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**Perspectives on Euthanasia: A Qualitative
Investigation of a Selected Sample of Health
Professionals and Lay People**

**A thesis presented in partial fulfilment of the
requirements for the degree of
Master of Education (Adult Education)**

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Glossary

This glossary contains the terms indicated with a number in the text of the project.

1. Active euthanasia occurs in those instances in which someone takes active means, such as a lethal injection, to bring about someone's death. Generally it is understood that the act is performed by a medical practitioner. The reason to perform euthanasia is to relieve a person who suffers a terminal illness or incurable disease of intolerable suffering. A distinction is made between voluntary (with patient consent) and involuntary (against the patient's wishes) euthanasia.

2. Passive euthanasia involves the intentional withholding of treatment. A distinction is made between voluntary (with patient consent) and involuntary euthanasia (without patient's knowledge). According to New Zealand law, withholding treatment does not constitute passive euthanasia.

3. Autonomy recognizes the individual's right to self-determination (according to beliefs, values and a life plan).

4. Beneficence means, "to prevent harm and promote good".

5. Nonmaleficence embodies the concept "not to inflict harm".

6. Justice deals with the concept of fairness; all people are required to bear an equal amount of benefits and burdens. The concept is sometimes used to advocate euthanasia since some individual's burdens are much more than those of others.

7. Vitalism This principle holds that life is a primary good.

8. Incompetent is defined as not having the necessary ability or skill to do something. In the context of end of life situations it often refers to a condition that renders the patient incapable of making an appropriate choice. Conditions such as a cerebral vascular accident, Alzheimer's disease or clinical depression fall in this category.

9. Competent is defined as having sufficient skill or knowledge to make a decision (Collins, 1999).

10. Understanding is defined by Collins (1999) as 'an appreciation, awareness, comprehension, grasp, or insight'.

11. Knowledge is defined as 'the facts or experiences known by a person or group of people, pertains more to feeling certain of the truth or facts' (Collins, 1999).

12. Spirituality; relating to a person's beliefs as oppose to his or her physical or material needs (Collins, 1999).

13. Suffering; to undergo or subjected to physical pain or mental distress (Collins, 1999).

Abstract

As a topic the practice of euthanasia is regularly in the news in New Zealand. It is also practised covertly such as withdrawal of treatment, mercy killing and withholding of futile treatment. Knowledge and perceptions regarding these practices differ. This study explores the possible difference(s) in knowledge base between health professionals and the general population in respect to euthanasia. This project, designed as a qualitative study was guided by the following research question: What is the knowledge base and decision-making process between lay people and health professionals regarding the practice of euthanasia?

The research was done through a qualitative approach by means of interview. In total fourteen participants from the greater Wellington area were involved in the research project, seven participants representing health professionals and seven participants representing the general population. The interview was designed to capture the knowledge base and insights and values of individuals with respect to euthanasia. Comparing the group of health professionals with the group of individuals from the general population resulted in some quantitative data.

The study initially looked at descriptive data pertaining to the topic of euthanasia, education and learning. Interviewing participants and analysing their responses in regards to the practice of euthanasia explored the cognitive and normative layers of knowledge. Educational theory was used to explain what was happening in relation to an individual's knowledge base regarding euthanasia.

The study found that the groups differed in educational background with respect to ethics and the topic of euthanasia with a higher percentage of the health professionals having received education pertaining to ethics and euthanasia. This may explain the fact that five health professionals were able to state a correct definition of euthanasia as opposed to two participants from the general population group. In both groups six of the seven participants were against legalisation of the practice of euthanasia;

however, five of the seven participants from the general population group and four of the seven participants representing health professionals were pro euthanasia.

Various ways of informal learning contributed to the knowledge base of the participants. Informal learning resulted in all participants being able to discuss issues related to the practice of euthanasia that were relevant, important and related to their value system. In this respect, there was no difference between the two groups.

This study has highlighted the difference in knowledge base between health professionals and the general population group. This difference being is the ability to define the term euthanasia. All participants in this study were able to voice opinions on whether euthanasia is practiced and should be practiced or legalised. This study showed that informal learning was important in the acquisition of knowledge and that participants from the general population group were less confident in their knowledge regarding the topic of euthanasia. In view of the findings of this study, it is recommended that since, euthanasia is practiced, an open debate at national level should take place. In view of the ethical issues encountered in everyday living, it is recommended that all New Zealanders are educated regarding ethical issues concerning euthanasia .

Chapter 1

Introduction

This study is focussed on euthanasia. In this chapter I will explain the relevance of the topic, my motivations for this study and the thesis outline.

