue to fulfil this role due to a movement away from traditional marae structures and a corresponding lack of skills in Māoritanga. Therefore, they may be left in an unenviable position of having to measure up against a wider set of fiscal criteria regarding a life's worth. This will be further compounded by the economic imperatives and neo-liberal aspirations of the next generation of whānau who may be less able or willing to accept the responsibility of care.

Conclusion

The various discourses drawn on within these analytical constructions allowed participants to make sense of euthanasia. However, these hegemonic discourses also act to marginalise and exclude other possible ways of understanding euthanasia. For example, the value and prestige attached to notions of autonomy and self-care simultaneously undermine the value of lives lived dependently. They preclude understandings of a 'life worth living' that are not based on cultural stereotypes and standards of 'normality' centred on the able-bodied, healthy individual. As Fitzgerald (1999) points out, the more people deviate from this norm the more troubling their position in society becomes. This is further compounded by the fact that many of the value judgments of worth are made from an "objective distance" (p.5) by those who most closely approximate the ideals of normality. Therefore, these dominant discourses can marginalise significant groups in society; the sick, disabled, elderly and terminally ill, and successfully silence other discourses that may offer the opportunity of empowerment for lives lived 'differently'.

The discourses constructing burden and duty seen in the study also operate to devalue the role of carer. They rule out the possibility that the care of vulnerable groups may contribute in any meaningful way to society and this is reflected in the low remuneration allocated to people employed in the sector. These discourses have become part of our 'common sense' knowledge but can also be challenged by alternative representations. For example, the

notion that the benefits ensuing from the very act of caring for the sick and dying can far outweigh the costs to society has the potential to dispute the legitimacy of these prevailing ways of understanding euthanasia.

Similarly, we need to question whether these discourses are also providing a 'smoke-screen' for underlying issues such as inequitable access to health care. For example, viewing euthanasia as an individual choice in the face of incalculable pain and suffering moves the spotlight away from a society that is not allocating sufficient resources to the care of the elderly and terminally ill; a society that is only prepared to economically support a viable labour unit who will contribute to production in a capitalist economy. This concern is borne out by the recent New Zealand Government's Health Select Committee recommendation that future health funding be prioritised to early childhood. The chairman of the committee, Paul Hutchison is quoted as saying, "The dollars spent early on pay off, certainly compared with later on" (Rutherford, 2013). The economic rationalisation of health care promoted by the select committee is a reflection of a Western neo-liberal ideology that can be masked by the prevailing discourses seen in this study.

Furthermore, the focus on the euthanasia debate can act to both diminish and detract from the issue of high elderly suicide rates. Statistics in New Zealand indicate that the number of suicides in the 65-plus age group is growing rapidly with men aged 85 years and over now having the highest suicide rates in the country. It is also likely that due to under-reporting this figure may actually be much higher (Harvey, 2013; Harress, 2011). Therefore, although suicide-prevention programmes are aimed particularly at the young and middle-aged who can be viewed as important economic assets, in practice there is a much higher rate of suicide in the older population; nor is this situation unique to New Zealand. A study by Wasserman and Ringskoy (2001) found a similar pattern in Sweden and argued that this was because the elderly were valued less due to difficult economic times and the growing elderly population, features that are shared by many Western societies. It is also important to note that as mentioned previously, since the introduction of the legalisation of euthanasia in the Netherlands the Dutch have significantly reduced the suicide rate for the over 50 age groups (Hendin, 1995).

The constructions of euthanasia highlighted by the present study made available a particular framework for perceiving the world that has implications for ‘appropriate’ social action for the elderly and terminally ill positioned within these constructions. However, most importantly, they form the backdrop for the self-formation of a subject who can ‘choose’ to die. A socially constructed category of body creates a particular sort of subject who can ‘freely’ accept the need for euthanasia as a therapeutic solution to a problematic anomaly. In Foucauldian terms bio-power ensures that not only will the expert ‘gaze’ of medical technologies seek normalisation but the individuals who have become constituted by that essence of bodily construction will ‘willingly’ subject themselves to euthanasia as a disciplinary technique. In doing so they are able to construct a version of self that fulfils societal ideals of a ‘good death’. This will undoubtedly function to normalise euthanasia and it could then become a reasonable expectation of those who as one participant put it have “past their ‘use by’ date”.

