

**MASTER OF HEALTH SCIENCE THESIS**

**EUTHANASIA: A Foucauldian analysis**

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fulfilment of the degree of Master of Health Science.**

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### **Attestation of Authorship**

I hereby declare that this submission is my own work and that to the best of my knowledge and belief, it contains no material previously published or written by another person, nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in acknowledgements.

Signed.....

Date.....

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I dedicate this thesis to the memory of my sister and best friend Leigh, who died from cancer in 2003.

## Abstract

The topic of this study, euthanasia, has become a modern-day issue that challenges some of societies traditionally held beliefs towards death and dying. This study drew upon the theoretical insights of Michel Foucault to provide a discursive analysis of the term *euthanasia*, and the issues surrounding the “right-to-die”. It involved an analysis of primary texts from; nursing, general, and legal literature as well as the media between the years 2002-2004. Drawing upon data researched, the study analyses the main discourses regarding the practice of euthanasia for terminally ill individuals. The two competing discourses that emerged were what I have termed the sanctity-of life-discourse and the right-to-die discourse. The aim of the study was to uncover the discourses understanding of “truth” regarding the right-to-die. The analysis revealed that a small percentage of cancer sufferers (5%) die with their pain insufficiently treated and the right-to-die discourse claims that no individual should have to suffer needlessly, asserting the individuals right to autonomy. Directly opposing this is the sanctity-of life-discourse which states all life is sacred and nothing can justify euthanasia as an acceptable practice in society. My findings indicate the need for effective palliative care and pain management when caring for the terminally ill individual. The legal, ethical and moral implications of euthanasia are many and this study discusses the effects these may have on health professionals involved with the care of terminally ill patients. The study revealed an increasing deployment of the right-to-die discourse in the media and revealed concerns regarding the nursing professions lack of preparation to deal with euthanasia if it becomes a legal option in end of life care.

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# CHAPTER ONE

## *Introduction*

This thesis uses a discourse analysis approach, based on the work of Michel Foucault, to investigate euthanasia. This method of analysis has been a valuable research tool because I believe it has revealed regimes of “truth” within the euthanasia debate, and has exposed some of the taken-for-granted aspects of caring for the dying patient within our current health care system. It involved an analysis of selected primary texts which is in keeping with a discourse analysis methodology. The aim of this study is to identify and analyse the discourses articulated in a broad context regarding euthanasia, and to uncover the different discourses’ understanding of “truth” regarding the right-to-die.

I selected euthanasia for analysis partly because of a previous study I did in Advanced Health Law. The study revealed the courts inconsistency when applying the law to specific cases, frequently citing “mercy” as a reason for giving lenient sentences. Euthanasia is a highly controversial area for discussion and the legalising of euthanasia would have major implications for health practitioners.

In New Zealand the highly publicised case of Lesley Martin in 2002 drew the public’s gaze to the euthanasia debate. Martin, a registered nurse, was found guilty of hastening her terminally ill mother’s death. Lesley Martin’s book *To die like a dog* uses the values of mercy, love and compassion to justify her reasons for euthanising her mother. I find it significant that Lesley would never have been charged with her mother’s death if she had not published the book, thereby forcing the authorities to take legal action.

Euthanasia is particularly relevant today because current research is indicating a change in people’s attitudes and belief systems towards supporting euthanasia. Society increasingly “likes” the concept of euthanasia and the general move towards autonomy has meant that traditional and previously accepted societal viewpoints are being challenged and questioned (Johnston, 2003; Keown, 1999; Moss, 2003; Richardson, 2002; Zinn, 2001). The increased public awareness and growing favourable attitude towards euthanasia has made it necessary, I believe, to look at the laws that prohibit euthanasia and assess their relevance and possible limitations when

applied to current society. I particularly feel that the Criminal Law, which determines whether an individual has committed murder, has its limitations in our Western society when considering individual cases of euthanasia. An increasing number of euthanasia cases are coming before the New Zealand courts, and I was interested to see whether the increasing public demand for autonomy, when making decisions about dying, could be as a result of this.

Having worked in the past as a nurse in areas such as critical care and operating theatres, I felt that there were grey areas regarding decision making around death and dying that potentially made the providers of health care vulnerable and exposed to prosecution in the eyes of the law. These grey areas encompass discursive practices such as removal of treatment and removal of food and fluids. The practice of double-effect is particularly relevant within this debate, and occurs when pain relief is given in such large doses that, as a consequence, the patient dies (Johnstone, 1994). This practice is discussed in more detail in chapter six.

Critical care is an area where many people are close to dying, and without medical and advanced technological intervention, the majority would in fact die. Decisions need to be made on a regular basis regarding the withdrawal of treatment and when further treatment is deemed futile. For example determining when a patient is brain-dead or when to remove ventilatory support (Loewy, 2001; Ravenscroft & Bell, 2000). Loewy (2001) claims that removal of ventilatory support and necessities such as providing food and fluids have raised much debate as to what in fact constitutes euthanasia, and I discuss this in chapter four and five. A generally accepted definition of euthanasia is: an act of killing or letting someone die that satisfies two conditions; the first being that the death benefits or is good for the individual who dies, and secondly that the person assisting is motivated to do it for the good of the individual (McMahan, 2002).

Because of the complexity of the issues surrounding euthanasia, this thesis focuses on a specific area particularly relevant to health practitioners, in particular the nursing profession. The main analysis centres around euthanasia and the desire to have it legalised if it is carried out to assist a competent, terminally ill patient, who is in pain, only has days to live and who has specifically asked for assistance to die.

Cancer sufferers are the largest group to die in countries that permit euthanasia, with the main reasons given for wanting this option being to alleviate or

avoid pain, and the belief that they should have the right to choose (Wilson, Scott, Graham, Kozak, Chater, Viola, de Faye, Weaver & Curran, 2000).

There has been a marked increase in support of euthanasia worldwide and this has significant implications for New Zealand health care. The Euthanasia bill presented to Parliament in 2003 failed to pass by only two votes, and suggests to me that if government is so evenly divided, then New Zealand might also be gradually accepting the concept of euthanasia. The “Right-to-Die” movement has an increasingly strong voice and is challenging society to question previously accepted “norms” regarding the death and dying process (Martin, 2002). A further issue faced by health professionals is that we live in a multicultural society and not all members choose to live within the Christian ethos that underpins the current law.

This study does not attempt to supply answers to the reader. Instead it lays out, using a Foucauldian approach, the competing discourses and their opposing viewpoints regarding euthanasia.

### *Study Outline*

#### *Chapter 2.*

This chapter begins with an over view of postmodernism and the concept of discourse provided by the work of Michel Foucault. Included in this section are his views on genealogy, power, power/knowledge, technologies of power and truth and subjectivity.

#### *Chapter 3.*

The method chapter contains an explanation of the data selected for analysis; the process of data analysis; the notion of crystallisation and reflexivity; issues of rigour, trustworthiness and limitations of the methodology.

#### *Chapter 4.*

A genealogy of euthanasia is provided to give the reader an historical overview of the debate. This includes the changing terminology and various definitions of euthanasia. It looks at specific events over time that have altered society’s perceptions of the definition of death and dying and how we have come to view death and dying today. It introduces the concept of autonomy and how this value has emerged and added strength to the right-to-die discourse in the last 30 years.

### *Chapter 5.*

The sanctity-of-life discourse is analysed, revealing the objects and subjects of the discourse which are evident in the data. The two main discourses are the; sanctity-of-life-discourse and the right-to-die discourse. The main subject that comes under scrutiny is the dying patient, and the discursive objects of the discourses are death, dying and pain. The discursive practice of palliative care emerges as an important object for study in this debate. The structural analysis consists of three axis; knowledge, authority and justification. Power relations are implicit within the data analysed.

### *Chapter 6.*

The right-to-die discourse is analysed in this chapter. The different construction of the objects and subjects of the discourse are contrasted and compared to reveal how they contest the sanctity of life discourse. Physician-assisted suicide as a discursive practice becomes a part of the analysis.

### *Chapter 7.*

Here the two main discourses that emerged are discussed; they are the sanctity-of-life discourse and the right-to-die discourse. Their competing regimes of “truth” are compared and contrasted. The implications of this for the nursing profession, recommendations, limitations and the significance of the study along with future research possibilities are presented.

## CHAPTER TWO

### *Philosophical context*

#### *Introduction*

Discourse analysis is an approach that has been developed from the postmodern belief that reality is constructed from multiple perspectives and “truths”. Within this paradigm the constructed nature of facts or knowledges that have often become assumed truths are highlighted. Therefore the understandings of ourselves and what we experience are dependent on the discourses that shape our behaviour and influence the position from which we view reality (Cheek & Porter, 1997). This chapter describes the theoretical underpinnings that are the foundation of this thesis and that are based on the work of Michel Foucault. His ideas provide a useful way of exploring current aspects of contemporary health and health care practice, in this study of euthanasia and the dying individual. The chapter explains the term *discourse* from a Foucauldian perspective, gives an interpretation of Foucault’s understanding of the terms truth and subjectivity and discusses his notions of power and power/knowledge which are an integral aspect of his notion of discourse. The concept of genealogy is discussed, as is Foucault’s application of it to show the historical emergence and political construction of discursive practices which become accepted as societies’ rules and norms.

#### *Postmodernism*

Postmodernism emerged out of a desire to critically analyse the principles of modernity and to question the assumptions made within this paradigm. The emphasis in modern theoretical analysis was on the big picture; for example, grand theories of social structure and action and searching for a single “truth”. Postmodernism challenges this assumption and emphasises the plural nature of reality, and the “multiple positions from which it is possible to view any aspect of reality” (Cheek, 2000, p. 20). Rather than accepting the modernist concept of a unified subject, postmodernism instead recognises the presence of multiple voices, views and methods when making an analysis. This paradigm discards the notion that all of society works

together in an orderly way, rejecting “modern assumptions of social coherence and notions of causality in favour of multiplicity, plurality, fragmentation, and indeterminacy” (Best & Kellner, 1991, p. 4). The postmodernist discourse analysis approach states that our ways of talking and acting do not neutrally reflect our world, nor our individual identities or social relations, but rather that it plays an active role in creating and changing them (Phillips & Jorgensen, 2002).

The postmodern approach enables the researcher to question what is being regarded as “normal” or “natural” and to explore how these “truths” came to be constructed. This in turn contributes to our understanding of the relationship between society, culture and health. The concept of multiple truths is a notion that appeals to me because the euthanasia debate presents two main competing discourses, each of which is claiming to be the “truth”. The study involves revealing the layers and multiplicity of discourses, the subject positions available, and how power is achieved and truth claimed.

Postmodernism aims to highlight the constructed nature of what have become these “truths”, and the taken-for-granted aspects of our reality, including accepted practices and procedures in the health sector. This approach can challenge the assumption that the health care system works together for a common good, looking at why changes are made and whether these developments and changes in health care are necessarily progressive (Cheek, 2000).

Foucault was an important postmodern theorist, and I will now outline of some of his theories that are relevant to my work.

### *Michel Foucault*

Michel Foucault was one of the most influential (and controversial) postmodern theorists. He resisted being situated within any paradigm but it is generally accepted that many of his analyses reflect a postmodern perspective (Cheek, 2000). Foucault’s work on discourse analysis considered how historically and culturally located systems of power/knowledge construct subjects and their worlds, emphasising the concept of power in specific human contexts. He challenged the modernist way of viewing the world by questioning the roles established institutions had played and then deconstructing these roles; examples of this are his works on prisons and psychiatric institutions. His style was characterised by an analysis of history or historical text, for example his works *Madness and Civilization* (1967), and *The Birth of the Clinic*

(1989). They were based on his reading of medical texts which dated from the 16<sup>th</sup> to the 20<sup>th</sup> centuries (Fillingham, 1993). His historical analysis showed the fluidity of our ideas over time, and he questioned the reasons behind this. Foucault challenged us with the assertion that what we see as the “truth” changes over time. Central to his work was the concept of discourse and its relationship with power and knowledge (Powers, 2001).

Examining this relationship makes discourse analysis a valuable research tool in health sciences because this method can assist in uncovering historical, social and cultural discourses of power/knowledge that construct our everyday practice. By revealing the objects and subjects of a discourse, it is difficult to then not refer to them as if they were real. Foucault saw discourse analysis as a way of thinking and; “speaking about aspects of reality” (Cheek, 2000, p. 22).

### *Discourse*

The term *discourse* has become very fashionable in recent years and multiple definitions exist. In some instances it can be used loosely as a synonym for *text* and others for *speech* (Fairclough, 1995, 2003). Foucault’s concept of discourse moved away from the idea that discourses referred primarily to language or speech, to the notion that it was something broader. Foucauldian discourse analysts therefore regard discourse as including; actions, thoughts, and beliefs with discursive arrangements including both linguistic and non-linguistic elements (Scarborough & Tanenbaum, 1998). My guiding definition of discourse is provided by Powers (2001), who defines discourse as “a group of ideas or patterned way of thinking which can be identified in textual and verbal communications, and can also be located in wider social structures” (p.1). Discourses are represented by lived patterns of actions (historically and institutionally) that broadly encompass their adherents’ lives, and discursive practice is manifest in patterns of talk and interaction that constitute everyday life. Gubrium and Holstein (2001) state, “Discursive practice, in other words, provides the footing for answering why recognisable constellations of social order take on locally distinctive shapes” (p. 502).

A discourse permits us to see things that have formerly been hidden and provides a framework for discussing the value of one way of talking about reality over other ways. Discourse consists of a set of common assumptions which provide the basis for conscious knowledge (Phillips & Jorgensen, 2002). The concept of discourse

can be difficult to grasp because discourses do not simply describe the social world, they also categorise (Parker, 1992). According to Parker, a discourse is found in small pieces rather than in a complete form within a text. This means that throughout a text, discursive practices are revealed by the language used and the practices discussed. “A discourse can be described as a system of statements that construct an object” (Parker, 1992, p. 5). In one of his early writings, Foucault (1972) states that his purpose in analysing the discursive practices of disciplines was to “unmask discourses as practices that, systematically form the objects of which they speak” (p. 49). Foucault emphasised the predominance of discourses in constructing the horizon of meaning at particular times or places, conveying the sense that discourses fully detail the subtle differences of everyday life (Gubrium & Holstein, 2000).

Foucault (1972) referred to the rules which limit what statements can be said within a discourse as rules of formation, and analysis involves identifying these rules that a discourse is subject to. Powers (2001) drawing on Foucault describes surfaces of emergence, the authorities of delimitation and grids of specification as methods for uncovering these rules of formation. The professional bodies that have the power to designate discursive objects are called the “authority of delimitation” and society attributes to them the knowledge and expertise to identify objects. The “grids of specification” are a classificatory system used to determine divisions between or within discursive objects. Diagnoses and prognoses of the dying individual can be given as an example of a grid of classification; this includes the type of disease process, the stage it has reached and the treatments available.

For Foucault (1980), power operated in and through discourse as the other face of knowledge, thus he introduced the term *power/knowledge*. Foucault viewed discourses as domains within which power and authority are conferred on some and denied to others (Popkewitz & Brennan, 1998). Discourses operate in particular sites and provide boundaries that are supported by various institutions, operating within certain rules of inclusion/exclusion. It is seen primarily as a means of constraint, but discourse can also be enabling; a set of techniques and procedures emanating from a particular regime of truth which influences social, political and administrative practices. To look at a discourse in the present, Foucault felt it had to be looked at in an historical context and hence his concept of *genealogy*.

While history is about the past, Foucault’s histories typically begin from the perception that something is wrong in the present, and discourses develop because of

the social and cultural conditions occurring at that particular time. Foucault describes these as the “surfaces of emergence” and it is these conditions of existence that enable an analysis to be made of things said or written at that point in time (Gutting, 1994). The genealogy examines the major influences on the development of a discourse; it is the history of the discourse and is discussed next.

### *Genealogy*

Foucault’s idea of a genealogy was to give an account of the historical emergence and political construction of society’s rules and accepted social “norms”. The key issue is the historical formation of the authority of the discourse and how it came to have the right to pronounce the truth in some area of experience (Rawlinson, 1987). It places the importance of power relations in an historical context and examines the effect this has on current social practice. A genealogy seeks the conditions that have enabled certain discursive practices to become acceptable practice in a discourse (Powers, 2001).

Genealogy assumes that there are historical influences that have had an influence on the regularities of the discourse and looks also at non-discursive factors such as: institutions, practices, politics, economics, media, and terminology (Powers, 2001). The genealogy can show the inadvertent historical position of the discourse. Therefore genealogy can assist us to obtain a broad picture of the historical contribution to the development of practices of power and resistance in the specific discourse under analysis. Foucault’s aim in conducting a genealogy was to understand the present and how it has evolved from the past rather than to just understand the past (Rabinow, 1984).

Whereas much of history tries to show that where we are is inevitable, Foucault aimed to show that the past ordered things quite differently and that processes leading to our present practices and institutions were by no means inevitable (Powers, 2001). Interpretations in language constantly shift and change in relation to the institutional and cultural markers they refer to and these vary with respect to the environment in which social interaction occurs (Gubrium & Holstein, 2001). Foucault saw language as a powerful tool in society, because it helps structure the way we think and understand our world (Parker, 1992; Phillips & Jorgensen, 1992). Genealogy involves uncovering the changing terminology used and how this leads on to Foucault’s analysis of power and power relations.

Influences on the construction of our attitudes, behaviour, and understanding are located in discursive practices that lie within larger historical and theoretical discourses which were originally imposed to maintain power (Grbich, 1999). In his genealogical work, Foucault developed a theory of power/knowledge believing that the genealogy will uncover discursive practices which have resulted in the current power practices. In common with discourse, power does not belong to particular agents such as individuals or the state or groups with particular interests; instead, it is spread across different social practices. Power is not something to be understood as being exclusively constricting but as a productive entity constituting discourse, knowledge, bodies and subjectivities (Phillips & Jorgensen, 2002). Parker (1992) stresses the importance of distinguishing between discourses and power. Discourses do not deliberately use power as a means of control; however, they often reproduce power relations.

### *Power and Power/Knowledge*

What makes power hold good, what makes it accepted, is simply the fact that it does not only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression.

(Foucault, 1980, p. 119)

Foucault maintained that there is no such thing as power as a whole. Powers (2001) states, “power consists of a continually shifting web or grid of individual positions of tensions between power and resistance” (p.15). The idea of discourse was used to explore and analyse the dynamics in the relationship between power and knowledge. The perspective that Foucault took regarding this relationship was his belief that there is an unremitting and unstoppable expansion of power favouring the administrators, managers, and technocrats in what he called a disciplinary society (Said, 1987).

We should admit...that power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); 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, 1997, p. 27)

I understand Foucault to be stating here that knowledge is used to construct discourses that legitimise power and that power is always bound up with knowledge and that power and knowledge presuppose each other. Power is what creates our social world and is responsible for the particular ways in which the world is formed and can be talked about. Power determines who can speak and can rule out alternative ways of being and talking (Phillips & Jorgensen, 2002). For example Cheek (2000) refers to the power relationship of nursing; how it is positioned with respect to a dominant medical discourse. How nurses and nursing are portrayed, both by themselves and by others, is to a large extent the result of power and practices that operate to position nursing in one way as opposed to another. Medicine dominates over nursing because society values the scientific knowledge of body processes over the ability to care. As a result of this the medical discourse has more authority than nursing and is more highly valued.

Powers (2001) describes Foucault's notion of power "as a network of interacting forces that are goal-driven, relational, and self-organised. Power creates tensions between, within, and among individuals or groups" (p. 14). This does not mean that it is a conscious strategy used by people and operates as a process in continuous struggles and confrontations; power versus resistance. Foucault's work acknowledged that the human capacity for resistance to domination and the capacity for self-creation was possible but even then social and political limitations restrict the exercise of those capacities (Popkewitz & Brennan, 1998).

Foucault states that: "Discourse is not simply that which translates struggles or systems of domination, but is the thing for which and by which there is struggle, discourse is the power which is to be seized" (Rabinow, 1984, p. 110). He did not see power as a negative force or the oppression of one group over another; instead he stressed the production aspects of power:

We must cease once and for all to describe the effects of power in negative terms: it ‘excludes’, it ‘represses’, it ‘censors’, it ‘abstracts’, it ‘masks’, it ‘conceals’. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth.

(Foucault, 1977, p. 194)

This quote makes it clear that Foucault saw power as a productive concept, as the operation of webs of power that enable certain knowledge to be produced and known (Cheek, 2000). He wanted to consider the effects of power, not in terms of simply controlling but in terms of shaping and constructing what we do and understand. Foucault offers a way of understanding power and its effects and I introduce his notion of technologies of power next.

### *Technologies of power*

In his writings *Discipline and Punish* (1977), Foucault explained his belief that in the 20<sup>th</sup> century power/knowledge worked through discourse as opposed to “sovereign” power whose authority had been exercised mainly through a threat of violence. He called this power/knowledge “disciplinary power” which occurs when power is exercised through a number of techniques such as surveillance and normalisation.

#### *Surveillance.*

Disciplinary power involves the process of inspection and scrutiny that is used mostly to modify behaviour (Foucault, 1977). The emergence of the “clinic”, Foucault believed, was a result of a disease-based model of care and he asserted that the clinic was the institutionalisation of the medical gaze: “a hearing gaze and a speaking gaze: clinical experience represents a moment of balance between speech and spectacle” (Foucault, 1975, p. 15). In *Discipline and Punish* (1977), Foucault used the concept of the panoptic gaze to describe the surveillance of individuals and populations by the gaze of the “experts”. The panoptic gaze was a mechanism of power that was used to monitor and control behaviour in prisons and was based on the concept of a circular prison by architect Jeremy Bentham. It consisted of a single tower surrounded by a ring-shaped building composed of cells for the prisoners. The prisoners could be constantly viewed by the guards and other prisoners and this real or implied surveillance led to self-regulating behaviour, thus removing the need for force. Cheek

(2000) describes contemporary health care as an example of the panoptic gaze where health professionals examine the patient. From this scrutiny emerges the goal of public health to control the expectation of treatment that the population can expect to receive. Foucault suggests that a consequence of such scrutiny is the development of docile bodies complicit in their own scrutiny and policy and the process of normalisation can help to achieve this.

### *Normalisation.*

Foucault (1977) described the process of normalisation as occurring when objects or behaviours are judged as either normal or abnormal. By defining what is considered normal, people become subjected to a system of regulation that disciplines behaviour. For example, Zimmerman's (2004) study on death and denial revealed that individuals are expected to conform to accepted norms of denial when facing impending death. To not "fit" in with these norms puts the individual in a category of unhealthy denial that the health professionals consider unacceptable and abnormal behaviour. The health professional then attempts to bring the patient's way of thinking around to what is considered acceptable. Foucault claimed here that surveillance and normalisation techniques combine to produce discipline which is used to promote self-regulation and obedient behaviour.

Current health practice generally aims to prevent illness and to restore health; i.e. it aims for health promotion and disease prevention. The dying individual, I believe, falls outside this norm and the medical *gaze* scrutinises the patient differently to one that can be restored to health. The term *gaze* as described earlier refers to the way in which disease, illness and health care are thought about and viewed (Cheek, 2000). For example, the patient is made the object of the health professional's gaze and the body is scrutinised within the medical specifications and discursive frame. The knowledge that the medical discourse possesses gives it the authority to instruct the tests, interventions, or any procedures the health professionals deem necessary. In effect the patient has lost the control over their body and the dominant discourse assumes power because of the knowledge it possesses (Parker, 1992). This powerlessness that patients feel when in the grip of medical technology is an example of the intimate link between power and knowledge.

### *Resistance.*

Powers (2001) states, “Power and resistance both constitute and are constituted by each other” (p. 17). Resistance works against power, and both power and resistance can be found in all points of the web of power relations. Power cannot exist without resistance because if there were no resistance there would be no power to be exercised. As a response to power being exercised, resistance results in an attempt to disrupt the flow of the power or contest it. On a subjective level, an individual may challenge the power regime that dictates he/she should conform in a particular way. Discourse produces a truth, and Foucault discussed truth and subjectivity as a means of helping distinguish what is right and what is wrong.

### *Discourse and Truth*

Foucault (1980) described truth as a means to persuade or influence regular effects of power, where society has its regime of truth supporting the type of discourse which it accepts and makes function as true. Foucault saw truth as a system of ordered procedures for the production, regulation, transmission, circulation and transaction of statements to determine what is true or false. He saw it linked in a circular relation with systems and effects of power and knowledge, a discursive construct which he called a “regime” of truth (Phillips & Jorgensen, 2002; Rabinow, 1984).

In another way, we are also subjected to truth in the sense in which it is truth that makes the laws, that produces the true discourse which, at least partially, decides, transmits and extends upon the effects of power. In the end we are judged, condemned, classified, determined in our undertakings, destined to a certain mode of living or dying, as a function of the true discourses which are the bearers of the special effects of power.

(Foucault, 1980, p. 94)

Knowledge of human beings, and people constructing what is true are the determining factors that help define people, and in turn have a major effect on society. If it is possible to get enough people to believe in a “truth” that has been decided by a discourse, then that may be accepted as more important than some unknowable truth and involves the power to create beliefs for people to accept a dominant discourses ideas (Fillingham, 1993). The people who decide, in the first place, what knowledge is, are in a position to claim to be the most knowledgeable and to know more about

other individuals than those individuals know about themselves. Foucault used this approach to question and show the connections between discourse, truth, power and knowledge. He believed that rather than “truth” being discovered or arrived at through reasoning and analysis, we as people create or construct truth (Barker, 1998).

### *Discourse and Subjectivity*

Foucault was concerned with the effect that discourses have on the production of the modes of our subjectivity and our experiences of ourselves as a subject. He proposed that subjects are created in discourse and argued that “discourse is not the majestically unfolding manifestation of a thinking, knowing, speaking subject” (Foucault, 1972, p. 55). The idea of subjectivity, offers ways of thinking about, talking about and perceiving ourselves, and ways of understanding ourselves in relation to our society. As the subject, we position ourselves within a discourse, or others may position us. For example, within the euthanasia debate, the dying patient becomes the subject for scrutiny in the sanctity-of-life and right-to-die discourses and the individual self becomes a medium for the culture and language of that particular discourse (Phillips & Jorgensen, 2002). Foucault refers to one’s existence in the world as a material object, which alone offers the possibility of putting into discourse, knowledge about one’s material existence (Barker, 1998). The possibility of fabricating any specific knowledge, even and especially in terms of what its subjects and objects might be, is already located within specific practices operating in the culture in which we find ourselves.