1.1 Preface

An elderly woman was admitted to a Coronary Care Unit for heart failure. Treatment options were discussed with the husband and children. The medical practitioner explained that, because of the nature of the disease process, heart surgery could be contemplated but the patient's survival chances were not very high and quality of life might not be much improved. The family expressed the wish not to prolong life and stated that it would be the patient's wish to die peacefully without further intervention to prolong life. The desire to shorten life was expressed, as it was perceived to be what the patient would have wished for. To intentionally shorten life is tantamount to euthanasia.

The withdrawal of treatment was, under the circumstances, as described in the above scenario an option and not illegal. However, the wish to have life intentionally shortened as with the case described above is not legal.

Issues arising from the aforementioned scenario were as follows. Firstly, would the patient in question have wanted the hastening of death? This was difficult to establish in this scenario because no consent could be given or obtained since euthanasia or hastening death is an illegal action. Secondly, although the family came across as sincere and wanting the best for their sick family member, should their wish have been granted without checking out ulterior motives?

Thirdly, who should administer the medication if it were legal to do so, nursing or medical staff?

I wanted to begin this thesis with a scenario encountered by myself in practice some years ago. Complex situations, as described above, do arise regularly in clinical practice and motivated me to do this study. Decisions were made in the context of which they occurred and this patient was given regular pain relief until she died. However, healthcare workers may come to different conclusions for the same situation. The fate of the patient was dependent on the legal constraints and decision making of the healthcare professionals. An important part of this study were end-of-life situations and the insights, views, values and ethical considerations of the participants in this study.

1.2 Introduction

In this Chapter, section 1.2.1 provides an introduction to the researcher and the relevance of euthanasia and a general overview of the issues regarding the practice of euthanasia are discussed in section 1.2.2. My interest in the topic and background as an educator, health professional and consumer of health services led to the research question outlined in section 1.2.3 and the development of this study is discussed in section 1.3.

1.2.1 The Researcher

First I would like to introduce myself and the areas of interest that led me to undertake this study. I need to begin with describing my own experiences and interests with end-of-life situations and euthanasia in particular.

As a healthcare worker I am at times confronted with ethical decisions regarding life and death, and withdrawal of treatment such as described in section 1.1.

As a citizen of the world, I have tended to my father who was terminally ill during the last four weeks of his life. Residing in the Netherlands, euthanasia was an option and formed a gratifying solution for my father. This experience brought to the fore some of the issues an individual may encounter when dealing with euthanasia such as consent, willingness of the medical practitioner to perform euthanasia, legal procedures, timing and place of death and the feelings of family and significant others left behind.

As a New Zealand resident, I would like to see the euthanasia debate, which at present finds place in the media, opened up so that a full debate (maybe with an introduction of the Death with Dignity Bill) can find place at Governmental level.

As an educator, I am interested in the education of healthcare workers and the best or most appropriate methods of teaching a particular topic, in this case ethical issues, and finding out how well we prepare students who wish to become health professionals to deal with ethical issues such as euthanasia in the workplace.

Euthanasia is of interest to me as a health professional, educator and resident of New Zealand since you are confronted with the issue of euthanasia on a regular basis from an ethical point of view and a practical one in the healthcare setting.

When reflecting upon the above areas of interest and experience, I realised that the topic of euthanasia is multi faceted and complex and that individuals have different options depending on the context they live in or, in the case of healthcare professionals, practice in. This brings me to the next section in which the relevance of euthanasia is explored.

1. 2. 2 Relevance of the practice of euthanasia

The practice of euthanasia has worldwide interest due to changes in medical care. Until the 1940's, medical care was often just comfort care and alleviating pain when possible. However, during the last 60 years, dramatic changes have occurred in medicine. Pharmacological and technological advances have led to the medical field being increasingly capable of postponing death which at times has led to suffering of the patient and requests for euthanasia or withdrawal of treatment.

Statistics show that a significant number of people are "for" legislation of euthanasia. Waller (1986) surveyed the result of opinion polls and found that, from the 1960's to 1985 there had been worldwide trends showing a greater acceptance of active voluntary euthanasia. According to this survey, 68% of the world accepted the right of a terminally ill patient to painlessly end his/her life with the assistance of a medical practitioner (Waller, 1986). Despite these statistics, euthanasia is not widely legalised.

Euthanasia was practised for one year in the Northern Territories of Australia in 1996 but has ceased because the decision to practice euthanasia was controversially overruled by the federal government for political reasons the following year. At present, euthanasia is legalised and practised in the Netherlands. In Oregon and Switzerland, euthanasia is not legal but the practice of assisted suicide is legal and practised.