Identity, reciprocation and duty and burden were identified as categories of construction utilised by participants in making sense of euthanasia. These were linked to discourses that produced ‘knowledge’ that not only moulds the way we think and speak but more importantly the way we can act. In a complementary fashion, the gesture to genealogy outlined the haphazard and arbitrary way in which these discourses emerged. A disjointed range of events that included moral edicts of self-destruction, medicalisation, eugenics, civil rights and neo-liberalism were all seen to contribute to the apparent inevitability of our present day understandings of euthanasia.

However, these prevailing discourses continue to receive the ‘stamp of truth’ because they successfully obscure the operation of power. They function to both support and legitimise the inequalities of power relationships in our society. This study may offer some insights into how we make sense of euthanasia but also the ways in which this perpetuates social injustice. It may also allow us to recognise other discourses that have been marginalised in society and the possibilities offered by accepting or resisting various subject positions within these discourses. More importantly, it may create a space for the voices of those

vulnerable members of society who are effectively disempowered by these hegemonic discourses of euthanasia.

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APPENDICES

Appendix A:

LETTER OF SUPPORT

To Whom It May Concern:

I have met with Anne Ryan regarding her research project “Discourses of Death” and had the opportunity to discuss all aspects of the research procedure with her. We have discussed the particular issues that may impact on Māori participants and I am satisfied that these will be managed appropriately. I am able to assist with the recruitment of Māori participants and will continue to be available for advice, guidance and support during the time period of the research project.

Gilbert Knowles

Kaumatua Ngāti Kauwhata / Ngāti Raukawa

Āpotoro Rehita Hāhi Rātana

Appendix B:

INTERVIEW SCHEDULE

Thank-you for talking to me today, as you know I am interested in how people make sense of issues such as euthanasia and assisted suicide. I would just like to start by asking you to describe your own ideal “good death”?

What reasons do you think people may have to want to hasten death?

Can you give me some examples or personal experiences of end-of-life decisions that you feel were appropriate / not appropriate? Who was involved in these decisions?

What link or relationship, if any, do you see between suicide and euthanasia?

What role, if any, do you think that law/ medicine/ religion has in end-of-life decisions?

What are your thoughts about the legalisation of euthanasia and assisted suicide?

Do you have any particular views on these practices?

Given that people are living to a much older age and often suffer long-term chronic illness before dying and the corresponding rising cost of health care, could you ever envision a ‘duty to die’?

Some people who are not ill, but may be simply tired of living, believe that they have the right to choose to die. What is your view?

Is there anything else you would like to add that may help us to understand aspects of euthanasia and assisted suicide that you believe are important?

Appendix C:

INFORMATION SHEET

Introduction

You are invited to participate in a research project being carried out by Anne Ryan, a student at Massey University, as part of a PhD in Psychology. The supervisors for the research study are Associate Professor Mandy Morgan who is the Head of the School of Psychology at Massey University, and Dr. Antonia Lyons, a Senior Lecturer at Massey University, Wellington campus.

Project Description

This invitation is to take part in an interview with the researcher discussing issues around euthanasia and assisted suicide. This will contribute to a series of interviews in which the talk will be analysed to try and understand how people make sense of these end-of-life decisions. The aim of this study is to examine the ways in which people make sense of euthanasia and assisted suicide, as these will be inextricably linked to the actions we take as a society to these end-of-life issues.

Participant Recruitment

Participants are to be recruited through existing networks available to the researcher and by a 'snowball' effect whereby participants may wish to suggest someone they know who may also possibly wish to participate. It is anticipated that there will be approximately 20 – 40 participants in total as it is thought that interviews with this number of participants will provide sufficient valid information for this type of project. The selection criteria will include any adult (18 years or over) who is proficient in English, and anyone who meets these criteria and would like to participate is warmly welcomed. A gift voucher of \$20 will be given to each participant to thank them for their time commitment to the project.

It is not expected that participants will experience discomfort or any risk as a result of participation. However, participants should be aware that some may experience a feeling of anxiety about discussing certain aspects of end-of-life issues and there is also the potential

to invoke painful memories of loved-ones dying. The experience of sharing very personal opinions on what can be viewed by some as a very taboo subject may also be highly emotive. Participants may be reassured that the researcher will respond sensitively to any issues and you may stop the interview at any time or decline to answer any question. In addition, information will be provided about locally available counselling services that may be accessed by donation only. It also should be emphasised that data management guarantees confidentiality for all participants.