### *Summary*

The philosophical underpinnings of this thesis are situated in the postmodern paradigm. This chapter discussed the concept of discourse and how discourse analysis can be applied to uncover the influence of knowledge/power by uncovering the ways of thinking and talking that affect our everyday social practices, and things that we take for granted. An historical genealogy shows a linking of past practices to present ones, and I have introduced the concepts of power, power/knowledge, technologies of power, truth and subjectivity and how they relate to discourse. Foucault offers us a way of understanding power and knowledge and its effects on society, suggesting that our knowledge and understanding of the world should not be treated as the objective

truth. The next chapter will look at discourse analysis as a method, describing the steps involved in the research.

## CHAPTER THREE

### *Research method and methodology*

#### *Introduction*

The main goal of social research is to uncover, understand and communicate the “truth” of situations. Qualitative research makes this possible by enabling the researcher to be creative and interpretive with their analysis (Gubrium & Holstein, 2001). With discourse analysis, the goal is to provide interpretive claims based on a description of power relations in the context of historically specific situations. The method selected is based on the anti-foundational perspective of critical theory and Foucault’s postmodernist power perspective (Powers, 2001). The method adopted by individual researchers may differ but what do not change are Foucault’s concepts of discourse/ power / knowledge or the lens through which data is read (Wetherell, Taylor & Yates, 2001). With discourse analysis it is asserted that there is no “truth” or reality, what exists are multiple truths in any situation. This approach claims that objectivity is impossible, and measurable reality can only exist at the simple, short-term level. Discourse analysis enables us to obtain a better understanding of ourselves, our behaviours, attitudes and belief systems. It reveals how over time discourses shape and influence the position from which we view reality (Cheek, 2000). It provides a lens for us to examine the current discourses that circulate in the euthanasia debate, and it allows us to examine the knowledge that is considered to be legitimate in current western society regarding issues surrounding the right to die.

This chapter looks at the methodological process of data selection, data analysis, and the notions of crystallisation, reflexivity and trustworthiness.

#### *Data selection*

I have been guided in this discourse analysis by the work of Penny Powers in *The Methodology of Discourse Analysis* (2001). I have also referred to Parker (1992), and his seven criteria for distinguishing discourses. Discourse analysis differs from other methods because of how the research is located philosophically, with the emphasis being on the theoretical underpinnings. While it does sort out one discourse from

another, it does not use a sorting process which is common to other methodologies (Parker, 1992). The method used here searches for patterns in language use and seeks to identify connections between language and other elements in social life. This methodology suggests that language helps create reality and that there is no single social truth to be discovered (Wetherell, Taylor & Yates, 2001). What I have aimed to do is to confine my analysis to the discourses that are constructed rather than the people who produced the talk or documents.

It is important to specify which texts will be studied and the criteria for selection, particularly when there is a vast amount of material available as secondary texts. A discursive analysis of texts should be critical and reflexive aiming to situate the texts in their social, cultural, political, and historical framework (Cheek, 2000). Interrogation concentrates on uncovering the unspoken and unstated assumptions implicit within them. Powers (1996) describes discourse analysis as the careful reading of text and commentary, and the interpretation of “patterns, rules, assumptions, contradictions...and inconsistencies” (p. 212).

The texts were selected from the various New Zealand sources that are representative of both sides of the euthanasia debate, Nov 2002 – Dec 2004 inclusive. 2003 was a significant year because euthanasia gained a very high profile within the public arena in New Zealand due to the introduction of a parliamentary bill on euthanasia and a high profile court case. It revealed that there are those who support euthanasia and those who oppose it. I wanted to ensure that the data included both these positions. Because this is, in essence, an argument where there are strong views for and against vying for recognition, it was important to select texts that reflect this. There are two main perspectives that shape the euthanasia debate, and these are the argument for the legalisation of euthanasia and the argument for it to remain a criminal act.

One piece of data was the New Zealand Parliamentary Bill on euthanasia which was voted on in 2003. This 2003 government document was produced by politician Peter Brown as a Member’s Bill. The purpose of the bill was to allow persons who are terminally ill, and /or incurably ill, the opportunity to request assistance to end their lives. This is an important document to analyse because it was only two votes short of being passed and its recommendations would have impacted greatly on the health sector if it had been passed.

The second source of data was *To die like a dog* by Lesley Martin (2002). This book is written in a play format and recounts the final months of the author's mother's life. Her mother was terminally ill with bowel cancer and this book provides interesting data regarding institutionalisation, and the moral argument regarding autonomy, mercy and compassion. The book promotes the call for euthanasia and exposes inadequacies in palliative care and health services in providing care to the mother and family. Lesley Martin is a New Zealand Registered Nurse who was imprisoned after being found guilty of assisting her mother to die. She was charged only after the publication of this book which resulted in much public debate.

The third piece of data was *And now Euthanasia*, a magazine on euthanasia published in 2003 by Family Life International which works in conjunction with the Catholic Church. The publication puts forward multiple arguments from a Christian perspective and is specifically directed at convincing its readers to reject euthanasia in any form. It was released around the time the parliamentary bill on euthanasia was due to be discussed in Parliament. It is a New Zealand resource paper providing an overview of the euthanasia debate and was financed by Family Life's friends and families, and the Auckland branch of the Knights of the Southern Cross.

The fourth data source I analysed were the New Zealand Statutes and Law regarding suicide and assisted suicide. The Criminal Code Act of 1893 requires that all criminal offences have to be statutory. No one can be charged criminally in New Zealand for any act, default or omission unless it is declared a criminal offence by the Crimes Act of 1908, or some other statute. The law is based on the British legal dictates which many consider to be outdated. The debate on euthanasia has a strong legal discourse and that makes the New Zealand laws surrounding suicide and assisted suicide worthy of analysis.

The fifth body of data I analysed were relevant material from New Zealand nursing journals, The New Zealand Nurses Association Code of Ethics, and media articles including the *New Zealand Herald* newspaper, *The Sunday Star Times*, *The Evening Post* and *The Listener*. Throughout February 2002 – December 2004 there was a large media response to the euthanasia debate; Lesley Martin's trial and the Death with Dignity Bill are all discussed in these articles. The media lens exposes both sides of the debate promoting their "truths" to the public. A search of Nursing praxis and New Zealand Nursing Organisation revealed little information regarding euthanasia. An article that was published in *Kai Tiaki*, in 2004 by Joy Bickley Asher

“The practice of euthanasia: More than a debate” has particular relevance to the nursing profession today.

The material selected is useful for the purpose of this study because it allows me to capture the widest possible variation in accounts regarding euthanasia. The inclusion of the New Zealand Herald, Sunday Star Times, and The Listener aimed to reduce bias because they address topical issues and present a variety of perspectives, unlike Lesley Martins book. In this thesis, it is the written word that is under scrutiny from the texts under analysis. The differences in the language used by these discourses are clearly shown in the material selected for analysis. Discourses can be powerful because they specify what is, and what is not. These knowledges or “truths” tell us what is “normal” and “natural”, establishing the boundaries of what is appropriate and acceptable and what phenomena are brought into our awareness. The selection of data was refined after reading vast volumes of material. The data were selected because they were current and appeared to give a good representation of both the pro-euthanasia and the anti-euthanasia debate within a New Zealand context.

### *Data analysis*

This analysis used a genealogy to document the historical conditions that revealed the existence of the discourses of this thesis. The socially constructed systems of power/knowledge are described in a structural analysis and the effects of the discourse within the web of social power relations are analysed under power relations. While I have chosen to present the historical analysis as a separate section, it is important to acknowledge that genealogy, and the structural and power analysis are often combined and are all closely related to each other (Powers, 2001).

### *Genealogy*

Genealogy emphasises the historical components of the discourse, and traces the development of a discourse. In doing so, it seeks the conditions that made possible the discursive practises of a specific discourse and this becomes the basis for identifying current power relations. Language can provide a wide range of ways of talking about or constructing an object and discourse analysis claims that people do so based on a repertoire of terms provided by history (Wetherell, Taylor & Yates, 2001). I have used Foucault’s concept of genealogy as a lens through which to read the history of euthanasia.

A dominant discourse results in the process of normalisation as discussed in chapter two. This is where the majority of society will assume the information given is the truth and an accurate description of the world. Genealogy exposes the all enveloping nature of discourse as a fluid, shifting medium in which meaning is created and contested (Wetherell, Taylor & Yates, 2001). Analysis has included looking at the various definitions of euthanasia, how the definition has changed, whom it serves and how truth is perceived by the two competing discourses revealed. The aim of genealogy is to widen the view, from where I as researcher and the reader currently stand, to include a broad picture of the historical contribution to the development or practices of power and resistance within the euthanasia debate. My goal has not been to give a complete historical account of the development of euthanasia; rather, consistent with Foucault's genealogies, it selects certain periods during which important events have occurred that have assisted in our understanding of what euthanasia means today (Barker, 1998).

In genealogy I look at why words in the discourse have a linguistic and social history that is significant for assessing the role of the discourse within current power relations. An example of this is the word euthanasia itself. I show how the meaning of this word has changed over time. This is significant because of the confusion produced by the varied definitions and interpretations of euthanasia that exist and how they help to serve the competing discourses. I explore the processes that enable a discourse to claim the right to pronounce their view-point as the dominant "truth", which involves looking at whose interests are best served, and how this is being challenged today. Powers (2001) states "Genealogy, interprets the historical power influences on the emerging discourse" (p. 54). On the basis of the genealogical evidence presented, interpretive claims are made and supported by reference to evidence from the analysis. The genealogy shows the contribution to the development of the practices of power and resistance that occur in today's society and these are examined in the structural analysis.

### *Structural analysis*

Rawlinson (1987) states: "A functioning discourse may be conceptualised as the horizon of thought for a participant in that discourse. The identifying features of this horizon are the concepts, rules and authorities that determine the discourse" (p. 375). Foucault advised that in order to conduct discourse analysis, there are general issues

within the structure of a discourse that must be considered. These are the systems of differentiation or privileged access to the discourse and the types of objectives of one group over another. It also requires considering how power relations are brought into being and in doing so, revealing surveillance systems, threats, forms of institutionalisation and a degree of justification that is required to support power arrangements (Powers, 2001). The structural part of the analysis is elaborated on three axes: knowledge, authority and justification.

### *Knowledge.*

The axis of knowledge includes analysis of the system of concepts and rules for the formation of statements and includes the rules for determining what is considered true or false. This is called the closed system of truth within the discourse and includes the rules of evidence and rules concerning what can be addressed and what can't, and it involves looking for the processes which produce the assumed truths (Powers, 2001). Powers claims that a discourse has inherent non-random contradictions which are ordered by certain rules, whether these are stated or unstated.

There is no unalterable structure to the four components of a discourse: the subjects, the objects, the styles of statements and the theoretical strategies. What is important about the structure of a discourse is the regularity or the rules that govern these four components. Here I investigate what the discourse does to the resulting subject and what order governs the multiplicity and diversity of the subjects, objects, styles of statements and theoretical strategies of the discourse.

### *Objects.*

Discourses are practices which form the objects of a discourse (Foucault, 1972). These can be described as layers of objectification. The first layer is the layer of "reality" that the discourse refers to. Discourses are the sets of meanings which constitute objects, and a discourse represents a practice. They construct representations of the world as a reality and data analysis will cause objects to be identified within the discourse (Parker, 1992).

The second layer of objectification that a discourse refers to is that of the discourse itself. A discourse is about objects and a discourse analysis is about discourses as objects. This involves describing the objects and talking about the talk as if it were an object, a discourse.

### Subjects.

The people talked about in the discourse become the subjects. The discursive practices of a discourse produce the subjects from the objects. The subjects of the discourse arise within the “space” or on the “surface of emergence” that was appropriated, named and made visible by the original discursive practices (Powers, 2001). An example given by Parker (1992) is the discourse of nursing which arose on the surface of emergence from medicine and science.

The object that a discourse refers to may have an independent reality outside discourse, but is given another reality by discourse. An example of such an object is the subject who speaks, writes, or reads the texts discourses inhabit. My own position is that I am situated outside the discourse, but using the notion of reflexivity I acknowledge I am also a subject as I am analysing the texts selected. Parker argues that it is important for the success of the analysis not to make assumptions and judgements about ourselves and others when analysing discourses.

### Coherent meaning.

The statements in a discourse can be grouped, and given a certain meaning to the extent that they refer to the same topic (Parker, 1992). The selected texts provide me with similar themes and statements for analysis which can be grouped together to provide me with a coherent set of meanings relating to euthanasia.

### *Power Relations.*

The power analysis looks at the system of power/knowledge. Foucault had a belief that religion played a significant role in power relations and his concept of *pastoral power* as described in Carrette (1999), is used to examine these relationships. Analysis aims to identify language processes and social processes that people use to constitute their subjective existences and to construct their understanding of social life, thereby either reproducing or challenging the distribution of power as it currently exists. Parker (1992) describes discourses as supporting institutions, reproducing power relations and having ideological effects. The analysis shows how social power is constructed, circulated and played out examining the power relations, and how domination is reproduced and maintained. Competing discourses are examined and analysis here explores sub-discourses of resistance, examining whose voices are being heard and whose are being left out. Controversy is not unusual with this form of

analysis because it involves the study of power and resistance, revealing the contesting and competing discourses struggle for power (Wetherell, Taylor & Yates, 2001).

#### *Authority.*

The axis of authority includes analysis of the rules for determining who has the right to speak in the discourse (Powers, 2001). It describes how the right to pronounce the truth is preserved, exercised and reproduced. This is Foucault's concept of power/knowledge, and I look at, who is allowed to speak and who is not. This includes looking at what speaking positions are available to people within the discourse and who isn't allowed to speak. It acknowledges that there are other discourses and examines their relationships to one another. The term authorities of delimitation can be applied here, since we look at another discourse that sets limits on the identification of subjects for the discourse in question. For example, an authority of delimitation for the discipline of nursing is medicine, because medicine is the authority that identifies cases for the discourse of nursing to consider.

#### *Justification.*

According to Powers (2001) the third axis is that of justification and the important structures for analysis here are the systems of regulation, organisation, normalisation and punishment, and the technologies of power. Discourse generalises its subjects, producing an ideal, a standard, the regular and the normal through its work. Discourse functions in a policy role to maintain the range of normal that it has described, by power and control. Here I look at how the technologies of power/knowledge are justified by the discourse, and what justification is provided for the disciplining of participants. I analyse here how the suppression of competing discourses is justified and what justification is provided by the discourse for its position as the pronouncer of the truth.

The structural analysis of the axes of knowledge, authority and justification can provide the answers to the questions raised here. When performing a discourse analysis there are processes that can be applied to ensure the researcher eliminates bias. One of these is the concept of crystallization.

## *Crystallisation*

Crystallisation provides a lens with which to view qualitative research and is particularly suited to postmodernism (Janesick, 2001). Crystallisation recognises the many facets of any given approach to society as a fact of life. Richardson (1997) sought to “problematize reliability, validity and truth” (cited in Denzin & Lincoln, 2001, p. 165). The way to achieve validity is by examining the properties of a crystal in a metamorphic sense:

I propose that the central imaginary for “validity” for post modern texts is not the triangle – a rigid, fixed, two-dimensional object. Rather the central imaginary is the crystal, which combines symmetry and substance with infinite variety of shapes, substances, transmutations, multidimensionality’s, and angles of approach. Crystals grow, change, alter, but are not amorphous. Crystals are prisms that reflect externalities and refract within themselves, creating different colours, patterns, arrays, casting off in different directions.

(Richardson in Denzin & Lincoln, 2001, p. 92)

Crystallisation therefore deconstructs the traditional idea of validity by implementing the concept that there is no single truth. Texts can validate themselves and this approach can provide us with a deeper, partial and complex understanding of euthanasia. The texts to be examined, can therefore like a crystal be turned in many ways, revealing multiple layers of meaning and these meanings can be refracted and reflected, helping to uncover hidden assumptions and perceived “truths”. Crystallisation recognises the many facets of any given approach to the social world as a fact of life. What we see when we hold a crystal depends on how we view it, from what angle we see it and whether we hold it up to the light or not. Discourses often overlap and interconnect, and while we can examine them in an historical context it is important to understand that they are not universal truths and are constantly and fluidly changing with time. There are discourses within discourses, and these often overlap and interrelate. Applying this concept will ensure that I am looking at the subject as if I am looking through a crystal; the many facets and fluidity of what I am viewing will help reveal the multiple truths and the ways in which these

are established within different discourses. Another popular concept with the postmodern approach that ensures the openness of the researcher is called reflexivity.

### *Reflexivity*

With discourse analysis, traditional research claims that the researcher should be neutral, and should not exert any bias on the process of data collection and analysis, become unrealistic. This neutrality is essential to one of the conventional criteria for evaluating research, replicability (Wetherell, Taylor & Yates, 2001). According to the criteria of replicability, a different researcher could repeat the research and obtain similar results. With discourse analysis most researchers would agree that neutrality is impossible because the researcher and the research cannot be meaningfully separated; in other words, the research is inevitably partial.

Reflexivity is the process of reflecting critically on the self as a researcher, consciously experiencing the self as inquirer and receiver of information. Reflexivity accepts that texts do not simply state and report an independent order of reality but are themselves a result of reality construction (Parker, 1992). The concept of reflexivity suggests that my position in this research is central and visible. I accept that the way I act on the world, my life experiences, and the way the world acts on me will influence the research, and this needs to be taken into account and utilised. During analysis it is important to remain self aware, taking time to step back and observe and question my own behaviour, in an attempt to understand how individual presence and actions might influence my findings. Self-awareness is incorporated into the writing up, and involves the assessing and qualifying claims as they are made rather than presenting them as statements of truth.

Reflexivity can be described as a means of exploring and clarifying the style of your own analysis (Potter & Wetherell, 1994). For me this means an acknowledgement that my own work is not immune from the social and psychological processes that I am studying. Writing is a process of discovery, discovery of the subject and the self and all knowledge is considered to be situated, contingent and partial. By using reflexivity as a process it should be possible to avoid illusions of reality and false ideologies. Reflexivity recognises that truth is unattainable because reality itself is not simplistic or unchanging. It is inevitable that reality will also be influenced and altered by the research process used to investigate and represent it (Wetherell, Taylor & Yates, 2001). Application of the postmodern techniques of

crystallisation and reflexivity will contribute to enhancing the trustworthiness of this research.

### *Trustworthiness*

Good discourse analytic research will conform to the broad requirements for other research methods, with adherence to the current standards of social meaning and logic which are required for any analysis to hold up to scrutiny by others (Powers, 2001). Rigour is the researcher's attempt to use as tight a research design as possible. In this study I prefer to use the term *trustworthiness* which postmodern researchers increasingly use to replace the quantitative implications and limitations which are associated with the term *rigour*. It is important to be honest, complete, consistent and systematic, using the currently accepted procedure for drawing inferences, making claims and for supporting interpretations.

As I am the researcher, I believe I am open-minded regarding euthanasia. I acknowledge that my opinion shifts depending on the persuasiveness of the material being analysed, but I believe my neutrality towards both discourses enables me to approach the data for analysis without undue bias. On a continuum I therefore consider myself to be positioned fairly centrally and this enhances the credibility of my work. While it would not be possible for another researcher to exactly replicate my work, it would be possible for them to uncover similar findings by following my method of research. There are methodological differences between this discourse analytic approach and other methods of discourse analysis, but it adheres to the current standards of social meaning and logic required for good research. I have applied the format for analysis diligently, with the aim of uncovering the power relations that are involved in the history and present functioning of the studied discourses.

Traditional realist academic research has conventionally used reliability, validity and replicability as the criteria for evaluating research. These criteria refer to a particular set of assumptions which belong to the positivist and post-positivist tradition and discourse analysis challenges these conventional criteria which are based on a stable social reality (Searle, 1999; Wetherell, Taylor & Yates, 2001). Instead there are three key aspects of language that the analytic framework used, and which I have focused on when reading and writing discourse analysis: contradiction, construction and practice. These three processes help show the intimate connections

between meaning, power and knowledge (Parker & The Bolton Discourse Network, 1999).

Contradiction relates to looking at what different meanings are at work in the text. Instead of trying to uncover an underlying theme, which will explain the real meaning of the text, analysis involves looking for the contradictions and different perceptions of reality between the discourses. The process of construction requires analysis of how the meanings of statements are constructed. It is important here to take nothing for granted and trace how texts have been socially constructed so that they make sense to the reader. The third process involves analysing what the contradictory systems of meaning are doing. This involves looking at the issues of power and observing where people push at the limits of what is socially constructed and actively endeavour to construct something different. These three criteria are incorporated into the structural analysis and power relations to ensure a critical analysis of the texts.

This approach of acknowledging my involvement should avoid the potential for concealment; it also abandons the claim to be discovering “truth”, and accepts that there are multiple truths. The reader should find this study useful for beginning to understand the complexities associated with the euthanasia debate, and while it offers no answers, it provides the reader with an awareness that there are multiple layers of truths relating to the concept of euthanasia and this understanding should be of use to the reader particularly in the health sector, and when caring for the dying individual.

### *Limitations*

Limitations to discourse analysis are well documented and arise from the methodology on which it is based (Cheek, 2000; Parker & The Bolton Network, 1999; Phillips & Jorgensen, 2002; Powers 2001; Wetherell, Taylor & Yates, 2001).

Discourse analysis reveals to the researcher multiple perspectives, and this multiplicity can be a strength of discourse analysis, but also a failing. Cheek (2000) states that limitations arise if the approach used “is poorly defined or not contextualised in terms of its theoretical origins” (p. 55). Cheek stresses how important it is that discourse analysis does not remain at the micro-level of analysis but ensures the social and political realities of the context are considered as well on the macro-level. This thesis shows my research findings and there is no claim made that my findings are the absolute truth. I have had no influence on the primary text but

accept that my selection choice could open me up for possible bias. I also accept that there are other, competing claims regarding the same discourse. In this study I have endeavoured to apply the general principles of trustworthiness in academic research, and have set out the particular criteria used for analysing and evaluating the data.

### *Summary*

Using the method of analysis adapted from Powers (2001) and Parker (1992), I have outlined my approach to the analysis of the selected texts. Influences on the discourses of euthanasia will be uncovered using this methodological approach, identifying the objects and subjects of the discourse and the influences of other discourses that may dominate or compete with the discourse under scrutiny. I have introduced the postmodern concept of crystallisation that recognises my research as unique. Like a crystal there are many facets to, and ways of looking at, the subject of euthanasia. The notion of reflexivity has been introduced as a technique for ensuring the trustworthiness of the research.

Data selection was guided by the goal of exposing both sides of the euthanasia debate. Thoroughly familiarising myself with the data for analysis enables me to identify themes, categories and objects of the discourse as well as the discursive strategies and techniques that are employed. Examples of data analysed and findings will be presented and summarised in the analysis chapter, showing how social power is constructed, circulated and played out. The next chapter provides a genealogical analysis, selecting and tracing certain events in history that have affected or altered the public face of euthanasia.

## CHAPTER FOUR

### *Genealogy*

#### *Introduction*

Genealogy...records the singularity of events outside of any monotonous finality. It does not oppose itself to history as the lofty and profound gaze of the philosopher might compare to the mole like perspective of the scholar, on the contrary, it rejects the metahistorical deployment of ideal significations and indefinite teleology's. It opposes itself to the search for "origins".....Genealogy...seeks to establish the various systems of subjection: not the anticipatory power of meaning, but the hazardous play of dominations.

(Foucault cited in Rabinow, 1984, p. 76)

An historical overview of the development of euthanasia is provided in this chapter. The subject area is complex and this genealogical analysis will reveal some of the events which have occurred through history that I believe have affected this development. For this reason I have outlined key events that I believe reflect the constantly changing face of euthanasia and this fits in with Foucault's notion of historical disruptions (Powers, 2001). Foucault's concept of an historical analysis is in contrast to more traditional historical accounts because, rather than giving a chronological historical progression through time, Foucault selected topics deliberately out of order (Marshall, 1996). The selected events and time periods will help uncover the discursive practices which have assisted in creating the current value society puts on life and death. My aim is to conduct the genealogy to show various processes which have contributed to Western societies' current perception and acceptance of what the term means.

Historically the term euthanasia is traced briefly from early primitive times. Following this I look at the Greek and Roman era and their attitudes towards euthanasia. This is followed by the effect Hitler had on the meaning of the word euthanasia through to the 1950s and the radical transformation of the health sector by

modern technological advances. There was a changing perception of death around this time and I show how such changes have influenced the euthanasia debate today.

Next I examine how the definition of euthanasia has changed over time and reveal how we have come to understand what the term means today. While the leaps from one period to the next may seem large, I have chosen each of the eras discussed because during these periods a change in thinking occurs relating to the concept of dying. Each of these changes, I believe, has affected the discursive practices relating to death and dying.

### *Historical influences*

A genealogy aims to reveal the difference in a phenomenon in such a way that it weakens the self-certainty of the present without presenting the past as an alternative (Dreyfus & Rabinow, 1987). Following this, the ability to end our own lives has been around since man first inhabited earth, and the act has not always held the negative connotations that are often conveyed by society today (Richardson, 2000). In some cultures it was used as a way to ensure the continuation of a tribe in times of hardship. According to Richardson (2000) the discovery that certain berries had lethal effects was used as a means of humane euthanasia for people who were very ill or badly injured. The use of such medicine was seen as a natural art, a solution to ease a persons suffering. However, even in those societies that have tolerated suicide, for example, attempts were made to confine it within fixed categories, for example, pain relief. In these early times, mercy and compassion were terms that described the actions of these people, euthanasia was not a way of removing the weak and dependent (Richardson, 2000; van Zyl, 2000). Instead when there was no treatment to help the ill or injured, these methods were available to alleviate suffering. So while euthanasia and suicide were not actively condoned by these societies they were not completely forbidden either. With the limited medical knowledge of these times, a short life expectancy and a simplistic approach to life and death, life and death choices were on the whole reasonably uncomplicated, and death and dying were seen as a natural process.

#### *Ancient Greeks and Romans.*

Translated literally, “euthanasia” means a “good death” and comes from the Greek language: “eu” meaning “easy”, “happy” or “good” and “thanatos” meaning “death”

(Birnie, 1998; Johnstone, 1994; Keown, 2002). “Eu thanatos” in ancient Greek and Roman times was commonly used to describe the nature of the dying process a person undergoes. For example, a gentle or easy death as opposed to a violent or tortuous death. However it is important to note that the original sense of the word did not include an act of killing as a means to achieve this “good death” as it appears to today. Euthanasia was not used to imply either a means or a method of causing or hastening death but was used in a broader and more metaphorical sense to describe the spiritual state of the dying person at their impending death (Sommerville, 2001).