Euthanasia is being practised covertly in New Zealand in the way that there is (overtly) withdrawal of treatment. Some situations, where withdrawal of treatment was practised, were publicly debated such as the Rau Williams case and baby L case (section 2.5.4 and 2.5.3 respectively). This latter practice appears to be accepted practice in cases where the patient is of sound mind to make the decision to have treatment discontinued or when medical practitioners perceive discontinuation of treatment to be 'best practice'. Withdrawal of

treatment is not considered euthanasia by the medical profession and general population; however, it is defined as passive euthanasia by ethicists.

In recent years, euthanasia has gained new relevance in New Zealand and is increasingly the subject of public debate (Ansley, 2003; Baily, 2003; Boland, 2003; Gendall, 2003; Martin, 2002). Many surveys suggest that the majority of people are of the opinion that euthanasia should be allowed (Gendall, 2003; Mitchell, 2002; Donnison, 2001). Developments in medical technology have increased the capacity to sustain life beyond hope of recovery. Patients with poor quality of life can and are sustained for long periods of time. Michael Laws foresaw that there would be an ongoing debate pertaining to euthanasia when he lobbied to have the Death with Dignity Bill introduced in 1995.

Finally, if we do not address this issue tonight, I have to say that it will come back to haunt us. Whether it is as a citizen's initiated referendum in 12 months or as another private member's Bill in the next Parliament, which could be less than 12 months away, this is the moral and ethical issue of our time. I hope we have the insight, the intelligence, the will, and ultimately, the courage to let people of this country share their wisdom with us. (NZPD 549, 1995, p.8725).

There is ongoing debate in newspapers regarding the topic of euthanasia (Ansley, 2003; Bailey, 2003; Boland; 2003, Deveraux, 2001; Haden, 1998; Johnson, 1998). Recently 'The Death with Dignity Bill' was put to Parliament again. This meant that a bill was going to be introduced which opened up options for individuals for assisted suicide. However, a small majority in Parliament voted against the bill which meant that there was no further debate. Some of the arguments for and against euthanasia are discussed in this study but the list is by no means exhaustive. The arguments put forward relate to the ethical principles of autonomy, non-maleficence, beneficence and justice.

For many people it is not the dying but the fear of pain, loss of dignity and loss of autonomy and self-determination that is of concern, as was in the case scenario described in section 1.1 (page 1). Many individuals consider voluntary

euthanasia as providing the ultimate control over dying. The loss of autonomy and other considerations mentioned are ethical issues that are discussed more fully in section 2.3 and form part of the arguments **for** or **against** euthanasia.

However, the practice of euthanasia is illegal in New Zealand and, because of possible legal ramifications, it is not an option to discuss euthanasia openly in a clinical setting. This brings ethical difficulties to the decision making process.

Even when euthanasia is legal, such as in the Netherlands, there are a number of issues that need to be considered. Ethical issues arise regarding consent if a patient is not able to indicate what his/her wishes are. Due to their individual belief system, not all medical staff are willing to perform euthanasia. Also, family members might not have the same view as the patient and have difficulties with accepting euthanasia.

When reflecting upon the areas of interest and experiences mentioned in section 1.2.1 and the relevance of euthanasia in section 1.2.2, it raised some questions such as “why have a debate about the practice of euthanasia?”, “why not a uniform practice of euthanasia?”, “what do people mean when they talk about euthanasia?”, “what is the knowledge base people have about the topic?”, and “which roles have educators regarding teaching of ethics and the topic of euthanasia in particular?”. These questions led to the research question posed for this study, such as outlined in section 1.2.3.

1.2.3 Research question and aims of this study

The research question is: **What are the differences in perspectives on euthanasia of health professionals versus lay people.** Because of my interest in education, I wanted to investigate the knowledge base of health professionals and the general population regarding the topic and examine if there was a possible difference.

A premise underlying this study was that, if a knowledge base is increased regarding the value system and the congruency in values between healthcare professionals and the general population, it may be expressed in improved healthcare in end-of-life situations. The knowledge will also be valuable in understanding what is happening in the New Zealand context.

The aims of this research project were to:

- Examine the difference in knowledge base between health professionals and the general population regarding euthanasia.
- Find out how participants are educated regarding ethics and euthanasia in particular.
- Explore the viewpoints, feelings, and ethical considerations that the general population and health professionals regard as important to the topic of euthanasia and their attitude and views on the practice of euthanasia.