Project Procedures

If you choose to participate in this study you will be asked to take part in an informal interview with the researcher that will be audio taped. Alternatively, you may prefer to be involved in a small group interview with others. However, it is recommended that if you wish to share information that could possibly be viewed as contentious or incriminating that you choose an individual interview. The interview will take place at a time and venue that is most convenient to you and take about 1-2 hours. The tapes will be transcribed word for word and you will have the opportunity at a later date to check the transcript for accuracy and change as needed, this may take approximately 30 minutes – 1 hour.

Data Management

The transcripts will be analysed by the researcher using a technique called discourse analysis to identify the ways in which people construct issues such as euthanasia and assisted suicide, how they make sense of them, and the possible function and consequences of these particular constructions. All participants can be assured that their identity will not be disclosed in the analysis, through the use of pseudonyms. The tapes and transcripts will be held in locked storage and all electronic data will be held in encrypted files. The tapes will be destroyed at the end of the research project and, as is normal for research data, the transcripts will be held for 5 years following the conclusion of the research project. A summary of the project findings will be made available to all participants.

Participant Rights

You are under no obligation to accept this invitation. If you decide to participate you have the right to:

Individual Interviews

- Withdraw from the study at any time until the analysis of the data is underway (i.e. 4 weeks after the return of the transcript).
- Decline to answer any particular question.
- Ask for the audio tape to be turned off at any time during the interview or stop the interview at any point.
- Request removal or amendment of any part/s of the transcript resulting from the interview.
- Ask any questions about the study at any time during participation.
- Provide information on the understanding that your name will not be used unless you give permission to the researcher.
- Be given access to a summary of the project findings when it is concluded.

Focus Group Discussion

- Decline to answer any particular question
- Leave the focus group discussion at any time
- Ask any questions about the study at any time during participation.
- Provide information on the understanding that your name will not be used unless you give permission to the researcher.
- Be given access to a summary of the project findings when it is concluded.

Project Contacts

If you have any questions or concerns about the research, please feel free to contact either the Researcher or Research Supervisors.

Researcher:

Anne Ryan

628 State Highway 57

RD 1 Levin

Telephone: (06) 3670902

Email: anne.ryan@xtra.co.nz

Research Supervisors:

Associate Professor Mandy Morgan

Head of School

Massey University School of Psychology

Private Bag 11222

Palmerston North

Telephone: (06) 3569099 ext. 2063

Email: C.A.Morgan@massey.ac.nz

Dr. Antonia Lyons

Senior Lecturer

Massey University School of Psychology

Wellington Campus

Telephone: (04) 8015799 ext. 62164

Email: A.Lyons@massey.ac.nz

MUHEC Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 10/38 If you have any concerns about the conduct of this research, please contact Dr Karl Pajo, Chair, Massey University Human Ethics Committee: Southern B, telephone 04 801 5799 x 6929 email humanethicssouthb@massey.ac.nz

Appendix D:

PARTICIPANT CONSENT FORM – INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to the interview being sound recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: _____ **Date:** _____

Full Name – printed: _____

Appendix E:

**JOINT INTERVIEW AND FOCUS GROUP PARTICIPANT CONSENT
FORM**

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree not to disclose anything discussed in the Joint Interview or Focus Group.

I agree to the discussion being sound recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: _____ **Date:** _____

Full Name – printed: _____

Appendix F:

TRANSCRIPTION KEY

(.) A full stop in round brackets indicates a noticeable pause, though not timed.

// A double forward slash marked the start of speech overlap.

Really Words in bold represent an emphasis in speech.

[Laugh] Words in square brackets signify the speaker's actions.

(a teacher) Words in round brackets are for clarification or explanation.

... Three dots indicate that the speaker omits material.

Appendix G:

MĀORI/ENGLISH TRANSLATIONS

ao – world

hōhā – tiresome, fed up

hongī – kiss

hurihuri – changing

iwi – tribe

karakia - prayer

kaumātua – elder

kawe mate – take the dead (back to their roots)

koro - grandfather

manaakitanga - hospitality

Māori – indigenous New Zealander

maro - hard

māuiui – sick

māuiuitanga – sickness

moko – grandchild

noa – ordinary (free from tapu)

pākehā – European

takahi whare – tramping the house

tangihanga – funeral

taonga - treasure

tapu - sacred

te reo – language (Māori)

tikanga – custom

tohunga - priest

tupapaku – deceased body

wairua – spirit

whakamutunga - ending

whakapapa- genealogy

whānau - family

whānau whānui - wider family