With the philosophical sophistication and knowledge the Greeks brought to society, attitudes towards death and dying were different as well. The ancient Greeks appreciated all things that permitted them to lead a good and virtuous life. However, human life was not considered valuable in itself, and did not need to be preserved at all costs. In the same way that Socrates’ wisdom was based on an awareness of his own ignorance, the wise physician recognised the limits of his art (Palmer, 2000).

The early Hippocratic guidelines to aid in the practising of medicine are quite different to today’s Hippocratic Oath (van Zyl, 2000). In those times it was not seen as “the right thing to do” for a physician to treat a terminal case. In actual fact, the physician was seen as less worthy for behaving in this manner. Success as a physician was judged on the success of treatment, not the risks taken. It is an ethical and moral viewpoint that is quite at odds with our current ethics and approach to the Hippocratic Oath (Gawler, 1999). Gawler (1999) states that today in contrast by not treating a patient a physician would be found professionally negligent for exhibiting this kind of attitude towards caring for patients.

The physicians of these times played a relatively minor role in society because of the strong competition that came from exorcists, midwives, surgeons, gymnasts and other “experts” in health and disease at the time (Palmer, 2001). Many members of the public remained sceptical of scientific medicine and distrusted the motives and abilities of physicians. Some believe this was the main reason that most ancient physicians refused to treat terminally ill patients – a dead patient was the worst possible advertisement, providing clear evidence of the lack of efficacy of medicine. The argument against the use of medicine was that the disease was stronger than the medicine available as stated in an ancient medical text called *The Art VIII*:

For if a man demand from an art a power over what does not belong to the art, or from nature a power over what does not belong to nature, his ignorance is more allied to madness than to a lack of knowledge... Whenever therefore a man suffers from an ill which is too strong for the means at the disposal of medicine, he surely must not even expect that it can be overcome by medicine.

(cited in van Zyl, 2000, p. 1)

With regard to assisting someone to die Gawler (1999) provides a grid of reference that states physicians were placed into four main categories. The first were a minority of so called “unscrupulous doctors” who would kill a patient on a bribe from the patient’s enemy. They would also help a patient commit suicide. The second group would only assist in a suicide if they felt there was reasonable justification for the request regardless of the health of the patient. The third group felt suicide was permissible but was not part of a physician’s role and the last group believed there was no place in society for suicide. This rather abridged explanation by an early physician shows the difference in values and quality between physicians in those times and physicians of today, where there has since developed the desire to keep patients alive at all costs.

Today, we would like to think that the Hippocratic Oath avoids such a variation in quality of physician and that it helps explain where the need for strict ethical guidelines regarding life, death and treatment emerged from. In my opinion, what also appears to be lacking in the Greek and Roman situation which was present in earlier times was the concept of compassion and caring. Decisions made regarding treatment in the early Roman era appeared to be more dispassionate, clinical and self-serving, with the physician’s primary concern being to maintain his reputation (Palmer, 2001).

One of the charges brought against the early Hippocratic physicians was that cures were a matter of luck and the majority of critics at this time believed that disease was caused by the Gods, and could therefore only be cured by them (Palmer, 2000; van Zyl, 2000). The Hippocratic physicians believed disease was caused by an imbalance in the natural constituents of the human body, which was usually corrected by nature, and the role of the physician was to assist this process. It is clear that a major shift in thinking has occurred between then and now. In those times, to

undertake a desperate case was a sign of incompetence; today *not* to intervene is a sign of incompetence and neglect, regardless of outcome.

Stoicism was an ancient Greek school of philosophy which developed after the collapse of the Alexandrian Empire, around 300 BC, and was built on the Cynic's idea of separation of oneself from worldly matters (*Oxford English Reference Dictionary*, 1996). Whereby the Cynics were characterised by a contempt for wealth and the pleasures of life the Stoics in contrast emphasised personal indifference to all things, and the Stoic philosophers attempted to practise the same indifference towards death as they did to life. This self-examination and taking stock of good or evil performed in regard to one's duties saw life as a progression towards perfection and the mastery and dominance of one's passions (Carrette, 1999). The Stoics were credited with making suicide not just acceptable but esteemed during this time. They saw it as a reasonable exercise of human freedom.

One of the classic cases was that of the Roman writer Seneca, who in AD 65 was accused of involvement in a conspiracy to overthrow Nero the emperor. Having been condemned to death, Seneca, had a dinner with his wife and, in the company of friends, cut his veins, then discussed philosophy and gave dictation to his secretaries, before finally drinking poison in a re-enactment of the death of Socrates (Clarke, 1999). In the light of our way of thinking about the value of life this lack of concern for life is an alien concept to us. When analysing Seneca's actions we find that the theme – which also emerges elsewhere, is the desire to control death and to face it nobly or with dignity. Seneca maintained control of his life by controlling the way and timing of his dying.

One of the main arguments relating to euthanasia today is the demand for the right to choose how and when an individual dies as well as lives: the concept of autonomy. The difference between today's society and that of the Greeks and Romans is that there is not an indifference towards life and death; instead there is a desire to live. In today's society we fear death and, increasingly, when death is inevitable there is a desire to choose one's method of dying. The fear of death can be located within the emergence of Christianity and its discursive practices (Carrette, 1999). "Dying well" became as important as "living well", and Stoics considered suicide acceptable in service to others (altruism), to avoid being forced to commit some evil, or to avoid impoverishment, chronic physical illness or mental confinement (Palmer, 2000).

However it should be borne in mind that the Stoics were only one group within Greek and Roman society and it would be incorrect to say that suicide was generally approved of; there were many Greek and Roman writers who were opposed to the idea of suicide (Downey, 1995). For example Aristotle in the *Ethics* condemned suicide as being an act of cowardice and an offence against the state. According to Downey (1995) Plato also condemned suicide in general and deemed that people who had committed the act should be buried alone in an unmarked tomb, a practice later adopted by Christianity. Suicide victims were refused a church blessing or burial in consecrated ground, and were condemned for ever in the eyes of the church.

#### *Influence of the Church.*

Throughout the Middle Ages a priest was usually present at the bedside of a dying person and it was deemed more important to guarantee a place in heaven than to prolong life. At this time there were books that provided descriptions on the art of dying, providing directives on how to die a good death. One of these directives was that the dying person had to accept suffering as God's rightful punishment for one's sins, and it stated if one accepted suffering, God's forgiveness could be obtained (Carrette, 1999).

The Catholic Church was all-powerful during these times, and the understanding of life and death was still based on superstitious, spiritual and religious thinking. It was the Christian sanction that resulted in all laws regarding life and death, living and dying being worded to include respect for the principle of the "sanctity-of-life". The word of the Church was effectively the law, and going against the Church's demands or wishes was beyond most people's comprehension. The power of the church, both covert and overt, ensured that its doctrines were enforced at all levels of society. Foucault (cited in Carrette, 1999) claimed that Christianity introduced a code of ethics fundamentally different from that of the ancient world, and it is the only religion that has organised itself as a church. Its emphasis has been that by an individual's religious quality which enables him or her to serve others: not as nurses, doctors, lawyers, educationalists etc, but as pastors. This is an important form of power because its ultimate aim is to ensure individual salvation in the next world. It is also a form of power that looks after not just the individual, but the whole community during their lifetime and demands total obedience to all Christian virtues. This form of power requires a special type of knowledge: knowing what is inside

people's minds and souls and understanding of the individual conscience. It can be described as a salvation-orientated form of power, as opposed to a political power (Carrette, 1999). It is an all-encompassing and widespread form of power which is linked to the production of truth, the truth of the individual. To support euthanasia would be to go against this power and to become a "sinner" in the eyes of the Church.

The religious sanction viewed any form of suicide as a rejection of God's gift of life and also of civilisation, since suicide was considered a failure to accept one's obligation to the state (Clarke, 1999). In effect, state policies were controlled by the Church and as a consequence all laws reflected the Church's influence. Early Christian doctrine condemns suicide on several grounds. The first is that it violates the commandment "Thou shall not kill", as this applies to one's own life as much as to another's. This commandment survives today, within the Christian discourse, and is the foundational basis of the argument against euthanasia (Family Life International, 2003). I find it interesting that the commandment against killing has always exempted killing in the context of war, whether a "Holy" war or defending one's country. To kill in self-defence has also been generally accepted in the eyes of authority throughout the Christian era, as it is today.

All the Christian techniques of examination, confession, guidance and obedience had the aim of getting the individual to work at their own mortification in this world. The aim was not death, but a renunciation of this world and of oneself, a kind of everyday death (Carrette, 1999). Death was supposed to provide life in another world, and it was the pastor that could demand absolute obedience to religion. This obedience differed from that of the Greeks and the Romans with their magistrates and laws; it was a total autocratic power, since never would they have thought to demand of someone a total and unconditional obedience in relation to someone else.

The church dictated that suicide also precluded any opportunity for repentance and was therefore deemed to be a cowardly act. These views went on to become Church Law over the centuries, and suicide victims, as mentioned earlier, were not given funeral rites which was deemed the worst possible punishment possible. The dominance of the Church in Western civilisation influenced greatly the formation of the laws and legislation in most Western countries (Clarke, 1999). This can still be seen today in certain countries.

Ireland, being a predominantly Catholic country, has been slower to change its laws to modern-day demands. Until recently suicide itself was considered a crime in Ireland, and those who committed suicide were not buried in consecrated ground. Suicide was also taboo and not decriminalised until 1993 (Richardson, 2002). According to Richardson there have been no cases of euthanasia before the Irish courts where it is still a criminal offence to aid, abet, assist and counsel in suicide (this is not saying that they do not occur). The dominant religious discourse in Ireland has determined the legal stance taken towards the subject, and has been created out of the reality that the overwhelming majority of the Irish, including medical practitioners are of Catholic background.

While the Catholic Church is very strong regarding euthanasia, it does not stand alone and Judaism and other Christian denominations support the Catholic Church on this issue (Family Life International, 2003). The control and power Christianity held over society shifted over time, with the development of the physical sciences, in particular the scientific and medical discourses which resulted in a power shift around the seventeenth century. Increasingly people began to look to the technological advances which were changing society as a more likely saviour than the traditions of the Church (Carrette, 1999).

#### *A Challenge to Science.*

Foucault (1972) claimed that power relations in modern civilisation resulted from several developments which occurred around the seventeenth century. These were the Industrial Revolution, the rise of capitalist nations and, importantly in this debate, the development of the physical sciences. It was Foucault's belief that the resulting changes occurred so gradually that Western society absorbed and adjusted to them unknowingly. It was also his view that they have resulted in the modern assumptions regarding science, society and power (Powers, 2001)

Over time gradual shifts of thinking have occurred that have resulted in the dominant values, ideals and belief systems we have today (Foucault, 1972). Since Greek and Roman times the concept of medicine as an art has evolved into the idea of medicine as a science. The rise of the scientific discourse gradually replaced the role of religious belief, superstition and emotion. In caring for people, the scientific discourse instilled the belief that the ideal was to attain knowledge that was universal, objective and value free (Palmer, 2000). Where the Greek physician had mainly relied

on his powers of intuition to diagnose the source of discomfort, and to provide care and comfort, this changed with the development and introduction of scientific methods of diagnosis, intervention and treatment. It was possible to alter the disease process; quality of life was improved and death could be prevented in previously hopeless cases.

The gradual shift was from a “hope and pray” to live desire, to a “demand” to live expectation. Today the medical discourse has created the general belief that suffering because of a disease process is not necessary, and there is the expectation that something can always be done. What has emerged here is a changing attitude towards the concept of suffering which historically has always been present and a central feature of human life (Hillyard, & Dombink, 2001)

The tremendous growth in power of Western medicine resulted in a corresponding decrease of the Church’s control over its people. Increasingly, people became dependent upon strangers within institutional settings to attend to their most intimate of physical needs, and increasingly the individual was objectified by the medical lens (Rabinow, 1984). Previously the majority of dying individuals had spent their last days at home surrounded by family and friends; now institutions (hospitals) offered hope that these last days could be prolonged.

Medicine began to take on the role of social regulation traditionally performed by religion and law. Physicians decided what counted as disease and then prescribed and performed the appropriate treatment. Patients were perceived as objects and had no power under this clinical gaze, which was objective and scientific (Powers, 2001). The element of compassion had been removed from the area of illness and disease. Technology allowed for greater accuracy in diagnosis and success in treatment; conditions that were previously incurable could now be cured, and an ethical reversal of responsibility occurred. A physician could now be charged with negligence and incompetence for failing to treat. The general result of this was for the medical profession to preserve life at all costs (Palmer, 2000). Decisions were now made that did not always include the wishes of the patients or their families; they had no control in the decision-making process. Now decisions were based on the technology available to prolong life. The medical discourse saw death as failure, and where previously death had been seen as a natural conclusion to life it was now seen as something to avoid, using technology if possible (Landau, 1993).

It was this ability to prolong human life at all costs that has resulted in a gradual societal shift away from a preference for medical intervention and the delaying of death, towards an emphasis on quality of life. Questions began to be asked: for example, should human life be maintained for as long as possible, and when is withdrawal of life-sustaining treatment morally justifiable? (Hillyard & Dombrink, 2001; Palmer, 2000).

Hillyard and Dombrink (2001) state that society began to raise these questions regarding the medical dominance in decision making regarding life and death, from the 1950s onwards. The euthanasia movement began to evolve as a result, gaining momentum and questioning the authority of medical dominance. Dissatisfaction appeared to be centred around the tendency of the dominant discourse to focus on the elimination of disease, physical pain and disability while disregarding a patient's emotional and human experience of suffering. In the United States, states like Ohio and Iowa discussed proposals to legalise voluntary euthanasia in cases of incurable diseases or traumas as early as 1906 (Thomasma, Kimbrough-Kushner, Kimsma, & Ciesielski-Carlucci, 1998).

English-speaking societies in support of voluntary euthanasia date back to 1935, since some societies in the United States were founded in the 1930s. The debate about euthanasia arose in opposition to new technological possibilities, where medical technology became capable of mastering and sustaining the biological aspects of human life beyond the existence of human dignity and personal meaning.

Throughout history the overall position of the medical profession has remained one of opposition to euthanasia (Dworkin, Frey & Bok, 1998). Consistently this opposition has been on ethical grounds and euthanasia has been perceived as going against the Hippocratic Oath and the sanctity-of-life doctrine. One of the main questions in the 19<sup>th</sup> century debate was: are physicians allowed to facilitate a merciful death by means of active medical intervention? However, the moral issue which emerged was linked to over-zealous physicians who refused to admit defeat (Keown, 2002).

Increasingly, people were taking cases to court, demanding that patients with no hope be allowed to die. "No hope" meant a variety of situations, including tetraplegics requiring full ventilation after injury who were considered officially brain dead, babies born with severe deformities who would have died naturally without medical intervention and people who were having active intervention even when their

outlook was hopeless. Discrepancies between the development of life-prolonging technologies and methods of pain management were cited as the main causes for the appeals to legalise euthanasia (Palmer, 2000). It was also claimed that physicians had lost sight of one of their most important roles: to prepare the sick and dying to accept what had traditionally been a natural conclusion to life: death.

Around this time, the definition of “death” was changed, and this contributed to many questioning the dominance of the medical discourse and its right to exercise authority and control over their dying (Johnstone, 1994).

### *The changing definition of death.*

A development that assisted in bringing the right-to-die debate to the surface occurred in 1968, when the legal definition of “death” was changed. Until then, it had been based on cessation of heartbeat and circulation, but with the invention of ventilators, patients could be kept alive even with severe brain dysfunction (Hillyard & Dombink, 2001). Now brain death has come to be accepted in western countries as an alternative criterion of death. Brain death means the irreversible cessation of function of the cortex, the cerebral hemispheres or the cerebrum (Singer, 2001). The changing definition of death is an example of how the “truth” can be created by a dominant medical discourse. This change was presented and accepted as an improved scientific understanding of the nature of death and therefore was not seen as an ethical issue but as medical advancement. Another reason put forward for the change in definition sprang from a suggestion put forward by a professor from Harvard University, Henry Beecher, who was motivated by the need to make “good-quality” organs available for the then new procedure of organ transplantation. Prior to this time, successful organ transplantation had not been possible because waiting for the symptoms of the traditional definition of “death” meant that vital organs suffered a lack of oxygen before they could be removed for transplanting. This new definition of death enabled health professionals involved in this area of care access to viable body parts that would previously have been unavailable (Singer, 2001). The new definition of death has enabled major progress in the area of organ transplantation, but it also raises important ethical issues. The need to obtain viable organs has resulted in the concern that prisoners facing execution in countries such as China, are being encouraged to sign over their organs prior to execution. Foucault (1977) wrote extensively regarding the effect of technologies of power on prisoners and one of the

expressed fears that have emerged in recent times is the economic potential for harvesting organs by the method of involuntary euthanasia (Palmer, 2000).

Around the time the definition of death was changed people began to challenge the scientific and medical regime, demanding that their voices be heard. Whereas previously individual bodies had been objectified by the scientific lens, and people had submitted themselves to the power/knowledge of the medical professional without question, a gradual change now occurred. People were asserting their right to have treatment withheld and were asking such questions as, “Why, if I’m dying, can I not be allowed to choose to die, and why do you wish to delay this?” (Doyal, 2001; Hill, 2003; Johnstone, 1994).

Increasingly, people became more empowered and began to take back some control over their bodies (Palmer, 2000). The dominance of the medical discourse was questioned by groups within society. The right to autonomy emerged and the relative control that the physician had had previously was now reduced. Physicians were now required to obtain informed consent from patients in an attempt to rectify the power imbalance that previously had existed between physician and patient. The voice of the patients were being heard and it was acknowledged that they had a right to determine the type and extent of the care they received (Landau, 1993). This has resulted in the assertion that patients have the right to refuse treatment, the right to non-interference and the right to not be used as research subjects. The previously held belief that life should be saved at all costs had changed its focus (Loewy, 2001; McMahan, 2002; Ravenscroft, 2000). This raises some interesting issues that potentially affect health-care workers because decisions now have to be made regarding when and when not to intervene and provide treatment (Johnstone, 1996). People are now put into certain categories, such as age, which assist in determining whether they are eligible for treatment or not. There has been a shift in power relations as a result of this, but interestingly the medical discourse still retains the decision making power because, now in contrast to before, the individual is categorised to see if they are suitable candidates for treatment.

While the choices made by the medical discourse were rational and clinical decisions, they generally aimed to preserve life. With the individual’s right to make choices and determine their outcomes, comes the potential for an economic discourse to emerge. An institution may now determine that the extent of care administered to an individual is relative to the availability of funds. This raises the issue and the

possible development of a “duty-to-die” mentality in the elderly where they feel as if they have become an unnecessary burden (De Haan, 2002).

The term the “slippery-slope” emerged from the sanctity-of-life concern that the right to live could be challenged by the increasing call for autonomy placing the vulnerable at risk (De Hann, 2002). Today the right to autonomy has become one of the main arguments put forward by the right-to-die movement and has assisted in its gaining momentum within our society. The central focus is the issue of control similar to that the early Stoics were concerned with. A right to autonomy is closely related to the euthanasia debate, and the idea of controlling the end of our lives just as we have had control over the way we have lived our lives.

### *Slippery-slope.*

Just as the right-to-die discourse with its emphasis on autonomy emerged, conversely, in opposition, did the slippery-slope argument emerge which supports the sanctity-of- life principle. The slippery-slope shows a particular construction of human morality and is a discursive construct. The slippery-slope argument claims that by legalising euthanasia for one group, there will be a gradual acceptance by society that other groups will be eligible, whether they request it or not (Scott, 2003; Sommerville, 2001; Van der Maas, 1991). van Deldon (1999) states “Although the Netherlands is an extremely flat country, it appears to have slopes that can even be skied down, when it comes to euthanasia” (p.22). van Deldon claims there have been cases where; euthanasia has been used although palliative care was a viable option, there have been cases of non-voluntary euthanasia and worryingly there appears to be an under-reporting of euthanasia cases.

Throughout history there have been many occasions when the actions and behaviours of a dominant group have resulted in treatments of repressed or minority discourses that transgress the laws society provides to protect its citizens. The organ donor need is an example of the medical discourse creating a truth that society accepted without question. However, many believe that human nature in general tends to seize concepts and notions and attribute to them the power of absolute truths. We then feel compelled to act them out and impose them on others (Birnie, 1998). Examples of how a society can be coerced voluntarily to behave in ways completely lacking in compassion have been demonstrated periodically throughout history. Examples are Pol Pot’s regime of terror in Cambodia, the political and ethnic

cleansing in Europe, Saddam Hussein's control of Iraq and the Nazi Third Reich, which I will discuss next. The following gives an example of an historical slippery-slope scenario which occurred during the Second World War. I believe it has had an important impact on society's perception of what the term euthanasia means and the risks associated with it.

### *Hitler.*

Critics of euthanasia often invoke the name of Adolf Hitler and events in Nazi Germany in the 1930s and 1940s as an example of what might happen if euthanasia were legalised (Loewy, 2001). One of the reasons the term euthanasia now tends to be avoided in discussions about the right-to-die is because it is considered too emotively charged to be used in political discourses on this subject (Johnstone, 1996). This social positioning emerged partly because of the Nazi interpretation of the term during the Second World War. To be a member of the Nazi party, one had to be identified as a member of the Aryan nation and there was a hierarchical order in terms of which groups were strictly excluded, for example, Jews and the disabled. According to the Nazi Party, these groups threatened the purity of the Aryan nation and therefore fell outside the limits of the community as defined by the discourse. Anybody who challenged the Nazi dominance and defied the dictate was excluded by marginalisation or death (Scarborough & Tanenbaum, 1998).

Political motives for the euthanasia programme emerged because of the economic crisis Germany faced after the First World War. As a result of this crisis, and exacerbated by the Great Depression, there were many stateless people in Germany, who had no guaranteed rights. Scarborough and Tanenbaum (1998) state that Hitler decided Germany's economic-medical-social resource pie was not big enough for all. The decision was made that only the racially and eugenically fit would be allowed to share it, and this was the original rationale for eliminating Germany's "surplus" people. Also targeted for elimination by Hitler were the "flawed", who were considered initially by him to be: the mentally ill, the feeble minded, the severely disabled and the elderly.

Part of the campaign Hitler adopted was called "Euthanasia"; in this case, the word meant: assistance given to ease the death of a person who is sure to die (Parsons & Newell, 1996). In 1939 Hitler drew up a programme of euthanasia that initially targeted children up to the age of three who were mentally ill and deformed; later

older children were added. Selection by physicians was based purely on personal reports and brief medical histories. Those deemed to be “unworthy of life” were euthanised. The publication by Family Life International: *And Now Euthanasia* (2003) describes the methods used at first included giving sedation as medication, or the withholding of care. One method of withholding care was to leave buildings unheated so that the children eventually died of exposure. Starvation was also used as a means of execution; however, instead of the sudden withdrawal of food, rations were gradually reduced until the children finally wasted away. Very soon similar programmes for adults were conducted simultaneously and Hitler authorised the mass executions by use of gas of selected individuals, many in the chambers later used to kill Jews and Gypsies (Loewy, 2001).

A misconception about the Nazi euthanasia programme was that it was carried out against the wishes of the parents. According to Parsons and Newell (1996) analysis of survey material from the Nuremburg trials showed that most parents had agreed to it. The policy adopted to ensure compliance was to word the release form signed by the parents in a quite vague way, in order that their conscience should not bother them later.

At least 100,000 deaths resulted from this euthanasia campaign before Hitler was forced to end it due to widespread complaints from Church officials and ordinary Germans. Applying Foucault’s notion of power/knowledge, we see that the Nazi programme of euthanasia was either ignored or tolerated for some time before the euthanising of these minority groups ceased. This was not because the average citizen did not know about it, rather they chose not to acknowledge that it was happening until the activity intensified and could not be ignored (Family Life International, 2003). The involuntary euthanasia argument gains enormous credibility when referring to this regime of “truth” because, regardless of these people’s wishes, they were euthanised because they “served” no purpose for Nazi Germany (Parsons & Newell, 1996). Parsons and Newell (1996) describe the Nazi approach as being in accordance with the social Darwinist principles based on the notion that we should ensure that only the fittest survive. This idea of survival of the fittest, however, does not match societies’ legal, cultural, ethical and moral principles, particularly the sanctity-of-life principle.

The form of euthanasia practised in Nazi Germany is not the type of euthanasia that the-right-to die movement is requesting to be legalised today;

nonetheless the atrocities committed during the Second World War have tarnished the use of the word in current society. Opponents of euthanasia use this as an example to argue that it would be possible for authorities to conduct a campaign along similar lines and cite it as evidence of the reality of the slippery-slope (Johnstone, 1994). They believe that by legalising euthanasia, those who are vulnerable or powerless could be at risk

Many still feel that what we should learn from the crimes of the Nazi regime is the ease with which a group can be made to respond to something previously considered ethically and morally wrong as if it were acceptable. It is possible (not probable), then, that we may respond to certain situations that may be ethically and morally wrong believing that it is the right thing to do. We can then potentially be guilty of, or encouraged into venturing of our own free will into areas that not only endanger the lives of others but also demonstrate a complete lack of compassion (Batavia, 2001; Scott, 2003). Ultimately it is this real concern that convinces many of the groups who are opposed to the legalising of any kind of euthanasia that this will be a very dangerous path for humanity to willingly go down and that it counteracts the demand for autonomy.

### *Defining euthanasia*

Stedman's Medical Dictionary (1990) defines euthanasia as: "1). A quiet, painless death. 2). The intentional putting to death of a person with an incurable or painful disease" (p. 544). The definition of euthanasia is constantly changing and for this reason it is important in this analysis to show and analyse the different meanings. The literature frequently refers to euthanasia as meaning something different depending on whether the argument is for or against euthanasia (Johnstone, 1996). Generally, the act of defining or redefining something can be seen as a move of power, and in the case of euthanasia the shift in meaning has been a very subtle and gradual. The terms *suicide* and *euthanasia* are concepts with blurred boundaries, because it is often considered unclear whether a certain act counts as suicide or whether it is an instance of euthanasia (McMahan, 2002).

One of the causes of blurring or confusion occurs because in current Western society, euthanasia is often called "assisted-suicide" because an act of euthanasia always involves the assistance of another. Another reason is that there are grey areas relating to euthanasia and the law, particularly within institutions such as hospitals

(Johnstone, 1996). The principle of double effect occurs when a patient is given pain relief with the intent to alleviate pain, and as a consequence of this the patient dies because of respiratory centre depression. As long as the intent was to alleviate pain and not cause death then the medical practitioner is not legally accountable and this raises ethical questions regarding what is considered euthanasia and what is not for many (Downey, 1995). This will be discussed in detail in the next chapter. In the eyes of New Zealand law historically and currently, euthanasia is an act that assists someone to commit suicide and is therefore considered by law to be a crime against society.