1.3 Thesis outline

To answer the research question and the questions underlying the research question, a literature search was required. This search focussed on the situation regarding the practice of euthanasia. These descriptive data, outlining the situation pertaining to the topic of euthanasia, form the first layer of knowledge.

The topic of euthanasia is multi faceted and this means that the literature review in Chapter 2 is extensive and discusses aspects such as ethics, the impact of bioethics and pluralistic ideas, definitions pertaining to euthanasia, ethical considerations, legal issues, the New Zealand situation pertaining to euthanasia and educational issues and theories.

Education is influenced by communication technology and this has increased our knowledge of ethical issues in other parts of the world and influences our views. Mainstream western bioethics represents the general views of the western

world on ethical issues pertaining to medicine and health. The main concerns are essentially orientated around medical issues with the most sustained attention being given to examining the ethical and legal dimensions of such issues as euthanasia. Because of the communication technology, this knowledge regarding ethical issues is not only made available to health professionals but also to the general public by way of newspapers, television, magazines and the internet.

The methodology of this research project is discussed in Chapter 3. General information about the participants representing the health professionals and the general population are found in Table 3.1 and 3.2 respectively in this chapter.

In Chapter 4, the results are discussed and these results show the differences between the group of health professionals partaking in this study and the group of participants from the general population. The opinions of the participants in this study pertaining to the practice of euthanasia are found in Table 4.2.

Chapter 5 is a discussion of the results. The scope of this work was limited to a small group of health professionals, both working in general areas of healthcare and palliative care, and a small number of individuals representing the general population in the greater Wellington area. In total, fourteen participants, seven individuals representing each group, were interviewed for this study. Their definitions, perceptions and understanding of euthanasia form the cognitive and normative layer of knowledge of this study. Learning finds place in educational settings and in life in general. The difference is that, in an educational setting, subjects are taught with the purpose of transferring knowledge to students and for the students to learn the curriculum in preparation for the workplace. However, this learning with a purpose does not apply to the general population. In regard to the topic of euthanasia, learning is very much by what is in the news and magazines. An examination of the impact of learning and education is part of the discussion of the results in Chapter 5 and relates to the general population and health professionals. Educational theory, as discussed in Chapter 2 is used to explain how an opinion is formed regarding euthanasia.

Chapter 6 discusses, in section 6.1, the recommendations pertaining to euthanasia and the practice of euthanasia. In section 6.2, recommendations pertaining to education of health professionals and the general population are discussed.

Chapter 7 forms the conclusion of this study.

Chapter 2

Literature review

The aim of this study is to explore the differences in perspectives on euthanasia between health professionals and the general population, and the differences in learning between both groups. For instance, health professionals acquire knowledge during education and this knowledge base is built with experience gained in clinical practice. The main objective of this study is to explore the viewpoints and ethical considerations that the general population and health professionals regard as important to the topic of euthanasia, as well as their attitude and views on the practice of euthanasia.

Mainstream bioethics represents the general views on ethical issues and represents contemporary healthcare issues such as euthanasia, as discussed in section 2.1.

To be able to discuss euthanasia, it is useful to clarify what it constitutes and what it does not. There are different opinions as to what euthanasia constitutes and whether it is practised. Some terms such as “assisted suicide” and “mercy killing” are used interchangeably with euthanasia but are significantly different in their meaning. I will endeavour to bring some clarity to these terms in section 2.2 so that the situations where euthanasia, withdrawal of treatment and “mercy killing” are discussed and can be judged on their true merits.

It is also useful to clarify what it means to make ethical decisions. What are the ethical guidelines and principles that can provide guidance to health professionals in their practice? Ethical principles that guide decision-making are discussed in section 2.3 and the same ethical principles are used in support of euthanasia and to oppose euthanasia.

Besides being guided by ethical principles in decision-making, health professionals also have to work within the law. Legal issues in relation to euthanasia are discussed in section 2.4.

The issues discussed in sections 2.2, 2.3 and 2.4 are illustrated with national and international examples and descriptions of end-of-life situations. It is important to explore the wider context in which ethical decisions are made and in regards to the practice of euthanasia and other end-of-life decisions. In section 2.5, some of the ethical and legal issues are discussed, concentrating on the New Zealand situation.

Section 2.6 discusses the issue of advance directives.

It is important to be informed about the ethical, legal and the socio-political situation since it is in this context that individuals are able to form an opinion. The difference between the general population and health professionals is that the latter group is educated regarding ethical, legal and socio-political issues in relation to their scope of work. It is important to have health professionals we can trust to make the right decisions regarding treatment, offering hope and treating individuals as they like to be treated. The way knowledge is imparted influences retention of knowledge and professionalism. The question is, "Can ethics and morality be taught and if so what are the best methods?" Some of these issues, with regards to the teaching of ethics, are discussed in section 2.7.

2. 1 Ethics and bioethics

This study has arisen out of my experiences with end-of-life situations. As a health professional, an educator and as a researcher, I wanted to explore the attitudes and ethical considerations of the general population and healthcare workers and their decision making processes in relation to euthanasia. First, I want to examine the terms "ethics" and "bioethics".

The term “ethics” comes from the Greek *ethikos* which means “pertaining to custom” or “habit” and “morality” comes from the Latin *moralitas* which means “custom” or “habit” (Johnstone, 1999). There is philosophically no significant difference between “ethics” and “morality”. The terms can be used interchangeably although some authors define “morality” as involving a more personalised set of values, in contrast with “ethics”, which is seen as involving a more formalised and universal set of values (Doane, 2002).

Mainstream bioethics represents general views of the western world on ethical issues pertaining to medicine and health. Mainstream bioethics has come to refer to and stand for issues such as euthanasia, abortion, genetic engineering but also portrays these issues as the most pressing bioethical concerns of contemporary healthcare in the world. The model of western moral philosophy that has developed over the past two centuries is demonstrably rigid, hierarchical, rule bound and it can be alienating (Johnstone, 1995). Its pattern of thinking requires an either/or mindset that polarises choice and that dismisses as ‘confused, contradictory and messy’ pluralistic models of thought and which encourages adversity. It is a pattern of thinking that begins with a perception of others as threats and an analysis of how we can defend ourselves against them (Johnstone, 1995).

Another outcome of the adversarial model of western thinking is that it can also contribute to the marginalisation and dismissal of unwanted views, particularly those that may challenge the status quo, not just of society but also of the bioethics movement itself. An example is the report about the cervical cancer enquiry in New Zealand (Coney, 1998). Attacks on the report were: (a) the judge is a layperson and misunderstood aspects of the case; (b) the enquiry was motivated by a man-hating feminist (Johnstone, 1995). These arguments were not related to the real argument of informed consent and appropriate treatment but they could undermine changes proposed to improve the existing situation and, therefore, maintain the status quo. The same occurs with arguments related to the practice of euthanasia; some people argue for change and some argue for the status quo to remain (Mitchell, 2002)

Euthanasia has been accepted practice in some countries such as the Netherlands and was practiced for some time in the Northern Territories (Mitchell, 2002). There is information that, although euthanasia is not legal, such as in countries like Australia and Belgium, it is practised in some way and the administration of lethal drugs without the request of the patient involved is significantly higher than in the Netherlands (Deliens *et al.* 2000). It is also a topic of ongoing debate regarding whether euthanasia is the right thing or wrong thing to do and whether it should be considered only applicable in certain circumstances such as for the terminally ill and people with intractable pain (eg. pain associated with some types of cancer) which is difficult to treat. Views on what are correct circumstances where euthanasia can be practised might be changing and pain is not the main consideration anymore. For example, there are individuals who claim euthanasia is the best thing to do in certain circumstances such as suffering due to loss of autonomy and independence, not only pain while dying of cancer (Chin *et al.*, 1999; Oregon Public Health Services, 2000).

The circumstance in which euthanasia is practised is changing all the time and countries develop their own policies regarding the practice of euthanasia. Besides the changing circumstances in which the practice of euthanasia is considered, there is increasing recognition that, besides individuals having their own moral standards, our moral standards are not absolute but are changing due to changing social circumstances. As Anderson (1990) states:

Morality....is the product of hard-won wisdom, a way of being that expresses wherever a person happens to be along the (hopefully) never ending path of understanding and re-understanding life, constructing and reconstructing the rules of relationship between self and others (Anderson 1990, p.156).

Pluralistic models see the world in terms of potential and of there being many possibilities just waiting to be actualised. The more pluralistic our world views then the more value systems are available to us. This may lead to uncertainty and controversy regarding moral and ethical issues, such as euthanasia, and lead to different views and practices around the world.

There are different views on the practice of euthanasia and on what the term “euthanasia” constitutes. To gain more clarity on what the term “euthanasia” means, it needs further exploration.