Key concepts and definitions of euthanasia, physician-assisted suicide and physician-assisted dying also differ from country to country and this can create further confusion and misunderstanding between politicians, professionals and the general public. Careful attention needs to be paid to definitions because they are not neutral and it has been argued that they are not just innocent tools that allow us to describe reality (Smith, 2004). Definitions have the power to shape our perceptions of reality and what we believe to be true and therefore they constantly need reworking over time. The changing face of euthanasia and the interpretation of meaning by different individuals and groups of individuals is an example of Foucault's belief that "truths" are constantly shifting and changing throughout history and serve the dominant group's best interests, reproducing power relations. Foucault questioned not what is true, but how this truth is created (Popkewitz & Brennan, 1998). The key issue here is the historical formation of the authority of the discourse and how it came to have the right to pronounce the "truth" in the euthanasia debate.

It was not until the end of the nineteenth century with the publication of an essay on euthanasia by an English physician, Dr S.D. Williams that the term came to be used in the modern sense of the *act* of painlessly putting to death those suffering from a terminal condition (Palmer, 2000). In Palmer it was stated that Williams argued that it would be the greatest achievement for a physician to take care of the needs and desires of a dying human being by performing euthanasia. The essay was not well received by fellow physicians who remained largely influenced by the Hippocratic Oath. However, the "right to die" movement emerged around this time. *The Collin's English Dictionary and Thesaurus* (1994) describes euthanasia as "the act of killing someone painlessly, especially to relieve suffering from an incurable illness" (p. 340). An act of euthanasia is an act of killing or of letting someone die that

satisfies two conditions: first, that death benefits, or is good for the individual who dies and, second, that the agent must be motivated to do what is good for the individual and must intend to benefit the individual in bringing about his/her death (McMahan, 2002). While this change in the word's connotation was written in the essay produced by Williams, it is difficult to say when exactly euthanasia became an act and not a description of the dying process (Palmer, 2000). However, this subtle change fits in with Foucault's view that language helps shape our perception of reality and consequently how we react to our surrounding environment (Parker, 1992). In the euthanasia debate words, have been used effectively to blur and in some cases to obliterate the lines of what is considered acceptable and what is not (Smith, 2004).

When the concept of "mercy killing" was introduced in the United States in 1939 by pro-euthanasia groups, they used terms such as: killing, euthanising "born defectives" and the word euthanasia was used quite freely to promote a new "mercy death law" where they identified certain groups of people who should be "mercy killed" (Johnstone, 1996). The harsh choice of words worked against the proponents of "mercy killing" and the move was not successful as there was a lot of public resistance, mainly from religious groups, to the terminology usage. I suggest that euthanasia proponents have learned since that it is possible to influence public and social perception of reality by the careful use of terminology when discussing or promoting the push for euthanasia. Today societies promoting euthanasia use gentle words instead such as: compassion, a gentle landing, deliverance, choice and dignity to help promote their cause (Birnie, 1998). More often than not the term euthanasia is replaced by "the right-to-die". Where euthanasia was once referred to as mercy killing, only the strongest opponents of euthanasia use that term today and most pro-euthanasia groups today avoid using it at all.

To further complicate matters, bioethics literature distinguishes between voluntary and involuntary euthanasia, and active and passive euthanasia. Johnstone (1996) provides the following terms which are generally accepted to describe these actions. *Voluntary* euthanasia is where an individual personally chooses to end their life, to end suffering with or without the assistance of others and dies as a result of this autonomous and voluntary choice. An example of this would be an individual taking an overdose of pills at a time and place of their choosing. The term *involuntary* euthanasia refers to an intervention that ends a person's life without obtaining their informed consent. Under the Crimes Act (1961) of New Zealand law this comes under

the criminal offence of homicide/murder (sections 151, 157, 158, 164, 179 and 180). Euthanasia is said to be involuntary when an individual who is competent to give or withhold consent is killed or allowed to die either contrary to his/her expressed will or when consent has not been sought (van Deldon, 1999).

*Non-voluntary* euthanasia is when it is not possible for the individual who is killed or allowed to die either to give or to withhold consent. This encompasses all cases of euthanasia in which the individual killed or allowed to die is a foetus, an infant, a congenitally severely impaired human being, or a human being who has ceased to be competent to form autonomous preferences about life and death, and who has not previously expressed an opinion on the matter. An example of this form of euthanasia is the type performed in Nazi Germany during the Second World War and this was discussed in detail earlier in the chapter.

Importantly, the above descriptions show how differently the term can be interpreted and that there are key differences between these terms (Johnstone, 1994). For example, referring to an act of euthanasia, as these variations show, requires a narrowing down of the more specific meaning. Ethically there is a vast difference in the application of the terms *voluntary* and *non-voluntary*; it is often this lack of distinction, however, that makes people respond negatively to the term.

It is important to also classify euthanasia further to be even more precise as to the meaning intended: Blank (1995) provides a similar summary of the categories of euthanasia. These categories demonstrate the need to be very explicit when using the term. It is possible for different individuals to have completely different interpretations of the term without these clarifying terminologies. Foucault (cited in Powers, 2001) would call these a grid of specification because the term *euthanasia* has been categorised. The grid of specification allows for further analysis:

## Categories of euthanasia

	<b>Passive</b>	<b>Active</b>
	Omission of measure to prolong life	Direct inducement of death
<b>Voluntary</b>	<i>Passive Voluntary</i>	<i>Active Voluntary</i>
With patient's express and informed consent	Conscious and rational patient refuses life-prolonging treatment and request is granted.	Conscious and rational patient requests and is given lethal injection.
<b>Speculative</b>	<i>Passive Speculative</i>	<i>Active Speculative</i>
Without patient's express and informed consent (i.e. comatose patient, infant, mentally retarded person).	Cessation of life-prolonging treatment for comatose patient or patient otherwise unable to give informed consent.	Lethal injection administered to comatose patient or patient otherwise unable to give informed consent.
<b>Involuntary</b>	<i>Passive Involuntary</i>	<i>Active Involuntary</i>
Against patient's express consent.	Cessation of life-prolonging treatment to Conscious and rational patient against his or her will.	Lethal injections administered to conscious and rational patient against his or her will.

Source: Blank, 1995, p.163.

For an act to be called euthanasia death must be intended, not be the result of an accident, and must be intended by at least one person other than the patient (Keown, 1999). To be called euthanasia death-causing acts must be motivated by beneficence or other humanitarian considerations. Acts which are not motivated by

humanitarian considerations are not acts of euthanasia, but acts of murder (Wallace, 1996).

Emerging from this analysis of the definition of euthanasia are some key concepts. Any act that involves another party is considered to be euthanasia and is therefore against the current New Zealand law (Wallace & Johnson, 1995). What has been established here is that there are many factors that determine the act and type of euthanasia that is discussed or performed and these are important issues with regards to this debate. These different definitions can act to serve different discourses. In the fight against allowing legislation to permit euthanasia, supporters emphasise the likelihood that voluntary euthanasia will lead to non-voluntary euthanasia (slippery slope).

The emergent “right-to-die” movement argues that legislation, clear definitions and protocols will prevent this eventuating. The current dominant discourse against euthanasia is served by these definitions which reproduce existing power relations by the legal requirements within them. These definitions all make euthanasia a criminal act under the current New Zealand legal system and that remains a deterrent for a society which seeks to obey the law.

### *Summary*

This chapter has provided an historical overview of euthanasia and issues surrounding the right-to-die. This genealogy shows themes emerging, throughout history that influence the euthanasia debate. In the euthanasia debate the emergent discourse in support of euthanasia has gained in power and in its right to speak and be heard in recent years. I will call this the right-to-die discourse. It is the patient’s claim for autonomy which has resulted in this power shift and this directly challenges the sanctity-of-life discourse which is the main competing discourse.

The right to choose and the concept of autonomy are popular concepts in society in 2005, influenced by the advancements of modern technology and the ability to keep people alive longer. I suggest that the “right-to-die” movements have made their ideas appear attractive to the public, re-defining well understood concepts and ethical principles by subtly changing a perceived reality so that previously understood concepts no longer apply. Historically reflecting on recent developments, it would be fair to say that regardless of the current political and legal stance regarding this

debate, the overall public perception of euthanasia is in contrast to this previously dominant viewpoint and has changed dramatically since the early origins of the concept.

What has been shown by this genealogy is the emergence of the arguments for and against euthanasia. The right-to-die discourse upholds the individual's right to autonomy. The sanctity-of- life discourse on the other hand, stresses not just that life is to be preserved at all costs, but also that the slippery-slope is a reality that may occur. The dying patient emerges as the subject of the discourse and the discursive objects of death, life and pain are revealed for further scrutiny in the next chapter.

## CHAPTER FIVE: The sanctity-of-life discourse

### *Data Analysis*

#### *Introduction*

This chapter will analyse the selected documents that bring into play the sanctity-of-life discourse. A Foucauldian lens allows me to lay bare the sanctity-of-life discourse and its construction of life and death. Analysis examines how the sanctity-of-life discourse constructs the dying patient, and includes the discursive practice of palliative care and the nurse's role within this. The objects of this discourse that were the targets for knowledge generation and intervention were the beliefs of life over death, and the call for an increased understanding of pain and pain management when caring for the dying patient. My analysis does not include discussion of any form of euthanasia which does not have the patient's expressed and informed consent, i.e. involuntary euthanasia, euthanasia of incompetent people (unconscious patients or children under the age of eighteen years) or people with disabilities. The sanctity-of-life discourse asserts its authority with the support of a powerful legal discourse and the slippery-slope argument is used to justify its regime of "truth".

#### *Knowledge axis*

The sanctity-of-life message is clear: Life is precious. The right to claim this discourse positioning as the "truth" appears to arise from the appeal to the "sanctity of life" principle which states that it cannot be right to take a life just to bring avoidable suffering to an end (Johnstone, 1994; Oddie, 1998). The sanctity-of-life discourse is in effect a Judeo-Christian discourse and it is asserted that there is a God who ordains all. It is a closed system of truth claiming that matters of life and death fall into the realm of divine providence. Sanctity-of-life means that God is in control of the timing of an individual's death. The fundamental belief is that to kill a dying person would be to reject that person, and to go against Gods will. This discourse proposes that a

health professional's duty should be to help the terminally ill physically, spiritually and emotionally through the dying process, so that while life is not to be extended at all costs, actions do not include hastening death (Family Life International, 2003). Within this discourse it is claimed that hope and meaning remain in the midst of suffering (Birnie, 1998). Euthanasia in the sanctity-of-life discourse is likened to abortion; both are seen as outside the ability to know God's will. An article suggesting the concept of God's will is provided here by journalist Barbara Burstyn which discusses Lesley Martin's act of euthanising her mother, Joy Martin:

But what if Joy Martin's difficult dying had other values to her? What if it was an intimate part of her personal mystery, her journey and resolution, something primal and outside of her reasoning? And what if her killing removed her from the fullness of that journey?

In the absence of any of us truly knowing, should we allow Ms Martin's determinist philosophy to infiltrate our world? Is shortening the dying process, and imposing the standards of the healthy, the answer? Or is it our beliefs around human function and meaning that must change?

As unfashionable as it may seem, we rely on a sense of morality that cannot be reduced or changed to suit individual circumstances. When Lesley Martin murdered her mother she stole her humanity and condemned her to, indeed, die like a dog.

*(New Zealand Herald, November 8, 2002, p. A19)*

This view seems to me to affirm the claim that to bring about an individual's death prematurely and assist in their dying goes against the fundamental basis of the sanctity-of-life discourse. It is an act that is described here as "murder". Life is portrayed as something to be revered, and the process of dying is seen as having an ultimate purpose which cannot be achieved if it is cut short. This view re-introduces the Christian concept of suffering which was discussed in chapter four, and believes there is a greater purpose to suffering which will ultimately benefit the dying individual.

Foucault believed that our contemporary culture is born out of religious tradition and that the conditions of our knowledge are embedded in religious discourse (Carrette, 1999). He was fascinated by religious influences on thought and

practice, and my analysis of the sanctity-of-life discourse would support his beliefs regarding the function of religion which was also discussed in chapter four.

The sanctity-of-life discourse demonstrates the power of the religious discourse; in that it has been incorporated into the legislation, rules and social norms of our culture, thereby influencing our thoughts, beliefs and practices (Carrette, 1999). For example, according to Carrette medical ethics grew out of the unification of Christian and Hippocratic clauses, resting on the assumption that human life is invaluable from the moment of conception. The “sanctity-of -life” doctrine has been so insidiously incorporated into Western society that it had generally been assumed to be speaking the “truth”, until the right-to-die discourse emerged in the 20<sup>th</sup> Century as a competing way of thinking about death and dying. An example of the means in which this has been achieved is the incorporation of the teachings of the church into society. Like a web its threadlike strands are woven into and throughout society, institutions, politics and the legal system. In *And Now Euthanasia* (2003), a publication issued by Family Life International, the Fifth Commandment of “You shall not kill” (Exodus 20:13 & Deuteronomy 5:17) is used to enforce the sanctity-of-life principle:

If it be necessary to go against the current of what is sometimes being thought and said on all sides, then let us never grow weary of repeating it: all human life must be absolutely respected; in fact abortion and euthanasia are murder  
( *And Now Euthanasia*, 2003, p. 11)

The rationalisation given here is that human life is sacred because the Christian religious discourse believes it involves the creative action of God, and life therefore remains forever in a special relationship with them. Within this discourse, God and only God is considered to be the one with the power to give or take life and no one can under any circumstances claim for himself/herself the right to destroy an innocent human life. The Fifth Commandment also forbids direct and intentional killing. It is considered “gravely sinful”. The sanctity-of-life discourse has produced, as a result of this Commandment, a reality and “truth” regarding the sacredness of life. This “truth” has resulted in an acceptance of thoughts and behaviour by society, and this acceptance has been incorporated into institutions including our political and legal system.

Lynda Scott, a National MP for Kaikoura in 2003 states:

When human life is not held sacrosanct, we cross a line that could lead to some of the worst excesses we have seen in other parts of the world.

It is easy to find reasons to justify taking someone's life. But there are many ethical and moral reasons not to go down this dangerous road. Human life is precious and should remain so.

(*New Zealand Herald*, March 14, 2003, p. A17)

She asserts here that to take a life is a relatively easy decision to make, but it would devalue life to do so. Talking about the value of life requires analysis of how death and dying are portrayed within the sanctity-of-life discourse and this is discussed next.

### *Death and Dying*

Foucault's concept of discourse describes how society assigns different truth values to specific types of knowledge (Powers, 2001). Within this discourse, death and dying have historically been constructed as subjects to be feared. In medieval times, when Christianity became a dominant discourse, death became something to be feared with many stories relating to the horror of death and dying circulating, for example the Grim Reaper waiting for another soul (de Vries, 1999). With the reduced power and influence of the Christian word, this fear of death itself has changed more to a fear of "how" death will occur. Foucault saw religion as part of the mechanism for controlling the function of human life and it was these ideas that he developed into his understanding of religion as a political power and a "technology of self" which he termed *pastoral* power. He believed that the individual is inevitably caught within the wider political technologies of control (Carrette, 1999). With modern medicine and its technological advances the majority of the population know that they can expect to live longer than their predecessors and many no longer see death as the sacred destination for the journey of life. A basic purpose of medicine is to reduce mortality and increase longevity, its traditional function being to cure and heal, to make well (Palmer, 2000; Thomasma et al., 1998).

The change in society's attitude towards death is an example of Foucault's notion that discourses change over time, and it is possible to uncover the layers of

ways of thinking and how they have changed through analysis (Foucault, 1972). Today, while more people are realising that death is an integral part of our lives, many still repress, deny, shun and withdraw where possible from reminders of death (Spilka, Hood, Hunsberger & Gorsuch, 2003). Death and dying receive little public attention. Journalist Phillipa Stevenson writes:

We talk, write and read endlessly about the living. The dead are subjects of discussion much less and the bit in-between – the dying – barely gets a look in. Euthanasia campaigner Lesley Martin, convicted last month of attempting to kill her terminally ill mother, contributed one view on dying with her book, *To Die Like a Dog*. The title alone- also now of a play to be made into a television documentary- suggests we allow our loved ones to die terrible deaths. It harks too, to the idea that we are kinder to animals because we mercifully kill some with illness. I've known animals die naturally and brought abrupt ends to the lives of ailing pets. Those deaths were nothing like the emotional, draining and uplifting dying days of people I have known, including my fathers nearly a year ago.

(*New Zealand Herald*, May 25, 2004, p. A9)

As Stevenson suggests, death is not a subject that would be readily discussed at a dinner party, for example, and in fact often the dying refuse to acknowledge the inevitability of death. Often people's experience of death is directly related to when someone they are close to becomes ill, and they are suddenly faced with a "taboo" area, ill equipped to deal with it individually or collectively (Birnie, 1998).

Stevenson (2004) refers to the emotional aspect of caring for a dying family member and it is the death of those close to us that help shape our perception and attitude towards death and our own mortality. The dying process is often a highly emotional one for the family and for the dying individual, and the stress of watching a loved one die sometimes in a less than comfortable environment leaves a determination in some that they will avoid at all costs a similar type of death (Palmer, 2000; Richardson, 2002). Many people are anxious about or fear death or a "bad death", and this is partly because of the inherent belief life that is precious, but also because of the fear of how we are going to die. The desire for physician-assisted dying often relates to the psychological or care needs of the patient (Emanuel,

Fairclough & Emanuel, 2000). What emerges from this are people's anticipation of death and the fear of the dying process: whether it will be long and painful, whether it will be surrounded by machines, or in the privacy of the home. Death could be said to be the ultimate threat to our sense of control, and religion has historically been the Western culture's dominant means of coping with this inevitability (Birnie, 1998). Religion traditionally has offered the answers to many and has made death seem less unknown, and offered hope of a life after death. The sanctity-of-life discourse argues against the right to complete autonomy. Lynda Scott states:

As a geriatrician who worked with the terminally ill and disabled, I thought a great deal about the issue of euthanasia, especially when faced with pain and suffering. My work with these people brought me to several realisations. Patients often choose the timing of their deaths. They will hold on until a special person arrives, or until an issue is resolved. It is only when the will to live goes that a person with a terminal illness finally dies.

Every doctor has patients whom they may have felt would have been better to have died one or two weeks earlier. There are other patients who pull through against incredible odds. A doctor's professional ethics state they should save life, not take life.

Terminally ill patients often have the means of taking their own lives because they have access to large doses of morphine, but they rarely do so. This is because every last minute is precious to some people, no matter how much they are suffering. No one but the individual can judge the quality of his or her own life.

*(New Zealand Herald, March 14, 2003, p. A17)*

Scott draws on her position as a doctor and her observations of dying patients to legitimate her claims. To me the writer is referring here to the inner spiritual being of an individual and to the fact that no one else has a right to make decisions regarding his/her dying. Scott asserts that it is the patients who exercise control over the timing of their death and while death may be inevitable, the timing is not always predictable. Doctors should allow this process of self-determination to occur and therefore the dying process should not be shortened because the sacredness of life means that every minute of living, even amidst suffering, should be celebrated. I

believe she is suggesting that euthanasia would undermine a patient's exercise of will, and also undermine the role of doctors.

### *Pain, suffering and compassion*

The sanctity-of-life discourse approach to pain, suffering and compassion is evident. The etymology of compassion means “to suffer with” and compassionate care involves coming alongside patients who are suffering, being with them and doing all that is possible to alleviate their suffering (Birnie, 1998). Suffering need not be just as a result of pain and the sanctity-of-life discourse recognises that spiritual, emotional, cultural and social factors can all contribute to physical distress of the dying patient (O'Connor, 1996). The sanctity-of-life discourse claims that most physical pain can be treated by good palliative care and that palliative care by its holistic nature attempts to alleviate all forms of suffering. Dr Jonathan Adler, a Wellington consultant in palliative care believes good palliative care can go a long way towards removing the distress and pain of death. Adler is quoted by journalist Ruth Laugesen as saying:

I don't think there is anything inevitable about pain at the end of life. And I think it's a very rare person who can approach this huge time in their life without feeling sad or threatened or frightened. But that doesn't mean that as they work through that process with the right support that they can't be comforted, so their suffering is eased,” he says.

While it is common for those approaching death to be frightened, and even to say “I can't cope with this, I'd rather die”, with the right help those feelings recede,” he says. [...] “Experts in the field have specialist knowledge on how to control pain and other symptoms such as breathlessness and nausea.

(Sunday Star Times, April 4, 2004, pp. C1 and C2)

I believe Adler is constructing pain and the role of care as a natural part of the dying process. Within this discourse suffering, other than pain, is perceived as sometimes a natural part of the dying process to journey through. Comforting and helping the patient through this journey is seen as an essential part of care. Terminally ill patients often have feelings of isolation, helplessness, dependency and loss of self-

respect which adds to their suffering, particularly when the medical authorities are unable to effectively relieve pain (Emanuel, Fairclough & Emanuel, 2000; van Zyl, 2000).

The claim is being made by Adler that compassion and appropriate care will alleviate suffering whether it is spiritual, emotional or physical. Within this discourse, compassion is described as providing care and comfort for the dying patient. It argues against the experience/ or suffering of pain being a valid reason for euthanasia, disputing the right-to-die discourse's claims that euthanasia is a humane and compassionate option in certain cases. The claim by this discourse is that most pain is adequately treated in terminal care and that euthanasia is an easy way out when the focus should be on improving pain medication and palliative services (van Deldon, 1999; Randall, 1996).

Birnie (1998) found a fear of death and of how a person is going to die, particularly a loss of dignity are the main reasons people seek euthanasia. Adler is asserting that with good care, a person can die with his/her dignity intact and without having to resorting to such measures. The sanctity-of-life discourse describes euthanasia as an abandonment of the dying individual at a critical time in his/her life's journey.

### *The Dying Patient*

When faced with death, the individual will have his/her own expectations, experiences, fears and hopes; these may well differ from society's accepted norms but are their own realities. It is impossible to pretend that death does not exist and, biologically, if there is one certainty in life it is that we will eventually die (Richardson, 2002). An individual's experience of death is often formed from their own observations of watching others die, but the actual experience of death can only be imagined in advance.

A grid of specification that can be used to classify cancer patients and determine the path of their treatment is the type and stage of cancer, and the subsequent prognosis given. In the case of the cancer sufferer, the diagnosis is made and the type of cancer fits into different categories such as benign, malignant, or encapsulated (Miller & Keane, 1972). Prognosis depends on the grade of cancer or how far advanced it is before detection. The type of treatment that is given depends on the analysis of this information. The labelling of a patient as "terminally ill" falls into

two distinct categories: terminally ill means having an incurable or irreversible condition that has a high probability of causing death within a relatively short time (one year) with or without treatment. Terminal disease means an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgement, produce death within six months (Drickamer, Lee, & Ganzini, 1997).

On an individual level, the patient is admitted to a hospital as a subject and immediately comes under the scrutiny of the medical lens. Foucault (1980) describes this when he discusses the effect of institutions on the individual in *power/knowledge*. A person can have various subjectivities, and in the case of the terminally ill, they take on the subjectivity of the dying patient. This defining of the patient as dying separates them from the patient who is not terminally ill and the nature of their relationship to care givers is different because of this. The identity of any subject is given by its insertion within a discourse. With terminally ill patients there is a whole new discourse of death and dying that opens up to them, including society's and their own attitudes and approach to death. In other words, the dying person becomes the dying subject and is not now seen as a curable subject or a treatable subject with the object of recovery in mind. The care they receive depends on the physicians' knowledge of care options available. In an article by Barbara Burstyn, Rod MacLeod a professor of palliative care comments:

People are dying deaths where there's a big reliance on the family to provide care because we don't have enough resources to support people effectively in the community," he says.

I think people are going through enormous distress, anguish, pain, suffering. They feel abandoned. And I just think it's desperately sad that a society like ours which prides itself on many qualities can give the impression that we don't care, he says [...] Often dying patients aren't referred to palliative care by their doctors, or are referred much too late. In some parts of the country there is a shortage of experts in the care of the dying. And some areas have little or no hospice services at all, or have inadequate around-the-clock nursing to relieve exhausted families.

(*Sunday Star Times*, April 4, 2004, p. C1)

The dying patient is being constructed here as an individual who is being neglected by society. Society, because of its reluctance to discuss death and dying, is not always meeting the needs of the dying patient: and does not always care for them properly. Families who end up with the responsibility to care for their loved ones are often unaware of what services are available, and have often had no experience in caring for the dying (Leichentritt & Rettig, 2002). While the dying patient remains relatively independent, they retain a degree of control over themselves and what decisions are made.

Once a patient enters an institution the power relations change in that patient's may be in a lesser power position than they were at home. Foucault (1997) termed this the "relation of power" (p. 291). While this balance remained, the patient/doctor relationship would remain relatively stable. A lack of resources results in inadequate care; the dying patient is suffering more than necessary in certain cases as a result of this and because of insufficient knowledge about death and dying. The dying patients and their families enter a professional aided dying discourse when they enter an institution for care. Choice in dying is more than an individual need; it is a collective health issue which often involves the family. I next look at the system of power/knowledge as described by Foucault (1980) that enables the sanctity-of-life discourse to maintain its regime of "truth".

### *Power Relations*

The sanctity-of-life discourse is essentially a religious discourse which maintains its position through a "technique of power". Rather than competing with other political and institutional bodies, pastoral power works within and is described as having gradually, over time, infiltrated all aspects of society (Carrette, 1999). The sanctity-of-life discourse is woven throughout our social structure in such a way that only by peeling away the layers does its influence become apparent. Discourses support institutions and they reproduce power relations (Parker, 1992). If we look, for example, at hospitals and care institutions, in fact even hotels, it is generally accepted practice that there will be a Bible in each room. Because of the way the sanctity-of-life discourse has applied this "technique of power", the speakers within the discourse are not necessarily religious. By this I mean that many of the rules and regulations enforced by it are not seen as being religious in origin.

Speakers for the sanctity-of-life discourse pronounce the necessity for health professionals to protect lives at all times, and states that caring for a patient does not involve the process of speeding up the end of their lives (Batavia, 2001; Parsons & Newell, 1996; Uhlmann, 1996). The trust between the physician and patient is an important bond. The speakers for the sanctity-of-life discourse claim this relationship would be irreparably damaged if euthanasia was legalised. Family Life International state:

In practice euthanasia will lessen confidence and trust in physicians. Physician trust is crucial to the patient-physician bond. Euthanasia will break that trust. In Holland it has been reported that the elderly are too scared to be admitted to hospital as they fear that they will not leave alive. This fear is due to euthanasia.