2.2 Definitions of euthanasia, assisted suicide and ‘mercy killing’

Euthanasia means “a good death”, or “dying well” (Johnstone, 1999; Jowell *et al.*, 2001). Although the terms “assisted suicide”, “mercy killing” and “euthanasia” are used interchangeably by the media and some researchers, there is a difference in legal and practical terms (Bailey, 2003). There is lack of consensus in defining euthanasia due to the emotive nature of the subject. According to Jowell *et al.*, (2001) it is more helpful to define euthanasia as one person deliberately bringing another person’s life to an end. However, this has to be taken in the context of illness or dying since the death penalty or death because of war activities are not meant to be included in this statement. Euthanasia is used more to refer to the act of deliberately inducing the death of an individual, who is in distress as a result of an incurable and terminal illness, by chemical means. Generally, it is understood that a medical practitioner performs the act. In order to discuss ethics and euthanasia in a meaningful way, it was important to clarify terminology and share common knowledge and understanding of ethical terms.

At present, ethicists make distinctions between different types of euthanasia such as active voluntary euthanasia, active involuntary euthanasia, passive voluntary euthanasia and passive involuntary euthanasia. Voluntary euthanasia is defined as a patient choosing death by euthanasia and involuntary euthanasia is defined as a patient not choosing for death by euthanasia but euthanasia is practised anyway.

Active euthanasia¹ is designed for patients who want to die and are unable to do so without assistance. Mercy killing, assisted suicide and suicide do not fall under this category.

The term 'mercy killing' is at times used interchangeably with euthanasia. Mercy killing generally refers to a situation where the patient is suffering. In these situations, the caregiver is often driven to kill the other person because of their own suffering. The context in which the killing occurs is often similar to euthanasia because suffering is involved. However, there is a difference since the killings are committed without patient consent (Johnstone, 1999; Glick, 1992). Mercy killing is sometimes done because the individual doing the killing is suffering him/herself and feels that they are sacrificing their own life looking after the patient who is suffering. For instance, there may be financial hardship, a very limited social life or high stress levels because of the burden of looking after another person. An example of "mercy killing" in New Zealand is discussed on page 33.

Assisted suicide is where an individual is assisted in taking his or her life. By implication, this means that the individual is conscious and willing to die and is able to take medication, inhale noxious gases or place a bag over their head. Assistance most of the time consists of medication prescribed by a medical practitioner to enable the patient to take their own life (60 Minutes, 2003). Assisted suicide, is strictly speaking, not euthanasia although assisted suicide is sometimes used interchangeably with euthanasia.

When euthanasia is practised, another person causes the death by chemical means. With assisted suicide, it is the patient who administers the medication, not the medical practitioner. This also means that the patient has to be capable of self administering while this is not the case with euthanasia where the person may not be able to self administer any more. Therefore, assisted suicide is not an option for everyone. Assisted suicide is practised in Oregon (United States of America) and Switzerland (60 Minutes, 2003).

¹ See glossary

Some individuals, to whom euthanasia or assisted suicide is not available, are able to assist themselves and commit suicide in such a way that is very violent. This makes their death much harder and difficult to handle with for those who are left behind.

For instance, suicide is not always by means of drug overdose, which leaves more ‘violent’ options such as hanging, placing oneself under a train and shooting oneself. Suicide may leave the people who are left behind struggling with feelings of anger, despair or guilt. It is interesting to note that, according to the Suicide Prevention Victorian Task Force, (1997, quoted in Johnstone, 1999, p.338) people bereaved by suicide are themselves more likely than the general population to die from self-inflicted deaths. Suicide is not legal in some countries and, specifically, the Catholic Church prohibits suicide and refuses a person who has died by such means a Christian burial (Johnstone, 1999). In the Netherlands, euthanasia is widely accepted and legal but suicide is not.

Passive euthanasia² occurs in New Zealand, and it relates to withdrawal of treatment. Some patients refuse to commence treatment and this choice can also be regarded as passive euthanasia. Passive euthanasia could be viewed as life prolonging. There may be a problem with passive euthanasia since withdrawal of treatment could possibly cause more suffering and, therefore, not bring about a “good death”. For example, I am aware of a case of a person who suffers from a degenerative muscle disorder has decided that once he can not swallow he will not have a gastric tube inserted so artificial feeding can not be commenced. Withdrawal of further treatment options, in effect, mean that he will starve to death and dehydrate. No doubt this will bring about suffering for him, his spouse and people who love him. If he accepts the artificial feeding he will eventually die of breathing difficulties, which he fears more and does not want to endure. This is an example of voluntary passive euthanasia as the person has made the decision himself to refuse further treatment after he can’t swallow. It could be

² See glossary

argued that, in this particular case, active voluntary euthanasia would be a better option.

There is no universal agreement on the definitions for euthanasia, which is why terms such as assisted suicide, mercy killing, suicide and euthanasia are used interchangeably. According to one view which has frequently been expressed in medical circles, the discontinuation of treatment does not constitute passive euthanasia. However, the term 'passive euthanasia' is commonly used in this context and is an appropriate label in circumstances where withholding or withdrawing of treatment was done with the object of hastening death (Weir, 1989). As discussed below, involvement in euthanasia influences whether one perceives withdrawal of treatment to be passive euthanasia.

There appears to be a difference in opinion as to what euthanasia constitutes, depending on the experience of the medical practitioner. Some medical practitioners looked at the practice of euthanasia as a continuum. According to Mitchell, (2002) medical decisions at the end-of-life that hasten death, such as terminal sedation or withdrawing nutrition, were perceived by the doctors who had performed euthanasia to be analogous to euthanasia while those who had not performed euthanasia stated that these actions did not amount to euthanasia. Terminal sedation refers to, "the intentional clinical practice of suppressing consciousness to control symptoms during the last days or hours of life" (Macleod, 2002, p.37).

There is no universal agreement on the definition of euthanasia because of the differences in opinion as described above. However, ethicists and educators use the terminology as described in the glossary. The media and researchers use some of the terminology such as "euthanasia" and "physician assisted suicide" interchangeably, which may be confusing and may inform the general public incorrectly (Bailey, 2003).

For this research project, the definition for euthanasia, "active euthanasia on a voluntary basis" applies and "withdrawal of treatment on a voluntary basis," is considered passive euthanasia. The reader, having knowledge of terminology,

will be able to interpret the situations discussed in this study. The reader will be able to make a judgement regarding the practice of euthanasia when guided by ethical and legal considerations, as discussed in the following section.

2.3 Ethical principles

“Ethics” is a generic term for ‘understanding and examining moral life’ (Johnstone, 1999). I have not discussed the ethical theories since it is outside the scope of this study. However, some understanding of ethical principles, which underpin the theory, may be of use since they have an important role in guiding ethical decision making and maintaining general standards of conduct.

Four principles form the basis for an ethical consideration of treatment practices. These principles are autonomy³, non-maleficence⁴, beneficence⁵ and justice⁶. Obligations, such as truth telling and to act in a trustworthy way, have to be taken into account. These principles are also used in the arguments for and against euthanasia.

The concept of euthanasia raises concerns about the ‘quality of life’, the accuracy of predictions about terminal or reversible illness, the prevention of unnecessary suffering and who should be involved in the decision making process (Kay, 1996). There are many arguments for and against euthanasia. The following arguments, in support of euthanasia, address some of the issues regarding the quality of life. However, this list is not exhaustive. Ultimately, only the individual concerned can determine if quality of life is acceptable.

Respect for autonomy relies upon truth telling, the exchange of accurate information about status, options, planned care and future expectations. Areas have to be explored: such as, the adequacy of symptom control such as psychological disturbances, depression, grief, anxiety, organic mental disorders;

³ See glossary

⁴ See glossary

⁵ See glossary

⁶ See glossary

support systems; and the patient's views to the meaning of life and the suffering. Parker (2001) makes this clear when stating:

Recent research has been undertaken into factors which may influence refusals of treatment, including clinical depression. That such research is now occurring arguably results, at least in part from a new, but unstated (perhaps unconscious), recognition that the need to explore and interpret requests for withdrawals is no different from the need in respect to requests for active assistance to die. If so, the acts- omissions distinction does not mark the moral boundary that the profession has long supported, but the fact that the research is recent also demonstrates how official doctrine influences both research agendas and clinical practices, both of which have important social implications.(Parker, 2001, p.5.)

This implies that it is important that all factors of the disease process and what they represent to the patient are taken into account so optimal care can be delivered. Yedidia and MacGregor (2001) identified dominant themes characterizing patient's perspectives on death during their last months of life. Several themes emerged and the awareness of the motives underlying patient's perspectives revealed that opportunities for effective intervention and euthanasia were not required.

There is a growing body of evidence that shows why people choose euthanasia (in the Netherlands) or physician assisted suicide (such as Oregon). Loss of dignity and loss of autonomy and independence are greater determinants or more important factors than pain for choosing euthanasia (Chin *et al.*, 1999, Oregon Public Health Services, 2000). This is confirmed by another study which states, "the three most common reasons patients gave for wanting assisted suicide were loss of autonomy, inability to participate in enjoyable activities, and loss of control over bodily functions but not pain" (<http://www.internationaltaskforce.org/iaa28.htm>, 2003). Poor quality of life, readiness to die and a desire to control the circumstances of death were also reasons for choosing to die (Ganzini *et al.*, 2000). The readiness to die and asking for euthanasia does not always result in euthanasia being practised. Stuy

(2003) states that there, are according to the Medical Association in the Netherlands, 10,000 serious requests a year for euthanasia and approximately 3,600 of the requests result in euthanasia. It often happens that the patient dies in comfort before euthanasia is required or before all the requirements for the procedure have been put in place, such as written consent obtained and assessment carried out by an independent medical practitioner not treating the patient. In other cases, a different and satisfactory way to alleviate suffering is found.