*(And Now Euthanasia, 2003, p. 6)*

Concerns have been raised about the economic risks that could be at stake if legislation does pass, since it may well prove to be economical for an institution to save money on hospital beds by hastening a patient's death. Sanctity-of-life speakers cite the Netherlands (where euthanasia is permitted in certain circumstances) as an example of a society where the current law has been flouted by the medical profession, and where the lack of good palliative care opens the door for the "duty-to-die" to occur, and where protective legislation and procedures have been flouted (van Deldon, 1999). The sanctity-of-life discourse portrays the right-to-die discourse as putting society at risk by wanting to legalise euthanasia. In contrast to this sanctity-of-life claims no motive apart from the protection of life.

#### *Domination of the dying patient.*

Within the sanctity-of-life discourse the medical profession possess the power/knowledge and therefore are the authorities that decide what treatment is required and who has the authority to speak. According to Powers (2001) "social agents have the duty of monitoring and upholding the status quo of power relations" (p. 104). Current practice assumes that, in general, pain can be effectively controlled at the terminal stages of an illness (Birnie, 1998). Pain scales are used to assess, evaluate and implement pain relief. At the terminal stages of a disease, within an

institution-type setting such as a hospital or a hospice, the patient can be dominated by the medical discourse.

The patient becomes vulnerable by this possible loss of control over the situation or knowledge of the reality of their impending death and dying process. Powers (2001) describes the patient as becoming objectified through the medical lens once they enter into a hospital. Patients are seen as an object of treatment to alleviate symptoms, and not as independent thinking autonomous individuals. The assumption is made by the medical discourse that their decisions are the right ones made in the best interests of the dying patient (Randall & Downie, 1996).

This domination is able to be continued because of the superior stance taken by the medical professionals as social agents and as a result of the vulnerability of the patient when given his/her prognosis. The patient is then categorised in terms of how he/she is coping with their impending death; assumptions are made regarding their progression through acceptance towards death and they are assessed through the medical and nursing lens as to their self-esteem, coping mechanisms, and knowledge (Johnstone, 1994). Within this regime of care, a patient requesting assistance in dying is currently labelled as a problem. Speakers drawing on this discourse argue that treatment of the likely causes for this request such as; depression, loneliness, fear of pain and not wishing to be a burden on others, will eliminate the request for a premature death (Birnie, 1998).

### *Family*

Society's current attitude towards the families of dying patients derives from traditional models of grief and cultural beliefs that have evolved from the "sanctity-of-life" doctrine. Coping with a dying family member is hard for family members.

Lynda Scott states:

It is hard on relatives to watch someone they love die a long, lingering death from a terminal disease but those carers do not have the right to decide when another should die just because of their own distress.

To ask someone to take your life puts a huge burden on that person – a burden they may not bear well if they act upon it.

Good palliative care is essential for the patient and to help families cope with a terminally ill or dying member. The patient must also have good symptom control and pain management.

*(New Zealand Herald, March 14, 2003, p. A17)*

I believe this quote refers to the difficulty and emotional stress the family members suffer having to watch the person they love die, and not always in ideal circumstances. Miss Scott is portraying the act of assisting someone to die as a difficult and onerous one that might have long term consequences. It might be a burden too heavy to bear. The trauma of losing a person in this way is immense and for them to not receive adequate care in the terminal stages adds to this trauma.

The sanctity-of-life speaker in this discourse is saying the family's distress and own suffering does not, however, give them the right or authority to take the dying patient's life. Orr (2001) and Emanuel, Fairclough and Emanuel (2000) claim that it is inadequate care physically, spiritually, psychologically and socially that can motivate desperate patients or their loving families to try to hasten an end to suffering. This excerpt claims that if adequate palliative care is made available, then the suffering of both the patient and the family can be eased. Caring for the terminally ill patient has emerged as a critical factor in this analysis and I will next discuss nursing and the discursive practice of palliative care.

### *Nursing*

A nurse's perspective focuses on meeting the needs of the patient. Communication is an important part of caring for the dying, and many patients want to talk about their imminent death and loss of hope (Johnstone, 1996). Nancy Rutherford's daughter died in a hospice and Nancy's story is retold by reporter Philippa Stevenson:

The hospice nurses didn't come in with sympathy and sadness but with kindness and nursing ability, says a grateful Nancy.

They seemed to have an inner happiness. They didn't leave you feeling worse than when they came in, helping you to work your way through it with hugs as they came and left.

*(New Zealand Herald, May 25, 2004, p. A9)*

Nurses play an important role in caring for the dying individual and their families, and part of their responsibility when providing care is to help the family and patient through the maze of difficult decisions that they face at the terminal stages of an illness (Johnstone, 1994). This can often be in direct contrast to the medical perspective which is to act in accordance with the treatment possibilities and with their responsibilities as a physician. Doctors spend very little time with a patient whereas the nurse is in constant close contact and administers therapy as required (Dawe, Verhoef & Page, 2002).

The success of a nurse's working relationship is partly dependent on the patient's perception of them. The medical lens is reflected back by the patient and the judgements made by the medical and nursing discourses affect these perceptions. A nursing judgement should be based on a humane and compassionate attitude and not one that is more medically orientated and which has a more technical and scientific base (Randall & Downie, 1996).

The sanctity-of-life discourse argues that legalising euthanasia will create ethical dilemmas for health-care workers, placing them in situations which will compromise their code of ethics and moral values (Johnstone, 2003). The caring aspect of the nursing discourse which emerges conflicts with the dominant medical discourse. Nurses also see themselves as more accepting of death than physicians; its naturalness and inevitability, and as patient advocates they wish for people to die in the way they choose (Asher, 2004).

The International Code of Ethics for Nurses (2000), states that nurses have four fundamental responsibilities: to promote health, to prevent illness, to restore health and to alleviate suffering. It cites:

The primary professional responsibility is to people requiring nursing care. This involves providing an environment for the patient that respects their human rights, values, customs and the spiritual beliefs of the individual, family and community. (p1).

By being members of a profession concerned with the well being of people, nurses have allowed themselves to be seen as being empowered to judge in public and private moral dilemmas for which in reality they have no more expertise than any other person (Johnstone, 1994). What they do have is the ability and experience to

care for the very ill and dying which gives them some claim to be listened to. Nurses have also been described as uncertain and indecisive in moral situations and respectful of rules and conventions. Nurses caring for dying patients strive to do the right thing for them (Birnie, 1998).

Moral conflicts occurred with issues relating to: end of life decisions, giving information to patients, the relief of symptoms and medical treatment (Georges & Grypdonck, 2002). Nurses are often faced with competing obligations when dealing with end of life decisions. They are responsible to patients and their families as care givers and advocates, and it is usually the nurse caring for the patient and interacting with the family that forms the closest relationship with them during this time.

The New Zealand Nurses Organisation Code of Ethics (p.14) states with regard to the nurse-client relationship:

Autonomy (self-determination): Creating a partnership within the nurse-client relationship, the outcome of which the client views as beneficial.

Supporting clients to enable freedom of choice and informed consent.

Informed consent requires that enough relevant information is provided to enable a reasoned decision to be made, and that that information is understood.

Cultural perception is an important component. Without understanding, no-one can make a reasoned decision. Nurses should support clients in making informed decisions by giving information and assistance, thereby ensuring that they become active participants in their own health care.

Ensuring the health service responds to cultural diversity and that the nurse recognises cultural norms.

Being aware that people may act as individuals or as part of a collective social system.

Within the sanctity-of-life discourse texts that were analysed, there was very little mention of nurses. The positioning of physicians within the euthanasia debate is clearly revealed; however, the role of nurses remains relatively invisible. Within the euthanasia debate I believe, nursing remains under the control and authority of the medical discourse.

Joy Bickley Asher, nursing academic states:

While nurses may think they are experts on death, this view is not generally shared by doctors or members of the public. Nor is it shared by the creators of legal structures regarding death practices.

*(Kai Tiaki Nursing New Zealand, June 2004, p. 20)*

This is consistently the case with all other areas of health care and the care given to the dying is no different in that decisions are made and handed out using the medical model that has been established as the “truth”, and this discourse keeps nursing invisible. The care given to dying individuals and their families is variable and is influenced by the type of institution and its practices along with the individual characteristics of health-care professionals (Johnstone, 1996).

*Domination of nursing by medicine.*

While it is true that in recent years palliative care presents a team effort in making decisions regarding best care practice, the medical discourse clearly dominates the practice of nursing as it does in other areas of health (Powers, 2001). The scientific knowledge of the disease progression of the dying individual assists in reinforcing this professional hierarchy. Historically, the relationship between the medical and nursing discourses has been complex and intimate, and in the field of terminal care, the medical discourse is seen as having the power/knowledge to maintain this domination. Nurses lack the autonomy and authority to act independently and this can result in feelings of insecurity and powerlessness within the institutional setting that is dominated by the medical profession (Georges & Grypdonck, 2002; Johnstone, 1994). The nursing profession have been described as uncertain and indecisive with respect to the rules and conventions associated with discussing moral problems around end-of-life issues. In contrast, according to Johnstone (1994) physicians are more assertive in style and express a certainty about the conclusions they put forward regarding the caring for the terminally ill and best practice.

A recent major national study of dying patients in the United States revealed that despite aggressive interventions by nurses serving as the liaisons between patients and physicians, nurses' interventions had little impact on reported pain, the timing of “do not resuscitate” orders, or the cost of intensive care in the final weeks of life (de

Vries, 1999). The study found that physicians' patterns of treatment were essentially unchanged, despite intensive nursing advocacy on behalf of the patients. This is supported by the literature reviewed (Georges & Grypdonck, 2002). According to these authors, nurses often appear to fail to recognise the moral dimensions of the problems that they experienced and lacked the skills needed to resolve them adequately. The dominant medical discourse and its discursive practices have resulted in nurses lacking autonomy and authority with regard to the dying patient (Johnstone, 1996). In the study by Georges & Grypdonck (2002) a lack of autonomy and authority resulted in feelings of insecurity and powerlessness, which affected the nurses' perceptions and attitudes relating to end-of-life issues, how they communicated with patients suffering, and appropriateness of medical treatment. Ingrained in the nurses' belief system is the idea that medical intervention aims to cure (not to have the patient die) and therefore the nursing goal is to help people recover. Anything else is perceived as failure. Wiki Alward, Joy Martin's hospice nurse, resigned from her job as a result of how she was portrayed by Lesley Martin as unsupportive and uncaring in the case.

Journalist Amie Richardson states:

Alward said they never expected Martin to provide medical care for her mother and gave as much support as she allowed them to give. Alward said: The best option would have been to have a night nurse there, so that she could've gone and had a good night's sleep so that she could face the day. She's saying now that she was totally stressed out but why didn't she take the offer? [...] I feel as though I have been totally disempowered, which is very hurtful when I've spent my life caring for others.

Alwards claims are backed by Wanganui hospice, her former employer, and Joy Martin's GP Bevin Chilcott, who says medical staff – and not Martin – were the ones on trial. [...] I was very surprised when we saw the figures to show all the help that was given and was offered by the hospice.

We were criticised harshly that [Lesley] wasn't asked about her spiritual needs but it was covered – she was offered a priest, she was offered a minister, she was offered all that and it was in Wiki's notes that she had done it .

*(Sunday Star Times, April 11, 2004, p. A2)*

### *Palliative Care: a discursive practice*

The discursive practice of palliative care functions within the sanctity-of-life discourse and the right to an autonomous decision regarding the timing of one's dying is not an acceptable option. Palliative care emerged from the medical discourse in Britain in the late 1960s and was introduced by Dame Cicely Saunders. It involved a shift in treatment goals from cure and prolongation of life, to the control of suffering (Randall & Downie, 1996). It is described as a programme of active compassionate care primarily directed towards improving the quality of life for the dying, and palliative care givers argue that there are very few people who cannot be helped by them. The aim of palliative care is to neither hasten nor postpone death but to provide the best possible quality care in the time left to the dying patient and their family. Good palliative care is argued by Scott (2003) as one of the main arguments against a change in legislation. The publication *And Now Euthanasia* (2003) produced by Family Life International states "at the heart of palliative care is the affirmation of life, not the choosing of death" (p. 35).

The goal of those involved in offering palliative care is to relieve pain and thus reduce the great fear of pain that is sometimes associated with dying. It is this fear which drives people to accept euthanasia as the only available option

*(And Now Euthanasia, 2003, p. 35)*

There is a truth that is being challenged here regarding the controlling of pain in the dying process, and I believe its aim is to pre-empt euthanasia as an option. Research clearly shows that 5% of terminally ill patients will suffer extreme pain at the end of their life which will be unrelieved by medication (Birnie, 1998). The practice of palliative care claim that it is the fear of pain that makes individuals request euthanasia, when in fact this anticipated pain will probably not become a reality. In an article by Bruce Ansley, Maurice Smith describes a journey of pain and suffering with his incurably ill wife, but describes how palliative care made this journey more bearable:

She has good palliative care. There have been four nurses here today. Smith had to fight for equipment and care when Bettine came out of hospital. He has

the experience and contacts to argue, struggle past growing waiting lists and the delays of an overloaded health system. But he agrees not everyone can do that. [...] Now she is totally dependent on others. The nurse who has just come is going to do her bowels. Bettine would be horrified if she knew those personal things were being done for her. She cannot eat. She can't drink. She has Watties baby food. I know Bettine will never heal, and she'll probably get worse. But I want to be here with her and the family. I won't change my mind now.

*(The Listener, April 12-18, 2003, p. 18)*

Palliative care attempts to assist dying individuals through the dying process so that they eventually accept their imminent dying and can face death with a spiritual confidence (O'Connor, 1996). Palliative care argues for better resources and facilities to provide care and compassion for the dying. Rod MacLeod quoted in the *Sunday Star Times* (2004) believes Joy Martin and her daughter suffered more than they should have because of a lack of palliative care services being offered. Journalist Ruth Laugesen quotes him as stating:

Joy Martin endured persistent nausea and vomiting for months. Her pain wasn't adequately controlled. And mother and daughter were going through a great deal of psychological distress. On all fronts, assessment and care from experts in palliative care, such as a hospice, would have brought considerable relief," says MacLeod. "Euthanasia should never have been an issue.

*(Sunday Star Times, April 4, 2004, p. C2)*

MacLeod gave evidence in Lesley Martins trial that the family were let down by the inadequate care received from medical services. Often palliative care is given too late or patients aren't referred and in some parts of New Zealand there is a lack of palliative care available. Early intervention with patients diagnosed with secondary cancer can assist with quality of life options. MacLeod goes on to state:

Too often, says MacLeod, hope is only defined in terms of quality of a cure. Hope can be reframed. "Part of our main role is to rekindle hope. People do have hope: they have hope that they're going to be free of symptoms; they

have hope that they're going to see their children; they have hope that they might get home. They have hope for feeling the sun on their backs or hearing the sound of waves.

*(Sunday Star Times, April 4, 2004, p. C2)*

The sanctity-of-life discourse argues against euthanasia by claiming it is unnecessary because palliative care treatments exist. Its speakers believe that requests for euthanasia are rarely free and voluntary, and deny the patient the final stage of growth (van Deldon, 1999). They claim that euthanasia would also undermine medical research and that more time and money should go into improving pain management. They acknowledge the importance of autonomy but do not condone absolute autonomy. It is believed that complying with the demands of autonomy and the right to die will change public consciousness and violate historically accepted codes of medical practice. The fear is that euthanasia will give too much power to doctors and will, over time, lead to involuntary euthanasia. Family Life International (2003, p. 5) takes an excerpt from the Jewish-Christian Declaration on Euthanasia:

When we ask if a treatment is useless, the question is: 'will this treatment be useful for this patient: will it benefit the life he or she has?'

When we ask the question if a treatment is burdensome, the question is 'Is this treatment excessively burdensome to the life of the patient?'

The question is not whether this life is useless or burdensome.

We can and should allow the dying to die; we must never intend the death of the living. We may reject a teaching; we must never reject a life''

I interpret this to mean that in certain circumstances it is now accepted practice to withhold some forms of treatment, and that it is also justifiable to withdraw and withhold treatment in certain situations. The law has been modified in recent years to accommodate these practices, and to enable physicians to make decisions regarding treatment or withdrawal of treatment without facing prosecution. These are described as grey areas by the right-to-die speakers when it comes to qualifying whether some acts are a form of euthanasia or not (Dunnett, 1999; Loewy, 2001; Palmer, 2000). The acceptance of these practices has led society to justify the idea that there are times when it is acceptable to not save lives at all costs. For

example, a physician is now legally allowed to discontinue life support with the knowledge that a patient will not be able to maintain his/her own respiration. This is justified by saying that it is permissible to let the dying die; that these patients would have died regardless of whether they had been given medical intervention or not.

This differs considerably from the concept of euthanasia as understood by the speakers in the sanctity-of-life discourse, because this involves the taking of a life, as opposed to allowing the dying to die (Loewy, 2001). Even if euthanasia was ordered by public authority, the sanctity-of-life discourse would never condone it. Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted, according to this discourse.

The use of pain killers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be in moral conformity with human dignity if death is not willed as an end to life, but only foreseen and tolerated as inevitable. This is how this discourse can justify the action of double effect. Sanctity-of-life argues for a return to the traditional values regarding human life, to put renewed faith back into the power of God and the Christian ethic. Family Life international states:

When legislative bodies enact laws that authorize putting innocent people to death and states allow their resources and structures to be used for these crimes, individual consciences, often poorly formed, are all the more easily led into error. In order to break this vicious cycle, it seems more urgent than ever that we should forcefully reaffirm our common teaching, based on sacred Scripture and tradition, with regard to the inviolability of innocent human life  
(*And Now Euthanasia*, 2003, p. 13)

Here I believe this discourse is putting out a powerful message. It is challenging the power of the state and its ability to make the “best” decision for society. The sanctity-of-life discourse seems to me to rationalise its power status by claiming it will not be influenced by social trends or political manoeuvring by the government or any institutional body. Rather, its strength seems to lie in its apparent lack of political motive, the primary motive appearing to be the protection of life (Randerson, 2002). This in itself is its way of bringing its power relations into being; to encourage individuals to remain within the teachings of their faith is a way of maintaining power over the individual. Foucault described this power as “pastoral

power” as stated in chapter 2. Foucault himself came from a strong Christian, Catholic background and it was his belief that religion was part of a set of force relations and discursive practices which have resulted in how we order our lives. Foucault wrote, “Historically, what exists is the church. Faith, what is that? Religion is a political force” (cited in Carrette, 1999, p. 107). The sanctity-of-life discourse has effectively used the legal discourse to empower and maintain its authority to speak and this is discussed next under the axis of authority.

### *Axis of Authority*

Within the sanctity-of-life discourse the right to pronounce the truth is preserved, exercised and reproduced through a powerful legal discourse. The law is aimed at protecting all members of society and promotes the belief that all humans are equal in the eyes of the law. For this reason the legal argument against euthanasia is that it is in the interests of protecting society as a whole and that death is not just a personal experience because it affects those around the dying individual as well (Wallace & Johnson, 1995). Hillyard & Dombrink (2001) put forward a powerful argument that it would be wrong to exclude people from the protection of the homicide laws based on the condition of their health. This could be seen as a serious departure from the principle of equal justice for all and opponents claim that it would lead to the literal destruction of the very lives that the government is charged with protecting.

Dr Lynda Scott states:

When euthanasia is legalised, it is difficult to control the potential for abuse. What happens to a society when we say it is okay to take the life of someone whom we believe can no longer make a contribution – for example, because he or she has Alzheimer’s disease, or who is suffering but whose suffering we cannot quantify?

*(New Zealand Herald, March 14, 2003, p. A17)*

It is argued that permitting a legal change will result in the wrong people using the law for the wrong reasons, or that the economically marginalised will be pressured to die against their will. The sanctity-of-life discourse has used legal activities to preserve, defend and enhance the dominance of this discourse in society. The New

Zealand law does not deal directly with euthanasia and instead places it within The Crimes Act 1961 including sections 151, 157, 158, 164, 179 and 180.

The sanctity-of-life discourse is served well by the power of the legal system. The law dictates how society is expected to conform and if a behaviour or actions are outside this set of rules then society is expected to deem it unacceptable as well. The legal system supplies the rules for determination and how “truth” is to be preserved.

I suggest that “suicide” and “euthanasia” are concepts with blurred edges, in that it can seem unclear whether a certain act is suicide or euthanasia. In the past this was an important distinction to make because it was widely accepted within the sanctity-of-life discourse that suicide excluded the individual from heaven. While suicide is defined as the intentional taking of one’s own life, a multilayered meaning emerges in a second definition which includes the self-destruction of one’s own personal interests (Quill, 1993). In medical literature, suicide is often referred to as an act of despair, depression or self-destructiveness, and described as something to be prevented and treated, in order to help individuals return to health and regain their desire to live. The Sentencing Act 2002 allows non-custodial and reduced sentences for murder at the judge’s discretion. It has, in effect, given the court power to grant leniency in sentencing where it is warranted.

Section 158: Homicide defined. Homicide is the killing of a human being by another, directly or indirectly, by any means whatsoever. This currently encompasses all acts of active euthanasia.

Section 164: Acceleration of death. If the act or omission of an action hastens the death of another, the person who acted or failed to act may be chargeable with an offence.

It would appear that the need to prevent killing greatly shapes the New Zealand laws and the law legitimates the sanctity-of-life discourse. The sanctity-of-life discourse argues that if the government is given the right to make life and death decisions based on assessments of each patient’s quality of life, then society as a whole will be in danger of exploitation.

In *The Weekend Herald* (2003), an anonymous reader responds to an editorial:

Your editorial proposing a royal commission to analyse voluntary euthanasia raises a reasonable point on the bill being referred to a select committee, but like most media discussion on the topic it confuses the issue of euthanasia with the role of the law. The problem is not whether ‘people with terminal or incurable illnesses should be given the right-to-die’ – they don’t need legislation for that. The key issue is whether the law should sanction others to assist in the killing.

The law is not impartial on its approval of rights. It always judges rights to freedom of choice against the interests of greater society, as it should.

Voluntary euthanasia is not in the best interests of society because the system would be too easy to abuse, and euthanasia without consent is merely a euphemism for murder. Parliament is wise to understand that from the outset.

*(The Weekend Herald, August 2-3, p. A22)*

I understand the writer to be using the law to assert the moral justification against euthanasia, thereby asserting the authority of the sanctity-of-life discourse. The potential for abuse that is raised here is discussed next under the axis for justification.

### *Axis of Justification*

The sanctity-of-life discourse puts forward a strong argument against the legalisation for euthanasia, called the slippery slope argument as discussed in chapter four. This claims that if the sanctity-of-life ideals are set aside to make room for the unlimited exercise of personal autonomy, then the lives of the disabled, the aged and the terminally ill will be threatened (van Deldon, 1999).

It is argued that these people will lose any power they have and that it will make them vulnerable to the wishes of the powerful and healthy. It is argued that it would be only a matter of time before cases of non-voluntary euthanasia occur and that it would be impossible to prevent abuse regardless of preventative procedures and legislation. The commonest fears are that mistakes would be made, that abuses would occur, and that the acceptance of killing in these cases will erode our sensitivity to the value of life and result in a more callous attitude towards killing (McMahan, 2002). This fits in with Foucault’s (1977) concept of “normalisation” where actions, objects

or behaviours are judged as normal or abnormal. By defining what normal behaviour is, people become subjected to a system that disciplines their behaviour. Journalist Barbara Burstyn writes:

Meanwhile, Belgium, which enacted mercy killing laws in September, is struggling with the immediate flouting of its regulations by MS sufferer Mario Verstraete. Verstraete was by no means in the last stages of the disease – a central requirement under the new law – when he arranged for his doctor to kill him.

Other MS sufferers in Belgium are reported as fearing the new law – and Verstraete’s immediate contravention of it – will lower the bar to public acceptance of their illness and continued right to live.

This threat to the public’s perception of the viability and liveability of life for people with illness, advanced age or disability is at the core of many arguments against euthanasia. And they are right.

With an ageing population, the transience of relationships and families and the increasing lack of accessible medical and support services, it would seem that legalising the removal of the infirm would solve a lot of problems.

*(New Zealand Herald, November 8, 2002, p. A19)*

Belgium legalised physician-assisted dying in 2002 under strict guidelines which have already been exploited by an individual determined to die with assistance. Speakers drawing on this discourse suggests that if we allow people to enact their choices to die by the legalisation or decriminalising of euthanasia, then we will create a society in which the lives of many others who do not choose to die will be at risk (Oddie, 1998; Parsons & Newell, 1996; Uhlmann, 1996). Therefore the people most likely to suffer will be the elderly, the disabled, and least powerful. Euthanasia, it is claimed, could have economic benefits to society because it is not as expensive as palliative care or the long-term care of the chronically ill or elderly.

This slippery-slope argument has been an ethical argument for as long as the issue of legalising euthanasia has been around and claims that acceptance of voluntary euthanasia will lead to the acceptance of involuntary/non-voluntary euthanasia as defined in chapter four. The argument states that even if a line can be drawn between voluntary and non-voluntary euthanasia, a slide will occur in practice because the

safeguards to prevent it cannot be made effective. There is some evidence in the Netherlands that imposed euthanasia is occurring, and that in many cases no explicit requests by the patient are made (Keown, 1999; Thomasma et al., 1998; van Deldon, 1999). It is interesting to note that in the Netherlands there are only a few hospices, and many believe that euthanasia has resulted in this lack of palliative care as an option at the end of life. In the *New Zealand Herald* an anonymous letter to the editor defends the right to protect society from euthanasia:

Proponents of legalised euthanasia are fond of emphasising that it is only for people who are in great pain and have no prospect of recovery. Safeguards could be built in, they say, and it would not become an invitation to assisted suicide. But, quite simply, it appears too difficult to create a system so robust that it cannot be abused – one that, in particular, would not be seized upon by those lacking respect for the lives of the old and the ill.

Today there is a grey area bordering on mercy killing. When pain becomes insufferable and death is imminent, some doctors are prepared to administer an overdose of painkillers. If loved ones know, they will not be inclined to bemoan the doctor's act. But this should never be confused with the granting of a legal right to administer drugs with the specific intention of ending a person's life. That would be going too far. As the law stands, Lesley Martin went that step too far.

(*New Zealand Herald*, April 2, 2004, p. A12)

From the sanctity of life perspective human nature and morals are portrayed as erosive, and the ease at which groups can so easily justify unjustifiable actions and behaviours was demonstrated in the genealogy. This letter to the editor supports the practice of double effect and expresses other speakers for the sanctity-of-life fears, that, if euthanasia were legalised not all people in society could be counted on to act morally if faced with the care or responsibility of a terminally ill person. Opponents to legislation permitting euthanasia use the Netherlands as an example of the reality of the slippery slope (van Deldon, 1999). Here, although assisted suicide and euthanasia are technically illegal, physicians can avoid prosecution by adhering to strict guidelines developed by the medical profession and the courts. Studies have shown that it is these procedural safeguards that have not been always followed, and in about

25-30% of cases reported involving euthanasia or assisted suicide, the patients did not make an explicit request for their life to end (Pollard, 2001; van Deldon, 1999). The sanctity-of-life discourse also justifies its stance by the assertion that it is society's responsibility to protect the disabled and the frail and that this must take precedence

Social pressure can be very powerful and it is possible that the idea of having "a duty to die" will become a theme, which may result in an expectation by some that they must opt for euthanasia rather than become a burden on others. This would place the dying patient in an even more distressing situation. The "duty to die" therefore refers to the idea that it is an individual's duty to volunteer for euthanasia if they become a burden on others or a perceived drain on society (Johnstone, 1994).

The concern with being a burden to others is frequently heard as a reason to request euthanasia and the slippery slope argument that is deployed by speakers of the sanctity-of-life discourse claims that if euthanasia were legalised, eventually we would end up euthanising the helpless or less fortunate against their will, and that this would be seen as an acceptable practice (Street & Kissane, 2000). Being a burden on others raises the economic argument that if active euthanasia were legalised, and there could be savings made on expensive treatments and drugs within the health system, the savings could be substantial to the political body in power. There are powerful people pushing for the legalising of euthanasia and the sanctity-of-life discourse argues that there could well be a financial motive lying underneath the "right to autonomy" argument (Pollard, 2001).

As mentioned earlier under palliative care, there is also the potential that research to find the solution to extreme pain may not continue, simply because euthanasia will be a cheaper and easier option. I find myself concerned that when looking at euthanasia from an economic viewpoint, there is no guarantee that the current New Zealand health system or, indeed, any health system would not consider economic needs over moral and ethical standards, particularly if the changes were introduced insidiously. Birnie (1998) also questioned the safety of euthanasia as a practice, or an option when governments worldwide reduce the health-care budget. The sanctity-of-life discourse questions whether it is really society's changing attitudes towards death and dying that are causing this interest in autonomy and the right to choose, or rather society is gradually and insidiously being encouraged to accept a new reality or "truth" that will economically benefit a dominant power.

## *Summary*

This chapter introduced the sanctity-of-life discourse and its speakers as a fundamentally Christian discourse which asserts that life is sacred and there can be no moral justification for euthanasia. I demonstrated how this discourse constructs death and dying as being under the control of God. The speakers of this sanctity-of-life discourse claim that there is a greater purpose in the process of dying and that some form of suffering may be necessary to achieve that.

Pain is a motivating factor for many people requesting assistance in dying and the sanctity-of-life discourse claims that good palliative care can alleviate most of an individual's pain. A lack of funding for palliative resources and pain research is put forward as a reason why some individuals suffer. If better services and funding were provided it is argued, then the requests for euthanasia would substantially reduce. Palliative care is the main discursive practice that the sanctity-of-life discourse promotes and its philosophy of care excludes the right-to-die discourse, claiming that while it is acceptable to not prolong an individual's dying, it is never acceptable to deliberately hasten its death.

Within the practice of caring for the dying, the nursing profession is relatively invisible in decision making regarding treatment. The sanctity-of-life discourse is strengthened by a powerful legal discourse which supports and reinforces the "sanctity-of-life" principle. Euthanasia is against the law, falling under the Crimes Act, which makes it a criminal offence to assist in another's dying.

The main justification against euthanasia that the sanctity-of-life speakers put forward is the slippery slope argument, in terms of which legalising euthanasia for terminally ill cancer patients with limited time to live will result in an eventual "duty to die" mentality. The next chapter introduces the right-to-die discourse which contests many of the sanctity-of-life arguments against the legalisation of euthanasia.

## **CHAPTER SIX: The right-to-die discourse**

### ***Data Analysis***

#### *Introduction*

In this chapter I will show how the right-to-die discourse contests the sanctity-of-life discourse, and argues that if suffering cannot be alleviated, then it need not be endured. My analysis examines how speakers of this discourse seek for it to become a legitimate discourse by pushing for a change in legislation replacing sanctity-of-life with quality-of-life as a means for justifying decisions in respect of life and death. Analysis shows how the right-to-die discourse constructs pain and the management of pain differently to the sanctity-of-life discourse. The limitations of palliative care that this discourse refer to are laid bare and examined along with the claim by the right-to-die discourse that euthanasia becomes an option of care. I am going to show that it is the right to autonomy that has become one of the main propelling arguments put forward by the right-to-die discourse. Analysis investigates whether the protocols, guidelines and legislations suggested will protect society from the slippery-slope. Justification for euthanasia centres on the hypocrisy of treatments and activities that the right-to-die discourse describe as covert, and this becomes part of my analysis.

#### *Knowledge Axis*

Since the 1960s a challenge to the traditional ethics in this debate comes from the increasing emphasis on the rights of patients to make their own decisions about medical care. Foucault believed a discourse develops because of the social and cultural conditions occurring at that particular time, and described these as the “surfaces of emergence” (Gutting, 1994). What has emerged is a gradual shift in public opinion in favour of euthanasia. People believe more and more that when the quality-of-life is gone, death becomes a better alternative and they do not want to be trapped in a prison of tubes and high-tech machines, lingering on, possibly for years, in pain and suffering (de Vries, 1999).

David Hill writes:

I repeat that no case for euthanasia I have ever heard presents it as other than a totally voluntary and strictly controlled choice. Those who do not want it as an option for themselves must be free to make that decision.

I believe in it as a choice because I want to live and die well. (This seems a good place to remember that the 'eu' in euthanasia comes from the Greek word for 'well/good'.)

*(New Zealand Herald, March 14, 2003, p. A17)*

The right-to-die speakers are challenging what is considered to be a "good" life, and is asserting the belief that an individual should not be forced to suffer the terminal stages of illness if they wish otherwise. While the following does not relate to a terminally ill patient, it is relevant because it highlights an example of an autonomous individual who insists on controlling and executing his right to die. Deborah Codington was an Act MP when she voted in favour of the Death with Dignity Bill. Michael Crew, a successful barrister and good friend of Codington, ended his life at the age of thirty-six by drinking poison having been left a tetraplegic after diving off a wharf into shallow water. Codington writes:

I loved Michael; why would I want him to die? I still support his decision – as owner of his life, it was his alone to take. And as someone who supports voluntary euthanasia, I believe his courageous decision did have the effect he desired [...] Where was his enjoyment of life, he asked, in having his food cut up for him, his spectacles strapped on with elastic, faeces manually extracted from his bowel, no sex? A bag was attached to his penis to drain his bladder and when clients overstayed their allocated time, urine would quietly seep into the carpet at his feet, under his desk. From the moment Michael decided he couldn't face another 40 years of this, he focused his attention on death. He tried to starve himself, figuring his kidneys would quickly malfunction. But his family, he said, 'went into hysterics' and he couldn't bear the thought of being admitted to hospital and kept alive – a vegetable – on life support machines.

*(Sunday Star Times, April 4, 2004, p. A4)*

Michael is an example of euthanasia. More and more frequently cases are being reported where people identified as intelligent individuals, make a conscious choice to end their lives (Birnie, 1998). It is not known who supplied the Paraquat. Michael could not have obtained it himself and this makes it assisted suicide, although it remains unproven if someone did assist. Michael was determined to end his life, previously attempting to deny himself food and fluids.

It is argued by the right-to-die discourse that if a patient has the right to accept or refuse treatment knowing that a refusal will lead to death, then should that patient not also have the right to request any treatment, including euthanasia? Arguments around the right to autonomy increasingly centre on patients' right to make their own decisions regarding death and dying, and studies done indicate that patients fear powerlessness more than anything else in respect of end of life issues (Loewy, 2001; Singer, 2001). David Hill, a New Plymouth writer, argues against the sanctity-of-life stances regarding euthanasia:

Life is a divine gift; no human has the right to end it. Those who hold such beliefs have every right to refuse euthanasia. They do not have the right to impose their views on those who believe differently.

Legalising euthanasia will result in a cheapening of life, and will lead to increased abortions. A decision to weigh up the purpose and state of one's life and to decide whether to end it seems to treat life respectfully, not cheaply. The abortion parallel does not hold. Euthanasia involves a deliberate choice made by the person.

*(New Zealand Herald, March 14, 2003 p. A17)*

Michael Crew's case and David Hill's statement are examples, I believe, that epitomise the argument the right-to-die discourse is making against the sanctity-of-life discourse. The right-to-die discourse claims the principle of autonomy as the fundamental right to pronounce the truth claiming it calls for respect, dignity and, most importantly, choice. The moral principle of autonomy demands that we respect other people's choices, even if we disagree with them (Sommerville, 2001). The right-to-die discourse focuses on the individual and this is in contrast to the sanctity-of-life discourse in which the central focus is society as a whole.

The right to autonomy the speakers of the right-to-die discourse argue includes the right to choose death and, increasingly, voices are being heard which say others should not interfere with a person's decision to die. People argue that while a group may have an ideological belief regarding the wrongness of killing, this is not enough to prevent an informed, competent, terminally ill patient from making and acting on the patient's own judgement about whether his/her life is no longer worth living (Singer, 2001). Lesley Martin writes:

Because the people who have been brave enough to contact me since *To Die like a Dog* was released, complete strangers who have trusted me with their most painful and dangerous memories, are the people I'm fighting for now, and for all those people who are blissfully unaware as yet of how cruel dying can be at times.[...] On a personal level, yes, for the people I love as well, because I never want to be in this position again and feel so strongly that no one should be. I believe in personal autonomy and freedom of choice. These are my reasons for supporting Peter Brown's Death with Dignity Bill. The time has come to begin working on this issue. The cry for voluntary euthanasia legislation will not be silenced. The voices are only going to become louder, stronger, more strident.

(*Sunday Star Times*, July 20, 2003, p. A9)

This is in complete contrast to the sanctity-of-life discourse's belief that the concepts of rationality and autonomy are not strong enough to substantiate a "right to suicide" and that the concepts of understanding and respect are more useful and better able to provide the foundation for responding to a person expressing a wish to die (Clarke, 1999). The right-to-die discourse interprets autonomy to mean that personal liberty is the most important societal value and is contesting the sanctity-of-life discourse which believes this cannot offer adequate justification for the legalisation of euthanasia (Orr, 2001). Reference is made here to "how cruel dying can be at times" and it seems it is this construction of the process of dying, the where and how that people fear.

The following is Lesley Martin's story of the events that led to her being convicted of the attempted murder of her mother. When it was clear that Joy Martin was dying, she discussed with her daughter her fear of a long drawn out death and

asked her daughter to assist her when the time came. As related by her daughter Lesley:

Joy: When it's time...please help me...please...don't let me lie there, not alive and not dead...please help me...be quick...

Lesley: Oh God, mum....

Joy: and don't get caught...

(Martin, 2002, pp. 132 – 133)

At this stage of the illness and with the rapid deterioration of Joy's physical state, Lesley Martin depicts Joy as having lost the ability to do anything to help herself. She had become powerless, totally reliant on caregivers to attend to her needs. Joy was being treated for bowel cancer and had gone through a series of medical and surgical interventions, all of which had failed and resulted in the breaking down of an anastomosis and the passing of large amounts of pus and blood rectally even though she had an ileostomy. She was reluctant to have further medical intervention and had accepted at this stage that death was inevitable. There is also the reference made regarding life and death, when death may be seen by some as preferable to living.

The proponents of the right-to-die argue that this is not living, but a prolonged dying, and speak of the futility of keeping a body in this state in a few days is inevitable and the patient requests death (Hill, 2003; Richardson, 2002).

### *Death and dying*

Dying individuals by the very nature of their state become vulnerable. Speakers of the right-to-die discourse claim that the opinions and wishes of the terminally ill are not being heard because of the dominance of the sanctity-of-life discourse. The terminally ill patient and their families are described as going through their own journey which often includes denial, anger, questioning and finally, but not always, acceptance.

There are individuals in society who will never die well, who fight to retain the control of their bodies in illness as they have in health (Birnie, 1998). I think Michael Crew is one such example. It is argued that it is these individuals who will request assistance to end their lives before their lives become not worth living, and that the voice of the dying individual needs to be heard. This discourse claims that currently not only are these people facing their own death, but that in some cases they are also

having to deal with the guilt that their families may be prosecuted if they assist them to die, given that it is a crime to assist an individual to die (Moss, 2003). Individuals who are determined to end their lives cannot reveal their plans or the time of planned death because it immediately makes the person assisting them liable to prosecution under the Crimes Act. In a letter to the editor, George Pirie writes:

The only conscience vote on this subject that matters is surely one's own – not those of others, who should have no right or mandate to interfere. My wife of fifty-five years, my children, my doctor and my lawyer respect my wish not to be resuscitated if I suffer a stroke or a horrendous accident that would leave me almost totally incapacitated, not officiously to be kept alive. That is passive euthanasia.

As to active euthanasia, why should my own conscience not be the only one that counts, provided that I made my wishes clear while still of sound mind, as I am now?

*(Weekend Herald, August 2-3, 2003, p. A22)*

The right-to-die discourse argues that while euthanasia will be morally unacceptable to some members of our society, there is growing support for the idea that the differing views of other people should be respected also. For autonomous individuals who wish to control their dying in the same way they have their living, to have that choice available would be comfort enough, and it would alleviate their fear of dying a painful death that many cite as the reason for wanting euthanasia.

The dissatisfaction with death and dying, resulting in the request for greater choice and self-determination, comes from what is perceived as a “bad death” (Hillyard & Dombrink, 2001). This is where a patient may die in hospital, in intractable pain, hooked up to tubes, surrounded by strangers, and at the mercy of events beyond their control. In her book *To die like a dog* (2002) Lesley Martin attempts to raise the reader's awareness of the need to change our approach to death:

What if our dying died in full view of the rest of us?

What if we were all made to observe death every day, in all its forms? How would we cope if we felt their pain and fear, every time we met their eye?

What then? Would we treat death differently? I believe so. But we continue to avoid this last taboo because, for the most part, we don't see it and we don't feel it until we are involved. It's too late then to decide that to allow someone to die slowly is inhumane. We all have a voice and every voice, every life is important.

It is your life, and your death is the most significant personal moment of that life.

(Martin, 2002, p. 195)

Here I believe Lesley Martin is drawing to our attention society's attitude towards death and dying. Death, she is claiming in my opinion is treated almost treated like a hidden or covert process. As a society we don't talk about death freely, or about the manner of dying. (O'Connor, 1996). Many people have never had to face the death of a family member or friend and when they are involved, they rely on previously held belief systems surrounding death and the dying process (Birnie, 1998). Because of the shock, worry, grief and trauma often associated with the imminent death of a loved one, they are then incapable of re-evaluating the dying process at this stage.

I understand Martin's (2002) book to be a call for the legalisation of euthanasia, to bring out into the open the method of one's dying and to abolish some of the old belief systems and values that have constructed our perceptions and beliefs regarding death. When individuals adopt a certain discourse, as in the case of Lesley Martin becoming an advocate for the "right-to-die" movement, they also adopt a certain identity for themselves by taking up a position within that discourse (Foucault, 1980). This fits in with Foucault's notion of "technologies of self" which was one of his technologies of power (Foucault, 1997). People may actively employ "technologies of self" to shape their behaviour in response to discourses. People choosing euthanasia is an example of technologies of self whereby people choose for themselves to take up certain behaviours in order to attain personal self-fulfilment.

The claim to autonomy as used here is a powerful tool to claim the right to control one's dying, just as one's living. It is an assumed truth that the physician will make the right decision (Street & Kissane, 2000). The demand for autonomy challenges these truths and demands individual recognition of people's differences, their different perceptions of death and dying, and the possibility that there may be

another acceptable alternative to the current discursive practice of dying in our modern, diverse Western society (Silveira, Dipiero & Gerrity, 2000). The right to control our dying as we control our living is an argument that has been gathering in strength over recent years. Journalist Bruce Ansley states that no health professional likes to witness suffering:

Here is a deathbed scene:

The patient has a terminal illness and constant pain that cannot be salved with drugs. The patient, let's say that, like most euthanasia subjects, she is a woman, asks her doctor for information on how to end her life and to prescribe drugs for it. The doctor does so. Later she deteriorates, can't take the drugs unassisted and asks for her doctor's help. The doctor holds the cup. But the patient cannot swallow. She asks for a lethal injection. The doctor gives it.

*(The Listener, April 12-18, 2003, p. 16)*

The article states that when Auckland University psychology researcher Kay Mitchell put this scenario to 120 Auckland doctors, 30% of them said the doctor was justified in administering euthanasia. The public seems to support euthanasia as research from Massey University's marketing department discovered. One thousand New Zealanders were asked whether the law should allow doctors in identical cases to that above to end their patients lives. The result, released in January 2003, showed that 73% said it should (Ansley, 2003).

The right-to-die discourse I believe is revealed here as becoming more prominent and the public increasingly "likes" the concept of choosing when to die and of retaining control over their dying, as they have over their living (Ansley, 2003; Richardson, 2002). Jack Jones, president of the Auckland chapter of the Voluntary Euthanasia Society says his wish to exercise control over his dying moments won't change at the final hurdle. Journalist Ruth Laugesen reports his feelings on seeing a friend in her dying days at the hospice, emaciated and semi-conscious:

She was completely out of it, not recognising anyone. It brought me to tears. She was drugged into oblivion and lived for four or five days like that. I was absolutely appalled that she should have been left to this. She would not have wanted it,' says Jones [...] He said his organisation supported plenty of

government funding for hospices and palliative care. 'But a lot of people would find going into a hospice repugnant. Who are they to decide if one's quality of life is irreparably diminished to a point where you can't take it any more?' says Jones.

"People should have the right to make their own decision on whether they want to go on," he says.

*(Sunday Star Times, April 4, 2004, p. C2)*

Family and friends witnessing the dying of a loved one in a way that they would not wish for themselves are often proponents for the right-to-die discourse as shown above. It is argued that once they are in an institutional type setting individuals lose their ability to maintain control of their dying (O'Connor, 1996). For example, within the practice of palliative care, the patient must conform to the regime of care offered. A large part of the dying process revolves around control or the loss of control. Recalling the 11<sup>th</sup> September, 2001 tragedy, people were horrified at the television images showing people throwing themselves off the World Trade Centre to certain death rather than face the flames moments after the planes flew into the towers. What these people did was maintain control of an impossible situation that they found themselves in, and they chose to die by jumping to certain death rather than waiting for the flames to claim them (Richardson, 2002). In other words, they retained the ability to choose how to end their lives. de Vries (1999) claims that two-thirds of Americans end their lives in institutions, and there is a link to the issue of control and the fear of being out of control with no choices at the end of life. As stated earlier, the public increasingly like the concept of euthanasia as journalist Frank Haden writes regarding Lesley Martin's case:

She is challenging the establishment's disregard of the 75% of the population who approve of voluntary euthanasia.

We saw how far the official insistence on patients enduring to the bitter end has drifted from the community's wishes when Medical Association chairman John Adams was quoted as saying doctors do not support 'deliberately doing harm to a patient'. What of the harm they inflict when they won't do anything to grant begged- for release?

*(Sunday Star Times, April 13, 2003, p. C2)*

It is argued by the right-to-die discourse that, by refusing to meet the demands for euthanasia from a terminally ill patient, the physician is in fact doing a moral disservice to the profession and the patient they are meant to be caring for (Blend, Szalay & Knox, 1992; Clarke, 1999; De Haan, 2002; Doyal, 2001). Zinn (2001) states that studies conducted in the Northern territory of Australia during the nine-month period when euthanasia was legal before the legalisation was overturned consisted of evidence from interviews, letters seeking euthanasia, medical reports, coroner's reports and media reports. These provided the basis for analysis of the motivations and knowledge that informed the decisions taken by these people. One study of patients with cancer identified that hopelessness, depression, anxiety, being unmarried and having a poor prognosis significantly predicted a desire for death (Street & Kissane, 2000). In contrast to popular belief regarding pain being a primary reason for requesting euthanasia, research emerging now shows that it is powerlessness, social isolation and incapacitation that is more feared than pain (Loewy, 2001). However the "Right to Die" bill that was presented to parliament, and the public's perception, of it are based on the need to show mercy and compassion to alleviate pain in the terminally ill sufferer.

### *Pain, suffering and compassion*

The right-to-die discourse appeals for mercy to be shown towards someone who is in unbearable pain and at the terminal stages of his/her illness, and that this calls for euthanasia as a means to end suffering (Johnstone, 1994; Street & Kissane, 2000). The speakers of the discourse claim that it is not possible to relieve pain in every situation regardless of the quality of palliative care and pain management. For example, a letter to the editor by Anne Wilks of Devonport in *The Weekend Herald* states:

The idea that supporters of the Death with Dignity Bill were merely trying to avoid the pain of watching their loved ones dying is an insult to those of us who have to see a terminal patient in much more agony than could be felt by those who have to witness it.

Those who invoke blind dogma are endorsing devilish barbarism in the guise of humanity.

(*Weekend Herald*, August 2-3, 2003, p. A22)

The inability to effectively manage pain in all situations can leave lasting impressions on family and caregivers. Who would wish a loved one in their dying days to suffer excruciating, relentless pain unrelieved by medication? The sanctity-of-life discourse promotes palliative care as the effective management of dying, but the right-to-die discourse contests that pain is always adequately managed in these institutions. The speakers of the right-to-die discourse contest that it is the fear of pain that makes individuals seek euthanasia as an option. This excerpt challenges the sanctity-of-life discourse and questions what it terms a humane approach to caring for the dying. The right-to-die discourse disputes the value in seeing or having to witness another human being suffer and claims that these deaths are not successfully managed (Singer, 2001).

Lesley Martin published her account of her mother's death using the title "*To die like a dog*". The title is designed to make an impact. There have been many comparisons to euthanising animals and euthanising humans and Joy Martin is not alone in her comparison of the suffering of humans and dogs (Street & Kissane, 2000). For example, Street and Kissane relate the suffering of people to that of animals, arguing that if we are prepared to relieve an animal from suffering then we should be prepared to offer the same relief to humans. In one section of her book, Martin writes about a conversation between her mother and herself a few days after Joy's birthday:

Lesley: and we all yell at the top of our voices, YOU  
DIRTY BASTARD DEATH!...FUCK OFF! YOU'RE  
NOT WELCOME HERE!...WE'RE NOT SCARED OF YOU!

Joy: But I am scared...

Lesley: Are you?

Joy: Only of how it will be...of lying there, going inch by inch...it's so  
cruel, so cruel...we don't let our animals suffer like that.  
We treat our dogs better, don't we? It must be better to die like  
a dog that to die like a human being. When there's no hope...  
when it's time....

Lesley: I'll know...I'll know when it's time...I won't leave you like that...  
I promise...and I love you so much.

(Martin, 2002, p. 139)

This excerpt from the book, I think, demonstrates the concept of suffering and the fear of pain that many people are purported to hold at the end of life (Birnie, 1998). The daughter tries to alleviate her mother's fears about having no control left at the end of the disease progression, by promising to assist in her dying. It is this loss of control and fear of suffering that has become increasingly important to people. They do not want to suffer (O'Connor, 1996). This book challenges the reader to ask why is it not possible to get help to die if you are terminally ill. Why wait for the natural processes to take their course, and what is a "natural process" in the context of severe illness and hospitalisation? Once within the realm of the medical institution, whether it be hospitals or a hospice, many fear that they lose control of their lives, and when finally they ask for help to die, it seems no one listens (Martin, 2002). This discourse argues for an option to be available to be peacefully released when there is no hope and suffering is severe.

While most people would choose to live if they could, proponents argue that the terminally ill should not have to suffer when they do not have to, and physicians should be obligated to respond to the needs of their patients (Mussen, 2003). Speakers share a conviction that pain and suffering are often a fate worse than death. There is also the perception that modern medicine is impersonal largely because of technical training and it is argued there should be no place in society to expect a terminally ill patient to endure extreme and prolonged pain (Hillyard & Dombrink, 2001).

The right-to-die discourse also argues for the legalisation of euthanasia using the double effect doctrine as justification as discussed earlier. In an estimated 5% of terminal cases, pain cannot be relieved and the deaths of these patients, this discourse argues, are a passive form of euthanasia anyway, because the only way to give relief is to sedate the patients into a state of unconsciousness until death arrives. Research shows that a large percentage of hospice and hospital patients continue to suffer pain during their dying process (Birnie, 1998; de Vries, 1999).

Modern medicine uses a variety of pain scales to assess the degree of pain a patient may be in, and prescribe medication in accordance with this. The amounts of morphine administered increase with the degree of pain. In the case of terminally ill cancer sufferers the degree of pain experienced can be well beyond any conventional pain scale (a grid of specification), and the carers are left ill equipped to effectively care for the dying patient. The right-to-die discourse argues that, in fact, inadequate palliative care can result in terminal suffering and an ignorance relating to effective

pain control. There have been cases where doctors have refused to give sufficient amounts of morphine to the terminally ill in case they become addicted (Birnie, 1998). In *The Weekend Herald* a key prosecution witness to Lesley Martins trial recalled how Martin broke down and cried after being asked why she gave her dying mother a 60mg dose of morphine. Journalist James Gardiner writes:

Retired hospice nurse Wiki Alward told the court that Martin said she administered the morphine not because her mother, Joy, was in pain but because her mother had told her she did not want a slow, painful death' She rang Lesley Martin on the morning of May, 27, 1999, to see how Joy was and was told her discomfort had increased to severe pain so Lesley had given her all the remaining morphine, 60mg, in addition to the 10mg loaded in the driver.

'I said to her that was an awful lot of morphine and I would need to notify the GP, Dr Chilcott.'

Martin said her mother was now unconscious but comfortable, Mrs Alward said. [...] But later, on a visit, Lesley told her: 'My mother did not have increased pain. I gave her the medication because my mum had indicated she didn't want a slow, painful death and I didn't want that either.

(*Weekend Herald*, March 20-21, 2004, p. A5)

As a registered nurse, Martin would have been well aware of the effects of overdosing with morphine. If it is administered not to alleviate pain but to end suffering, then it became an act of euthanasia (McMahan, 2002). If a physician had given the morphine and had said it was to relieve pain, then there would have been no case. This is the hypocrisy that the right-to-die discourse currently highlights. The dilemma this discourse highlights is that while everyone believes a person should be able to die with dignity and be free of pain, the reality is that modern medicine has not been able to completely alleviate pain.

### *The Dying Patient*

Subjects within a discourse acquire, through the process of identification and identity, their position relative to others, and the dying individual by the nature of their illness

is vulnerable and reliant on those with the knowledge/power to care for them (Scarborough & Tanenbaum, 1998). Within the medical discourse when patients are diagnosed as terminally ill, by the very nature of their illness they are viewed in a different light to those who will be treated and returned to health. The physician knows that they will not be able to return the dying individual to health, and their main aim is to relieve suffering and treat the symptoms as the disease progresses in accordance with current accepted practices.

By diagnosing the patient with a specific illness, the physician can then treat the condition. In doing so the physician objectifies the subject (Powers, 2001). This enables the physician to objectively make decisions regarding the technologically best intervention to enable temporary survival or remission of the patient. The conflict occurs when the course of treatment prescribed differs from the request or wishes of the patient. Journalist Deirdre Mussen (2003) writes:

Alex Schuiten wants a good death. His desire encapsulates euthanasia, a blend of two Greek words – ‘eu’ translates to ‘good’ and ‘thanatos’ means ‘death’. Under current law, the 56-year-old Auckland physiotherapist has little hope of such luxury. Instead, he faces a suffocating struggle to breathe with respiratory muscles wasting from motor neurone disease.

Maybe I will die peacefully in my sleep but probably not.

If I knew [voluntary euthanasia] was allowed here, I could sit down and relax. It would give me peace of mind knowing I could have a peaceful death.

The thought of suffering when dying is a daily concern.

Hospice says you don’t have to suffer. They say they can look after you but that’s bullshit. They can give you the best palliative care in the world but you can get to a stage when quality of life doesn’t suit me anymore.

Euthanasia should be a part of palliative care – I’m so amazed that so many people in palliative care are so against it.

*(Sunday Star Times, July 27, 2003, p. A10)*

Alex is adamant in his desire for another option to be available to him. He is a health professional. As a physiotherapist he knows what his death is probably going to be like. He also knows that he will not have the motor skills left to be able to carry the act out himself and he does not believe that palliative care will provide him with the

support he wishes for when his death is imminent. The conflict for caregivers is how to meet the autonomous request of the individual when fulfilling the request is quite clearly against the law (Johnstone, 1994). In many cases the desire to show mercy and compassion and assist the demands of their dying family member are over-ridden by the legal bindings of the “sanctity-of-life” doctrine (Ansley, 2003). This can leave family and caregivers frustrated and disappointed that they may have failed the patient and the patient’s request for dignity. Dignity is interpreted differently here than within the sanctity-of-life discourse, which claims dignity can be retained throughout suffering. The right-to-die discourse is claiming that dignity is retained through release of suffering, and that assistance to do so in certain situations should be permitted. Writer David Hill states:

Most of us wish our lives to be good and dignified shapes. Legalised euthanasia seems one resource among many of achieving a shape that does not end in disintegration and ugliness.

*(New Zealand Herald, March 14, 2003, p. A19)*

The right-to-die discourse suggests that the patient is not always the central focus within this debate and what care is given, or not given, is often aimed at treating the family, the institution, the law, the health care team, or a variety of them (Loewy, 2001). It argues that there are individual cases where euthanasia is justified, and that there is no benefit in prolonging life any longer. If there is no obvious quality of life for a terminally ill individual in their last days then the question arises whether there is any value in that life.

Stress and loss of control often accompany a chronic or acute illness, and a terminal illness and the dying process that it initiates are often viewed as the ultimate loss of control (de Vries, 1999). In the Netherlands the reasons reported by physicians for providing assistance to die were severe physical and emotional suffering, and it was stated that these people wished to die in a dignified way, rather than in pain, being dependent on others and that they were generally tired of life (Van Der Maas, van Delden, Pijnenborg & Looman, 1991). The speakers for the right-to-die-discourse assert that it is their right to retain autonomy and control by requesting euthanasia. The current power relations that exist in institution type settings would be affected by euthanasia if the patient were to be given this right.

## *Power Relations*

In applying Foucault's (1977) interpretation of domination and resistance, it is possible to look, on the wider societal level, at the right-to-die discourse which is increasingly challenging the current laws, medical ethics and societal traditions with regards to the right-to-die. The right-to-die movement are groups who are united by common ideas. These include values and beliefs about the rights of people to make these self-determining choices in regard to life-sustaining care and treatment (Birnie, 1998) The right-to-die discourse is attempting to change the current laws regarding euthanasia which would enable an individual to determine how and when he/she may die. It is a call for the right to autonomy (Martin 2002; Moss, 2003).

The invisibility and pervasiveness of power in modern society was discussed at length by Foucault (1977). He argued that "disciplinary power" emerged with the introduction of the modern institution, such as hospitals and hospices, extending throughout society. The result of this until recently has been seen, I believe, in the sanctity-of-life discourses continuity in power relations. The right-to-die discourse is contesting this right, it is a very visible discourse and uses this visibility to contest the practices of the sanctity-of-life discourse whose power has been more pervasive, as described by Foucault in (Carrette, 1999).

Within the micro-systems of power, and at an individual level, the right to autonomy in current society is an example of the disciplinary power of the self that Foucault believed increasingly has been influencing the power shifts of modern-day society. While the traditional law dictates one particular action, i.e. not assisting another to end their life, the right-to-die discourse claims that it is an individual's right to choose the way they die just as they choose the right to live. Foucault analysed power as something which circulates, or functions as part of a chain, and which is used through a net-like organisation (Foucault, 1980).

The right-to-die discourse is constantly using opposing practices to strengthen its position regarding legislation being passed in respect of the right to die. Specific individuals and groups promote or resist particular ways of experiencing deviance, hence promoting or rejecting policies on euthanasia and this gives rise to the inevitable link between deviance, political action and social change (Hillyard & Dombrink, 2001). The claim for the right-to-die is a defiant and resistant discourse

that is challenging the moral standing of the sanctity-of-life discourse. The right-to-die discourse's challenging of the laws and of traditional medical practices concerning treatment withdrawal and the re-drawing of the line between "killing" and "letting die" has resulted in major political and cultural controversy.

*Domination of the dying patient.*

The request for assistance in dying goes against the traditional view the medical and nursing authorities seek to promote, and is not within current ethical accepted practices. Therefore the patient becomes the target to resolve this conflict if they request euthanasia. The wish to be able to function as an autonomous individual within this setting is most unlikely to be fulfilled. The power/knowledge that is held by the authority in this case supplies the treatment to care for the dying individual, increasing the power of the medical and nursing profession while reducing the patient's power and instigating their perceived preferred outcome, not the patients (Mussen, 2003).

What stands out quite clearly and what is different from other power imbalances within the medical institutionalised power/knowledge conflicts is that in the terminal stages of life the patient has completely lost their power to compete, and for their voice to be heard. Perhaps this is why we are hearing the request for euthanasia from people who are still categorised as "healthy" and not "terminal". Dr Hilary Moss planned his death by euthanasia. His wife Emily Moss (2003) writes:

He told me of his plan to take his life and why he wanted to do so. He believed in euthanasia, that after living a full, healthy, successful, rewarding, fun life with the girl he loved so deeply, it was time to turn it in and end it on a high note. [...] I could identify with his frustration and felt the suffering and loneliness he had by not sharing this most difficult decision with me. [...] We coped with his illness in a mature way, perhaps confusing the medical profession while trying to strive for a quality of life.

*(Weekend Herald, March 15-16, 2003, p. A5)*

Moss chose the timing of his dying rather than spend his final dying days in an institution. Even though a hospice claims to have a holistic approach to caring for patients, it cannot I believe accommodate people such as Moss whose demand for

autonomy is so strong. Moss and his wife retained control by remaining outside of the dominance of the institutional setting, with its previously discussed power imbalances. Leichtentritt & Rettig (2002) state that the social setting families and patients find themselves in can have a huge impact on the dying process. His wife comments that the medical profession were a bit confused by their approach. Implicit in this is the knowledge that Moss had his death planned and this gave them the confidence to cope with his illness. Personal, interpersonal, social and cultural issues are all important at this stage and the communication between the physician and the patient can have a huge impact on how the dying individual perceives their imminent death (Birnie, 1998).

Social psychology reveals to us that society in general is intolerant towards the non-productive, out-of-control and the physically unattractive (de Vries, 1999). de Vries states that these attributes have been shown to be anxiety provoking to others and if we look at dying individuals, these are all attributes that can be used to describe them. To effectively care for the terminally ill requires a great deal of skill. The possibility of a terminally ill patient being legally able to request physician-assisted suicide or physician-assisted dying raises important issues for nurses.

### *Nursing*

In general nurses' feelings and attitudes to physician-assisted suicide have been shown to be ambiguous (Georges & Grypdonck, 2002). While many see physician assistance in dying as unnatural, and even perceived it as murder, these feelings can change when suffering is involved. Assistance in countries where euthanasia is acceptable is seen as enhancing patient comfort and allowing a pain-free death and therefore as justifiable.

The nurse functions within competing discourses, and the complexity and different ways of seeing death and dying can result in conflicting feelings and emotions. (Dawe, Verhoef & Page, 2002). It is an example of how even though categorised as "a professional body", within this professional body each individual is unique and has the potential to see things quite differently. Dawe, Verhoef and Page (2002) found that nurses' beliefs about the morality of their compliance was influenced by: their views on patient autonomy; their conviction about the avoidance and relief of suffering; their degree of religious activity; the number of years they had been in practice, and their perceived role in the decision-making process.

The New Zealand Nurses' Organisation Code of Ethics presents a view that respecting the patient's rights is essential. Within the nurse–client relationship, under “Beneficence”, it further states:

Creating a partnership the outcome of which the client views as beneficial.  
Respecting the rights of clients to define safety factors related to the  
beneficence of nursing through their own subjective experience.

(New Zealand Nurses Organisation, 1995, p.14)

According to Johnstone (1996), sometimes a conflict occurs because the nurse has professional responsibilities to physicians and the institution they work within regarding patient care protocols and compliance with medical orders. This conflict can occur when patient's requests regarding care are not in line with the accepted dominant truth regime. Not only can nurses find themselves in a position where they may respect the autonomous rights of the individual, and have the essential qualities required to give good care, such as compassion, but they are also answerable to the physician, institution and legal system. Importantly, nurses also bring to work their own value systems and consciences about what they believe is right and wrong (Dawe, Verhoef & Page, 2002). Within the right-to-die discourse the major conflict that nurses face is autonomy, and respecting the patient's right to autonomous decisions versus the immorality of the act and the fear of prosecution. The nursing discourse results in nurses adopting certain subject positions that are fluid, depending on the environment they are in (Latimer, 2003).

Johnstone (1996), believes that one of the main dangers facing nursing is not the failure to formally state a position within this debate but that it lies in adopting a position that is too rigid to accommodate the diversity of values, beliefs and views of the nursing profession, the community, and individuals and groups who will rely on nurses for care at the end of their lives. Nursing needs to look at and address these issues, moving beyond the ethical and moral arguments and face the reality of the situations nurses are finding themselves in every day.

The perceived inappropriateness of medical treatment is frequently described as an important source of moral difficulty for nurses (Georges & Grypdonck, 2002; Ravenscroft & Bell, 2000). Disagreements with physicians' decisions regarding end-of-life issues and the use of advanced technology on terminally ill patients lead to a

conflict of care between the medical and nursing profession This conflict arises because the nurse's duty is to try to ensure that the patient has the most dignified and gentle death possible; however, they are in a sense "handmaidens" to the medical discourse and the physicians' decision making. Within the realm of the dying patient, nurses are often faced with situations that, while not contravening their code of ethics, fall outside their procedural guidelines. For example, Asher (2004) states that nurses have for years been complying with the medical instructions which result in the doctrine of double effect. Joy Bickley Asher a New Zealand nurse academic states:

Nurses and doctors carry out other practices at the end of life, where one of the known effects is the death of the patient. These practices occur in a context where legal guidance and control exist, for example the Crimes Act 1961, The New Zealand Bill of Rights Act 1990, and the Health Practitioners Competence Assurance Act 2003.

(*Kai Tiaki*, June 2004, p. 20)

Asher raises the controversy surrounding the covert nature of double effect. The fact that double effect is not discussed or brought out into the open could have emotional consequences for the caregiver who has to follow orders unaware of whether they are in fact liable for prosecution by breaking the law. Within the right-to-die discourse, it becomes an essential necessity for health professionals to address the impact that a change in legislation giving patients the right to die would bring. Health professionals are obviously involved in acts, on occasion, that may be considered euthanasia and there is little the law offers in the way of protection if an investigation were to be undertaken. The right-to-die discourse argues that a change in legislation would offer protection to the health practitioners who are currently involved in these covert practices.

### *Palliative Care: a discursive practice*

The right-to-die discourse recognises the importance and value of palliative care but draws upon its shortfalls to strengthen its argument for the legalisation of euthanasia. Proponents of euthanasia argue that this should be introduced as an option into palliative care for those who choose it and particularly for the few that do suffer. The right-to-die discourse emphasises that no patient should be made to die in ways

that, while meeting the moral or religious precepts of some, are not the same as their own (Singer, 2001). Journalist David Hill writes:

Medical science will keep finding new ways to alleviate pain and prolong happy and productive life. Excellent. When this happens, who would wish to die? Until it happens, why should some people have to suffer pain and degradation?

*(New Zealand Herald, March 14, 2005, p. A17)*

The right-to-die discourse raises the underlying concern for its speakers regarding the aims of the carers, which may differ from those of the patients, and how they need to be able to cope with the emotional problems of the patient and family; this includes spiritual anxieties (Georges & Grypdonck, 2002). An example of this is a letter to the editor by Terry Verhoven where he asserts claim to autonomy, he states:

From the skin inwards is my jurisdiction, is it not? I choose what may or may not cross that border. Here, I am the customs agent. I am the coastguard. I am the sole legal and spiritual government of this territory and only the laws I choose to enact within myself are applicable

*(Sunday Star Times, July 27, 2003, p. C9)*

I think this gives an example of the completely opposing views of the two contesting discourses. I interpret the quote by Terry as a very clear statement to the reader that he is in sole control of his body, and no one has the right to dispute that claim. This supports my earlier claim that many of the people who are pushing for a change in legislation are described as intelligent people who are determined to maintain control of their lives (Birnie, 1998). Although palliative care offers its services to all dying individuals, I believe Terry would struggle within this regime of care because of opposing philosophical beliefs. The right-to-die discourse speakers claim that they should have the right to ask for assistance if that is their wish; their dying process is unique to them and we should respect the individual goals and values of the dying patient even if these goals conflict with the current practice of care (Hillyard & Dombrink, 2001; Oddie, 1998; Richardson, 2002). The right-to-die

speakers argue they should be entitled to have their wishes heard over others. David Hill states:

The reverse of this argument is whether others' wishes should be placed ahead of the patient's. If the dying person makes it clear the decision is entirely his/hers, any guilt should be minimised.

*(New Zealand Herald, March 14, 2003, p. A17)*

An integral part of the concept of autonomy is the ability to make choices, and self-determination (Clarke, 1999). Within the discursive practice of palliative care, the carer has power over the patient because they are in possession of the skills that the patient needs in order to be cared for well. This creates a difference in the power balance between patient and carer which is also evident in access to the resources for treatment; the patient can only get them through the carer. In a social context, the patient may feel inferior with regards to the language used, i.e. the medical terminology. This may result in the patient becoming disempowered by such feelings (Birnie, 1998). A physician will often have a stronger justification as to why a treatment should be used than the patient's counter argument and this can lead to the patient complying with the "experts" opinion and setting aside their own.

We are also dealing with the healthy versus the dying here, and this situation results in physical strength and stamina as power inequalities in themselves. These inequalities of power can have the result that the patient takes the path of least resistance; their autonomy is compromised. They become vulnerable and at the mercy of their caregivers. These inequalities have resulted in the patient's voice not being heard. A dying patient is not going to complain about the caregivers they are dependent upon, and the families are often too distressed and dealing with their own grief to do so (Randall & Downie, 1996). I think this reveals the importance of the physician's role in this debate that will be discussed next.

### *Physician-assisted dying*

The enforcement of informed consent, strict legislation and protective measures, with the physician acting as a gate-keeper, the right-to-die discourse claims, will be sufficient to protect society from the slippery slope (Keown, 1999; McMahan, 2002). Physicians should be the providers of comfort as much as they are healers. If we

accept that physicians are fundamentally responsible for relieving discomfort or disease, then it could be said that euthanasia is also part of their role. It could also be argued that contrary to the idea that the patient will feel mistrust towards the physician regarding their ability to dispense lethal drugs, they will in fact feel more fear when they are suffering intolerably with no other options available than those currently at the disposal of the medical profession.

Since the 1970s codes of medical ethics increasingly have added “respect for patients’ autonomous decisions” to the duties of non-maleficence and beneficence. Research in New Zealand indicates that of 693 general practitioners who had made a medical decision at the end of life of a patient in the previous 12 months, 5.6% had supplied or administered drugs with the specific intention of ending the patient’s life (Mitchell, 2004). That physicians are assisting their patients, when requested, to end their lives is supported by studies elsewhere, and the results indicate that physicians themselves may be confused as to whether their actions constituted euthanasia or not (Van der Maas et al., 1991; Kuhse, Singer, Baume, Clark & Rickard, 1997). Martin Johnston similarly comments:

In one year, 39 GPs have performed euthanasia or helped a patient commit suicide, a researcher has found.

The study found that in 225 cases, GPs were in a legal and ethical grey area of stopping or withholding treatment or boosting pain relief, such as morphine, at least partly with the intention of hastening death.

The patients in both groups had been close to death or suffering a terminal illness” [...] Euthanasia is legal in Belgium and the Netherlands and doctor assisted- suicide is permitted in the American state of Oregon.

Dr Mitchell said there had been only 91 cases of doctor- assisted suicide in Oregon since its legalisation in 1997. ‘This idea that the floodgates will open is not being supported by the figures.’ [...] Dr Mitchell said the 225 cases of withheld treatment or increased pain relief were a grey area because the doctors may have been intending to reduce patient’s suffering as well as to hasten their deaths.

*(New Zealand Herald, March 21, 2003, p. A8)*

Western society functions quite differently to many other societies and as a democracy we live according to the rules and laws that this society has constructed

over time. Within this debate, the medical profession is often perceived as the group that knows what is best for society with regard to medical care and treatments available and it is this that is being challenged by the pro-euthanasia movement (Dunnett, 1999). Chapter four showed the emergence of the power/knowledge basis of the medical profession and its influence on current laws and acceptable societal rules when caring for the ill or dying individual. Its dominance over the human body since the 19<sup>th</sup> century has led to the general acceptance of the medical professions decision making regarding treatments and options available.

The physician acts as the gatekeeper in this relationship. The physician holds the power/knowledge as to what treatments are available, if any, and knows reasonably well what the journey ahead entails. It is therefore the physician who has the authority to justify treatments to the patient. The sanctity-of-life discourse speakers use the legal system to affirm its truth status and this is contested by the right-to-die discourse. The right-to-die speakers argue the limitations of the current laws. These speakers propose that strict procedural regulations and guidelines will serve to protect society and this is discussed next.

### *Axis of Authority*

The right-to-discourse claim their right to speak by contesting the discursive practices of the sanctity-of-life discourse. The speakers of this discourse reveal covert practices to the public in an attempt to encourage dissension and controversy. Highlighted are stories of patients and their families who speak out in an attempt to claim their right to autonomy (Horwood, 2003; Moss, 2003; Verhoven, 2003). These individuals and their families assert that society needs to redefine what is deemed morally acceptable and what is deemed not, such as treatment withdrawal and assisted suicide (Ravenscroft & Bell, 2000).

The right-to-die discourse argues that these boundaries determining what acceptable practice is and what isn't have become blurred. The legal line that has traditionally been used in Western society is between killing and letting die. This has changed and the right-to-die discourse argue that some of these acts are in fact a form of euthanasia (McMahan, 2002). The list of the once fundamental distinction that has now been erased include: withholding versus withdrawing treatment; the rights of the competent versus incompetent patients, the rights of the terminally ill versus those of

non-terminally ill patients; and the distinction between extra-ordinary treatments (artificial respiration), and ordinary treatments such as artificial foods and fluids (Hillyard & Dombrink, 2001). The legal mechanisms that have accomplished these changes include the introduction of living wills, power of attorney, substituted judgement and rules of evidence. The relevance of the laws has also been challenged, since this discourse argue that the New Zealand law is based on a dated English legal system. Journalist Frank Haden states:

Opponents hope defeat of the bill will reinforce the power of the legislature, the medical profession, the courts and the conservative churches to insist patients must go on suffering right up till the moment an all-knowing, all-powerful God decides they have suffered enough and lets them die  
[...] Never mind the far-fetched scenarios of greedy relatives ganging up on rich uncles. Voluntary euthanasia aims at no more than a gentle and easy death for as many terminally sick people as want it.

*(Sunday Star Times, April 13, 2003, p. C2)*

I see here that Haden is quite clearly stating an aversion to the current rules and institutions that are upheld by the sanctity-of-life discourse. He is contesting the right of the sanctity-of-life discourse to enforce its “truth” on others who wish otherwise. It appears he is making a mockery of sanctity-of-life’s assertion regarding the slippery slope and economic abuses that the speakers of the sanctity-of-life discourse claim could or would occur. The right-to-die speakers are arguing that the laws need to be adapted to our current social environment, and that the autonomous individual has a right to be heard (Clarke, 1999). The right-to-die discourse is claiming a change in legislation is needed because they say individuals are covertly using the practice of euthanasia. The reference to the courts here addresses the leniency that the New Zealand courts are showing to individual cases that they term “mercy killings”. For example journalist Alison Horwood reports:

A Kapiti Coast couple celebrated their 60<sup>th</sup> wedding anniversary one day before the wife was found dead with a plastic bag on her head, her unconscious husband lying beside her. The 89-year old husband spent two nights recovering in Wellington Hospital and was yesterday charged with her

murder. [...] Both had spoken about dying. 'They said there was nothing left for them in this life and that they were happy to go.'

*(New Zealand Herald, January 1, 2003, p. A5)*

There is no question in this case that the husband was not devoted to his wife. Both had been members of the Voluntary Euthanasia Movement. The determination of speakers within the right-to-die discourse to follow through with their fundamental beliefs regarding the right to die is creating difficulty when these cases come before the courts. This is how the speakers claim their authority and right to speak. They are openly flouting the law. It is asserted by the speakers of the right-to-die discourse that introducing legislation that allows euthanasia in certain situations will reduce the number of covert acts of euthanasia that are happening in New Zealand (Asher, 2004; Horwood, 2003; Martin, 2002; Moss, 2003). An anonymous reader states:

The time has come for the law to recognise that those dying in intolerable suffering have a right to be helped to die.

Surveys consistently show that most New Zealanders approve of voluntary euthanasia. Lawmakers should ponder the deep moral sense that informs this view.

Most people, confronting the suffering of a loved family member whose life is ending, feel that it is right to heed the call for deliverance. When the individual finds life intolerable and considers death a release, who are we to argue otherwise?

This is the answer to those who say that helping others to die is to play God. To refuse to help, is also to play God, if that means making life-and-death decisions about a person in pain.

*(Sunday Star Times, July 20, 2003, p. C8)*

This excerpt to me sums up the right-to-die discourse speakers' call for the legalisation of euthanasia. It claims that until the law acknowledges the public's demand for euthanasia, covert acts and individual cases will keep coming before the courts. The fact that it is the Crimes Act that is used to judge the people involved in these documented cases of euthanasia in New Zealand is also being challenged. However, within the current legal system, the law is clear. Regardless of an

individual's or even society's call for euthanasia, to assist a person to end their life is illegal. Any act that is seen to hasten an individual's death is against the law and acts as a powerful deterrent to the majority. The right-to-die discourse justifies euthanasia because of their right to autonomy; it also claims euthanasia is a current covert practise under the guise of "double-effect". This is discussed next.

### *Axis of Justification*

Lesley: Well, sometimes the so called right thing isn't right and the so called wrong thing isn't, really wrong at all...know what I mean?

(Martin, 2002, p. 35)

The proponents of euthanasia claim the individual right to autonomy as justification for introducing euthanasia as an accepted option at the terminal stages of a dying person's life (Clarke, 1999). This was discussed in depth at the beginning of the chapter. The right-to-die speakers state that procedures and guidelines will avoid the slippery slope which the sanctity-of-life speakers use to justify their stance against euthanasia.

While the law has traditionally prohibited suicide, it has permitted the other treatment decisions previously discussed which have resulted in the death of the patient, i.e. withholding and withdrawing treatment. The most common justification for the distinction between treatment withdrawal and suicide assistance is that suicide assistance involves the act of killing while treatment withdrawal only entails letting patients die from their disease (Orentlicher, 2001). The right-to-die discourse, however, disputes the practice of double effect which is considered to be within the law, and claim that it is in fact euthanasia. Nursing academic Joy Bickley Asher writes:

Euthanasia practices do occur in New Zealand. This is borne out by nurses stories and research. It is common knowledge about an uncommon act, e.g. a doctor or nurse injecting morphine into a terminally ill patient, knowing that there are two likely effects – pain relief and death.

(*Kai Tiaki*, June 2004, p. 20)

Whether for or against euthanasia Asher and others argue that euthanasia is performed under the guise of double effect and that is really physician assisted

suicide. Legalising euthanasia, the right-to-die discourse argues will actually help many physicians and health professionals who face ethical dilemmas in respect of this issue (Johnston, 2003; Singer, 1998). The relief of suffering is considered by many carers to outweigh the risks associated with double effect and it is generally accepted that those who are terminally ill benefit from alleviating suffering from sedation, if all else has failed (Randall & Downie, 1996). Dr Philip Nitschke is an active euthanasia campaigner. He writes:

Some doctors would help selected patients, but the ‘help’ offered was always in the form of an offered slow increase in morphine over a period of days so the doctor could plausibly argue that their prime concern was the relief of suffering; death if it occurred, would have to be described as an unwanted but unavoidable consequence.

(Nitschke cited in Martin, 2002, p. 204)

Nitschke is critical of the principle of double effect and believes that it is wrong to send people into “pharmacological oblivion” often lasting days, and believes it is time for a more honest approach to the care of the dying. There is a conflict of opinion between the two discourses here. The sanctity-of-life discourse argues that the role of the doctor would change by legalising euthanasia, and the right-to-die discourse speakers such as Nitschke believe otherwise. The right-to-die discourse claims that the current perceived hypocrisy of medical practice at the end of life does in fact do little to install confidence in the medical profession (Dunnnett, 1999). The call for a more honest and open approach to caring for the terminally ill and the treatments given is how the right to die discourse justifies its call for the legalisation of euthanasia.

### *Summary*

This chapter has analysed the data selected using a structural analysis and an analysis of power relations. Within the axis of knowledge the right-to-die discourse emerged as a competing discourse within the euthanasia debate. The dying patient became the main subject for scrutiny and the objects of the discourse were death, dying, pain, suffering and compassion. Within the axis of authority, the right-to-die speakers are challenging the law, which is a powerful determinant in ensuring that the sanctity-of-

life discourse preserves its regime of “truth”. The right-to-die discourse challenges this authority and is challenging the limits set within the euthanasia debate. The third axis is that of justification, and proponents of the right-to-die argue that current practices are covert in nature and that society needs to adopt a more open approach to death and dying. Power relations are complex within this discourse and time was taken to reveal the role of the physician within this discourse. The right-to-die uses resistance practices such as encouraging public debate and highlighting public cases of euthanasia to promote its cause. The speakers of the discourse point out that the sanctity-of-life discourse does not meet the needs of a large sector of society that doesn’t conform to its regime of truth.

The next chapter will discuss the findings of the analysis chapters and the implications of these findings.

## CHAPTER SEVEN

### *Reflection and Discussion*

#### *Introduction*

This chapter reflects on the analysis and discusses some of the possible implications if legislation is passed in the future allowing for euthanasia. It involves looking at the influences speakers of the sanctity-of-life and the right-to-die discourses have had in promoting their belief systems, and how they have put this influence into effect to promote their particular regimes of “truth”. The findings and issues will be identified and discussed followed by limitations of the study and recommendations for future research.

#### *Discussion*

The distinction between euthanasia and letting die remains fluid and is being repeatedly reconstructed by the two competing discourses resulting in a blurring of the boundaries, interpretation and ever-changing definitions of euthanasia (McMahan, 2002). The genealogy revealed the emergence of the right-to-die discourse, and how the scientific and technological advances of the 20<sup>th</sup> century have resulted in the medical conviction to preserve and save life at all costs. From this I believe I have shown how the demand for the right to autonomy emerged, resulting in an increased awareness regarding death and dying. A growing aversion arose to dying in an environment surrounded by machines and high technology, where the patient had lost the right to speak and had come under the control and objective scrutiny of the medical lens. People have more recently questioned and challenged this, and demanded the right to choose how to end their days, and retain control over their dying (Hill, 2003; Mussen, 2003). The right-to-die discourse emerged from this increasing demand for autonomy in life and death decisions and challenged the previously dominant sanctity-of-life discourse.

Euthanasia is a highly controversial and complex subject and my genealogical analysis revealed the influence the principle the “sanctity of life” has had until

recently on Western society's perception of the ethical and moral "wrong" of euthanasia. In Carrette (1999), Foucault is cited as having described this insidious absorption of religious discourse throughout our society as "pastoral power". This power enabled the sanctity-of-life discourse to claim its "truth": that life is always sacred. However, this claim is being actively contested by the rapid growth in numbers, strength, power and publicity of the "right-to-die" discourse campaigners who promote euthanasia as a "right" for all individuals, i.e. the right to have a choice in how they die.

An example of how this has been achieved is the introduction of subtle changes in language use which has helped quietly, to transform society's perception of euthanasia, from being an unacceptable idea to being an appealing concept for many (Smith, 2004). As described in chapter four, euthanasia has been replaced by terms such as "a gentle landing" or a "death with dignity" in order to soften and increase its gradual acceptance in society.

The recent media interest and Lesley Martin's conviction in 2004 for attempted murder, has also served to bring to the New Zealand public's attention issues regarding euthanasia which had previously been covert in nature. As a consequence, many people previously ambivalent or uninterested in life and death issues have been forced by the media interest to consider whether they are for or against euthanasia.

In chapter four, a careful effort was made to define the term euthanasia, because euthanasia has been used to describe many different ways of assisted or non-assisted dying; each way is quite different from the others. For this study, I restricted analysis of euthanasia to a broad examination of the two competing discourse. Because of the complexity of the euthanasia debate and the issues that were revealed during analysis, it was necessary to confine the study to the terminally ill individual who is thought to have only days to live and to focus on the nurses role rather than the physicians.

The analysis makes it clear that it is not using the term euthanasia as either involuntary or non-voluntary as defined in chapter four. The use of the term is very specific. The group that is being considered fall into the 5% of society who, despite modern medicine, are destined to die in intractable pain; their deaths are inevitable; and they request assistance to avoid unnecessary suffering (Birnie, 1998). What became evident during this study was the growing public support for euthanasia. As

stated in chapter six, a Massey University survey of 1000 New Zealanders, conducted in August and September 2002 showed that more than 70% of these New Zealanders support assisted suicide for someone with a painful incurable disease, provided it is a doctor who gives the assistance (Ansley, 2003).

New Zealand criminal laws have changed comparatively little since first introduced and it is argued by the right-to-die discourse that they were constructed in a different social environment to that in which we currently live. In contrast to this, our society has changed considerably in most aspects of life. Examples were given in chapter four of the change in attitudes to withdrawing and withholding treatment. In today's society right to die issues are being questioned by people deploying this discourse. The right-to-die discourse is challenging the fact that it is the Crimes Act which is used to determine whether a person is guilty of euthanasia or not. Instead they are proposing strict legislation and guidelines enabling euthanasia which would protect the vulnerable. While the courts show sympathy towards what they term "mercy killings", the legal system has been shown to be a powerful force in this debate and in effect supports the sanctity-of-life discourse.

Today, on a political and social level, ethical and moral reasoning by governmental, medical and institutional forces remain guided by the "sanctity of life" principle. The Hippocratic Oath is also based on this doctrine, and it is this that creates the medical and nursing professions' potential dilemma with respect to euthanasia, regardless of where their individual or collective sympathies lie (Johnstone, 1994). Whatever an individual's opinion regarding euthanasia may be, the current law is clear with respect to assisting in another's dying: it is illegal. For health professionals this gives clear guidelines to follow in their professional, ethical and moral conduct. Regardless of their personal wish to respect a patient's autonomy; nurses and doctors will be breaking the law as it stands if they openly assist any patient to die and this is a powerful deterrent. The right-to-die discourse challenges the value put on the sacredness of human life. Its emphasis is more on the quality of life, and it questions why is it not possible to relieve suffering when death is imminent and it is requested (Singer, 2001).

Foucauldian analysis has been a valuable method for studying euthanasia and healthcare related to terminal care because I believe it uncovers current practices which are constructed within the contested sanctity-of-life discourse. It raises awareness, and challenges many of the taken-for-granted aspects of New Zealand

health care, in particular palliative care. It also shows the dominance of the medical discourse. The vulnerability of the dying individual, I believe, has been shown in this study with the relations of power revealing how the current health institutions maintain control and therefore power over the dying patient.

Research indicates that there are more and more individuals and groups of individuals in society who are dissatisfied with the care dying patients receive and with their loss of control over their dying (Hill, 2003; Moss, 2003; Mussen, 2003). Palliative care's philosophy in caring for the terminally ill is constructed around the "sanctity of life" principle. While palliative care unquestionably provides society with an invaluable service, how well it serves the groups who do not follow the Christian ethos and have alternative belief systems is questioned by the right-to-die discourse. While patients are grateful for the care this service provides, they do not always wish for the implicit spiritual or religious dimension of care offered, and wish to retain control by choosing their time of dying, with assistance if necessary (Henzell, 2004; Mussen, 2003; Singer, 2001).

This is not possible within the current system and regime that palliative care offers. The sanctity-of-life discourse constructs effective palliative care and pain management as the best options for meeting the needs of the dying individual. The right-to-die discourse argues that not only are these services often inadequate, but that there is also a small percentage of terminally ill patients whose pain cannot be effectively managed, hence the need for an alternative such as euthanasia to alleviate their suffering if they so request.

On a subjective level, the terminally ill individual becomes an object of scrutiny under the medical lens, with many claiming that they lose any feeling of control over their own health (Martin, 2002). While many patients who become ill make a similar claim, the dying patient falls into a different category because ultimately there is no cure. Often they are made even more vulnerable by their poor or failing health, which leaves them unable to do the things a healthy person is capable of. This frailty occurs not just as a result of their physical deterioration but also because of their spiritual and emotional vulnerability (Dunnett, 1999; Hillyard & Dombrink, 2001; Moss, 2003; Palmer, 2000). In analysing the data it became clear just how vulnerable the terminally ill become within the current health system. The sanctity-of-life discourse states that society has a fundamental duty to treat all people as equal. The right-to-die discourse argues that the dying patient is quite clearly not

equal: their illness makes them vulnerable and they have needs that differ from those of a healthy individual.

The dying individual is perceived as different by their very diagnosis. They are placed in a separate category by many. People react to them in a different manner and it is argued that many are uncomfortable when it comes to caring for or dealing with a dying person (Birnie, 1998). It emerged throughout this study that Western society in general has an uncomfortable attitude towards death and dying: we do not like to discuss it or deal with it. Perhaps it is this that makes the discussions on dying “right” and individuals demanding the right to die so controversial.

In a society where the emphasis has been on curing disease and illness, and where death has often been perceived as failure of treatment by the medical profession, the dying patient clearly is not going to recover, and they are certainly not healthy. Therefore, the right-to-die discourse claims they have different needs which must be addressed (Sommerville, 2001). Because death and dying have been treated in such a covert manner it is argued that the voice of the dying has not, and is not, being heard; it is claimed they have the right to retain control over their dying as they have over their living and therefore the right to choose another alternative if they so wish. The proponents of the sanctity-of-life discourse argue that it is a fear of death and of a pain-ridden dying process that drives an individual to seek euthanasia as an option, whereas the right-to-die discourse claims that what patients tend to fear the most is powerlessness. It is in the domain of this desire to retain control that the notion of autonomy becomes a major player in the demand for euthanasia.

The speakers for the sanctity-of-life discourse claim that many terminally ill individuals requesting assistance to die are depressed, and state that if the depression is treated then the patients will lose the desire for a premature death. In fact, the most common reasons cited by patients for wishing to end their lives are: depression; excessive, chronic pain; being given a terminal prognosis; decreased quality of life; degenerative illness; to save costs associated with care; loss of independence; loss of dignity and a lack of control over life (Robinson, 2001). Similarly, in the United States, studies based on interviews with terminally ill patients revealed that 8.5% expressed a desire to die that was associated with depression, pain and poor social support (Drickamer, Lee, & Ganzini, 1997). The study revealed the importance of understanding the source of the patients’ suffering and the reasons why they do not want to live. In the majority of cases depression can be treated and pain can be

successfully managed. However euthanasia is requested not for one single reason, but for a combination of many, therefore the request for euthanasia is complex and many faceted.

In the state of Oregon where physician-assisted suicide is legal, only 4% of all patients actually die from euthanasia even though the option is available (Blend, Szalay, & Knox, 1992; Street & Kissane, 2000). The main reason is thought to be that patients' perceptions have been shown to be unstable and to change in relation to the degree of illness. Often patients, who wish for the right to euthanasia at the beginning of their illness, change their perceptions as the disease progresses and die a natural death. Studies that have been done on euthanasia in the United States show that the majority of Americans support the possibility of euthanasia for patients with unremitting pain or who are terminally ill (Wilson et al., 2000). While a majority of those surveyed found euthanasia acceptable for the terminally ill suffering unremitting pain, less than a third supported it when the patient desired it because of fear of being a burden on the family.

Foucauldian discourse analysis provides an opportunity to examine the circumstances in which domination and exploitation can occur. The sanctity-of-life discourse, with its claim that life is to be preserved at all costs reinforces the more traditional attitudes towards death and dying that have remained unchanged for a very long time. Within this discourse the dying patient remains very much under the dominance of the legal and religious "truths" that to take a life under any circumstances is a crime.

The sanctity-of-life discourse also claims that rather than the focus being on the individual's needs, we must instead consider the welfare and protection of society as a whole. A major concern put forward is the slippery slope argument, which states that the moment it is legally permissible for certain categories of people to die, then gradually this will be extended to other people who are not terminally ill with or without their consent (van Deldon, 1999).

The law dictates what is right and what is wrong; therefore currently euthanasia is a criminal act in the eyes of the law, the government and therefore wider society (Wallace & Johnson, 1995). This puts many dying individuals and their families in situations where, if they wish to end their lives at a time of their choosing, they have to do so by covert means and without the love and support of their families, knowing that in the eyes of the law they are committing a crime. Research and media

articles used in the analysis indicate that this is happening in our society today and the speakers of the right-to-die discourse argue that it is time that society addresses this and acknowledges that there are people who will follow through with their desire to end their lives (Ansley, 2003; Johnston, 2003; Moss, 2003). The right-to-die discourse speakers assert that the health system, and society's current laws and legislation are letting these people down, and suggest we need to look at a more dignified way to meet the needs of these people and their families. The "truth", they claim, is that people are taking their own lives rather than face a pain-filled death, or lose control over their dying. This, they also claim, is reflected in the growing following of the right-to-die movement. Giving strength to the right-to-die discourse is the literature available that indicates some form of euthanasia is occurring today, that it is obviously under-reported, and rather than continue to hide it, perhaps it would be better for it to be legally and morally accepted as an option (Birnie, 1998; Johnston, 2003; van Deldon, 1999; Zinn, 2001).

Current legislation forces the health profession to ignore these requests for euthanasia from patients even though a significant number of doctors believe that assistance to die should be given in certain situations, and some would say is given (Johnston, 2003; Kuhse et al, 1997). Within the sanctity-of-life discourse, voluntary euthanasia will always be morally unacceptable and considered an abhorrent practice, just as abortion remains morally unacceptable to many. The right-to-die discourse argues that euthanasia should become an available legal option, just as palliative care and withholding treatment are options (Singer, 2001).

Within the sanctity-of-life discourse, the physician retains the role of expert in decision making based on the best care options available for the patient. The legal system and the Hippocratic Oath function to regulate members of the profession and society, thus helping to uphold the beliefs which this discourse promotes. The physician is portrayed as having a duty to provide the best possible care to the patient and euthanasia is considered a threat to the trust that currently exists in the doctor-patient relationship (Birnie, 1998). The right-to-die discourse, in contrast, claims to offer the patient a more powerful position by asserting their right to autonomy and control. This alters the power balance between physician and patient. Although the physician still retains the ultimate power, because professional knowledge determines the final say on care given, and ultimately the physician has the legal right to refuse a patient's request. In contrast to the sanctity-of-life discourse, the right-to-die discourse

claims that euthanasia should be seen as being part of providing the best possible care to the patient (Hillyard & Dombrink, 2001; Singer, 2001).

People who choose to work in palliative care often have a strong spiritual desire to help the dying, and these people could feel conflict about being involved if requested to assist in an act of euthanasia (Birnie, 1998). However, there are also an increasing number of health professionals who feel their obligation to provide care, including respect for the rights of individuals and their claim to autonomy, means they should respect a patients' right to control their dying if so requested (Kuhse et al., 1997; Johnston, 2003). Members of the health profession have traditionally been taught that their role is to save life and not destroy it; consequently, many have pro-life attitudes and the issue of euthanasia creates conflict with their professional ethics (Oddie, 1998).

The right-to-die discourse claims that traditional approaches to treatment haven't taken into consideration the quality-of-life for those who are dying and many believe that the current accountability of the physician to uphold the Hippocratic Oath and the law has hindered the quality of many individuals' deaths. The speakers of the right-to-die discourse claim that there are cases in which death would improve the overall value of the patient's life, taken as a whole, and where continued life can only diminish it. It is argued that for some, death is a preferable option to a life devoid of quality (Mussen, 2003; Hill, 2003; Martin, 2002). The oppositional stances these discourses take to euthanasia are laid out: the sanctity-of-life discourse claims euthanasia is equivalent to playing God, whereas the right-to-die discourse argues that it is playing God not to help people die if that is their wish.

Against the sanctity-of-life discourse it is argued that sometimes the attempt to prolong life can make that life less worth living, and once medical intervention has been commenced it is much more difficult to then decide that it is futile and to remove it (Dunnett, 1999). As revealed in the analysis chapters this creates ethical dilemmas for nursing and medical professionals in many situations. There are grey areas when it comes to discussing death and dying. My analysis has revealed just how grey some of these areas are. An individual can choose to have no further treatment and they can choose to starve themselves to death by receiving no food or fluids (Loewy, 2001). This process does not ease the suffering of the patient but it does protect the medical and nursing professionals' from legal prosecution. The right-to-die discourse claims that it is unethical to watch a person die in this way, when the health professionals'

code of ethics states that they are to care for patients in a humane manner. Speakers of this discourse claim these unethical practices do nothing to alleviate the patients' suffering, when care should be aiming to provide physical, spiritual and emotional comfort. Physicians are also faced with questions such as: in an emergency situation when do you choose to actively intervene and when do you not, and when is it permissible to withdraw treatment without facing prosecution? (Landau, 1993; Loewy, 2001; McMahan, 2002; Palmer, 2000; Ravenscroft & Bell, 2000). More recently it has become a generally accepted belief that the role of health professionals is not to preserve life at all costs, but that to make lives as good as they can be (McMahan, 2002).

Pain emerges as one of the driving forces in the quest to legalise euthanasia. The right-to-die discourse argues that 5% of terminally ill cancer patients will suffer excruciating pain that remains unalleviated by medication (Birnie, 1998). Birnie found worldwide agreement that one of the main reasons why many die "bad" deaths (characterised by unnecessary suffering) is poor communication between doctors and patients. It emerges from investigations into why acute pain remains inadequately addressed, that the treatment of the disease still appears to be more important than treatment of the pain experienced. There remains a reluctance to give large amounts of addictive pain relief within some institutions, when it could be argued that addiction is not an issue in the case of the dying patient (Birnie, 1998).

The treatment of pain can result in a form of treatment termed double-effect (condoned by the sanctity-of-life discourse), which is used when all other methods to alleviate pain have failed. Terminal sedation is used with the full knowledge that no further treatment will be given, and it is given when pain management is insufficient to alleviate the symptoms of the dying individual. In effect this practice renders the dying patient unconscious. Usually the patient dies within a few days, and ultimately the goal here is to enable the patient to die in comfort (Randall & Downie, 1996). The right-to-die discourse speakers argue that the claim that this type of sedation is provided to relieve pain and not intentionally to kill is just a way for the medical profession to avoid breaking the law (Martin, 2002). They claim that it is only this lack of stated intention that differentiates double effect from euthanasia. It would seem to me that no one would argue that it is the humane way to care for the dying individual, but terminal sedation is bound up in murky and unclear definitions. A more honest acceptance of the inevitable outcome of terminal sedation could,

however, result in another gradual shift towards enabling euthanasia to become a more acceptable option.

It is this doctrine that speakers deploying the right-to-die discourse claim is in fact a form of passive euthanasia. They argue that there is little difference between double-effect and euthanasia (Johnstone, 1994). This discourse argues that in a controlled environment and with strict guidelines, physician-assisted suicide would not result in more people being euthanised involuntarily. These people are literally days away from dying, and there is no escape from the disease progression which is ravaging their bodies. By this time they have usually travelled their journey of grief and acceptance of the inevitability of death, and many just want to end what they perceive to be a life filled with misery (Doyal, 2001). A desire to be dead is not the same as a desire to be no longer alive, but many feel it is preferable to living in a way that they do not wish to. While palliative care tries to assist the dying individual move through the process of accepting death, health professionals are limited by their own institutionalised belief systems, and these will not always be the same belief systems held by the dying individual (Henzell, 2004; Moss, 2003; Mussen, 2003).

The double-effect reveals hypocrisy in the care of the dying. It quite clearly is used to alleviate suffering, but it also hastens death, as a consequence. According to the current law, the deliberate acceleration of death is not acceptable, even if it is given for extreme suffering. The double-effect gives the nursing and medical profession a way around the law: their aim being to alleviate suffering; not, they say, to cause death. The solution will not be simple. The issue is clearly not just about improving palliative care or legally allowing euthanasia to be introduced into society. It is not just about suffering, mercy, compassion, or belief systems; it is also about choice and the individual's right to choose how they die as they choose how to live (Birnie, 1998; Singer, 2001).

Optimal pain management is essential for effective palliative care. It would appear a technique of normalisation has occurred where it is expected that pain relief will cover a patient's pain. My analysis revealed this is not always the case and the discursive practice of palliative care hides dying people from the public eye. The right-to-die discourse reveals to the public this suffering and asserts that no human should be made to suffer. What emerged is what I believe to be of fundamental importance in the euthanasia debate: the need to protect society as a whole and yet try to meet the autonomous requests of the dying individual.

My analysis shows in the literature an increasing public acceptance of assistance being given to a terminally ill person in their final days, if they are in pain, and if so requested by the individual ( Ansley, 2003; Asher, 2004; Johnston, 2003). The demand for euthanasia, I believe, originates partly from society's aversion to discussing death as a natural part of life. If New Zealand follows the worldwide increased tolerance towards euthanasia, then there is a high chance that there will be law changes in the future with regards to euthanasia, recognising that a physician has the right to assist a terminally ill patient at the final stages of their illness to the best of their ability, even if this entails complying with a request to die with the provision of strict protocols and guidelines. The right-to-die discourse claims that the slippery-slope will remain exactly what it is... a theoretical principle which will not become a reality. The guidelines set out in the "Death with Dignity" bill are a start towards this goal. The guidelines ensure the protection of the weak, the elderly, the vulnerable and society as a whole from potential abuse; however, there can be no 100% guarantee. This bill would make it possible for the terminally ill to face their imminent death knowing that they would not have to suffer unnecessarily, and that there would be an option available to them that they do not currently have.

### *Limitations*

Problems arose regarding the very nature of Foucauldian analysis and the complexity and multiple layers that were revealed in this debate. It became necessary to close down certain areas of interest and relevance, such as the influence of Living Wills and Advanced Directives. I felt I only touched upon the place of the family and the implications of care given with regards to the family and the dying individual are considerable. It was a difficult task to stay within the word restriction of a Master's thesis because of the complexity of euthanasia and the surrounding issues, therefore these limitations had to be set to contain the subject and I acknowledge that I have only considered two of the many discourses that make up the discursive field of euthanasia.

### *Implications*

A concern I felt at the time I gathered material for this thesis was the relatively silent voice of the nursing profession. If euthanasia does become a legal option, then the nursing profession is faced with re-writing The Nursing Codes of Ethics and other legislation and protocols for protecting and guiding nurses in the workplace. The implications for the nursing profession and health professionals are, I believe, quite significant.

One of the original aims of this research was to use New Zealand nursing research and material for analysis. What I discovered is that the nursing voice is comparatively silent on the subject of euthanasia. There are no current guidelines for nurses to follow, which means they must rely on their experience and own judgement when dealing with day-to-day situations. If euthanasia were legalised in this country, I believe the nursing profession would not be ready, or equipped to deal with it because there are no guidelines prepared. Other countries such as the Netherlands and the United States have suffered similar problems and there is no reason to think that New Zealand would not face the same issues (Johnstone, 1996).

There must be clear guidelines and legislation to assist health professionals to deal with this issue, while fulfilling their professional responsibilities and facing their own moral and ethical dilemmas in respect of euthanasia (Georges & Grypdonck, 2002). The research presented in the analysis demonstrates that this is already an issue overseas for nurses who find themselves in the situation where they administer care that conflicts with their belief systems.

The worldwide leaning towards acceptance of the right-to-die should encourage the nursing profession to look at implementing possible change and the best strategies to prepare for it. Future study is required on pain management in palliative care, and individual attitudes towards death and dying; to determine the extent these attitudes may have in influencing society's leaning in favour of euthanasia.

## *Conclusion*

The euthanasia debate is not simple. The aim of this study was to uncover the different discourses understanding of “truth” regarding the right-to-die. The issues involved are very complex and the two main discourses presented provide persuasive arguments both for and against the legalisation of euthanasia. The debate is made even more difficult because of the different definitions of euthanasia that abound, and because of different perceptions held by people as to what the term euthanasia means.

Individual aspects that appear to affect public and personal opinions and viewpoints on the subject are personal experiences of witnessing a loved one suffer at the end of their life and the desire to maintain control over their death as they have had control over their life. If this fear of death and the dying process could be alleviated, perhaps the call for euthanasia would abate. This could perhaps be achieved by raising the public consciousness of death issues and by alleviating current fears regarding how individuals die.

Increasingly, public opinion favours euthanasia being legalised and the possibilities of abuse that this could create should not be played down. The slippery slope argument is valid and unless legislation and procedures for euthanasia are watertight, there is the possibility that abuse could occur. Literature suggests that this is happening already in the Netherlands and the risk should not be taken lightly. The aged, disabled and disadvantaged are potentially at risk if legislation is passed, according to much of the literature. Economically it is a much more viable proposition to euthanise the elderly and disabled rather than pay for costly rest-home or palliative care. There is a fear that the interests of the family or community may be placed before those of the patient.

A strong argument for legalising euthanasia is the right to individual autonomy. This is countered, however, by the sanctity-of-life discourse which is questioning anybody’s right to complete autonomy when we live in a society that dictates our behaviour, formation of belief systems and how we perceive the truth. It is argued that the principle of the “sanctity of life” overrides any right to autonomy. The argument claiming all life is sacred is powerful with the strength of the Catholic Church and other Christian and Judaic denominations supporting it. Within the healthcare profession, this principle has formed part of the Hippocratic Oath which medical professionals vow to adhere to throughout their careers.

Our society has changed dramatically and embraces many different religions, cultures and societies and the right-to-die discourse argues that the principle of the “sanctity of life” should not be forced upon cultures that do not necessarily support it. Many may also question whether it is a valid enough reason to change the current law which claims to be safeguarding society with the primary purpose of protecting and valuing human life because of the 5% of the population who will suffer excruciating and unremitting pain at the end of their lives. While the literature is unanimous that nobody should suffer pain like this, this study has revealed that while pain management is very much a current issue in palliative care for terminal patients, it is not just pain that is the main issue. Both sides of this debate support the idea that relieving a patient’s pain is of primary importance when caring for the dying. The nursing profession needs to be assertive in caring for these patients, arguing for sufficient pain relief and effective management of their pain. Criticism comes from the apparent hypocrisy of how it is deemed acceptable to induce death by relieving pain, but it is not legal to overtly induce death by this manner because this would constitute euthanasia.

While pain is put forward as one of the main reasons for the legalisation of euthanasia, my analysis revealed that, in fact, it is the call for autonomy that is the driving force within the right-to-die discourse. A concern that emerged is the possibility that if health resources were stretched, it may in fact become more financially viable to legalise the right to die. As a result of this study, further research is required to ensure more effective pain management is provided for terminally ill patients. Increased funding and resources need to be provided to palliative care facilities to ensure that the dying individual receives the best care possible.

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