Suffering can also be caused by aggressive or cure orientated treatment. This type of treatment may not be suitable for a person or against a person's wishes and would be in violation of non-maleficence. Unnecessary and unwanted over sedation and uninformed withdrawal of treatment, which might be the case in involuntary euthanasia, may be another.

Treatments should be used for 'promoting good' and removing symptoms or suffering. Cessation of treatment can be appropriate and an act of beneficence where life and/or treatment is viewed by the patient as harmful. Treatment plans in line with patient's goals would convey beneficence (Latimer, 1991). According to Swarte *et al.*, (2003) a 'good death' is good for the patient but also for others since it was found that bereaved friends and family of cancer patients who had died by euthanasia coped better than those of cancer patients who died a natural death. This means that the principle of 'promoting good' is extended to not only the patient but also to others close to him or her.

When discussing the topic of euthanasia, the focus is on alleviating suffering by shortening the lifespan. However, having euthanasia as an option does not always result in shortening of the lifespan and may be life prolonging. Patients do not have to commit suicide while still able to do so but can go on living until the individual decides that quality of life is not acceptable. There is anecdotal evidence that an individual has the courage to continue living since they have control over the timing of their death and their quality of life. Boland, (2003) cites Alex Schuiten, a person suffering motor neuron disease, "...if I wait too long maybe I won't be able to do it (referring to committing suicide)". Alex

Schuiten indicated that he wanted to determine the timing of his death, preferably with the practice of euthanasia, and stated, “even with all the palliative care, they are not able to give the quality of care I want” (Boland, 2003). The option, of having euthanasia, may allay fears that unbearable suffering does not have to be endured. Some patients may die without any intervention to hasten death because, at the time of death, there is no perceived need to intervene (Muskin, 1998; Stuy, 2003). It could be argued that the principle of ‘promoting good’ is adhered to in situations where the option of euthanasia gives the patient the courage to carry on living.

There are difficulties with the consideration of patient’s claims to have the right to die by euthanasia because of poor quality of life. It would be impossible to formulate legislation for it, however humane the intentions, that could not be abused by the unscrupulous. This is a classic statement of the “slippery slope” argument which is the most common and compelling argument against euthanasia. In its simplest form, the slippery slope argument says that, once we embark on a course of action it may lead to an unintended and undesirable state of affairs. If we accept that there are occasions where killing is the right thing to do, this will somehow, so the argument goes, undermine the moral principles, which protect the right to life (Beauchamp & Childress, 1983).

Society and the healthcare professions have been reluctant to move euthanasia into the same arena as abortion and enact legislation covering practice; yet, in both cases at a basic level, one talks about killing. The slippery slope argument has made society as a whole very cautious. However, as Harris (1985) states, we do not outlaw effective contraception because we fear that to practise birth control is to step onto a slope that leads to the extinction of the human race. The same argument can be applied to euthanasia, the availability of the practice of euthanasia for terminally ill patients who are suffering immensely does not lead to killing patients unnecessarily and safeguards can be put in place to avoid inappropriate practice.

Beauchamp and Childress (1983) argue that we have to be clear what is encompassed by the slippery slope arguments. The slippery slope argument

focuses on moral reasoning and the logic of distinctions between the different acts. If we argue that one course of action is right then it will have logical implications for another sort of act that we would generally consider to be wrong. For example, if a severely damaged fetus should be aborted, then a severely damaged baby should be killed. This argument rests on Kantian ideas of universality, which demands that relatively similar cases be treated in a similar way.

Beauchamp and Childress (1983) argue that ethical and legal mistakes repeat themselves because of this universality argument. They argue that, if it is defensible and morally right to allow patients to die under certain circumstances, then it is rational and morally defensible to kill them under the same conditions. In other words, if death is in the best interest of the person, it is of no relevance how death occurs. In principle, I do agree with the statement of Beauchamp and Childress since passive euthanasia or withdrawal of treatment may prolong suffering. However, it is a very personal choice and religious and other beliefs and values will impact on the decision of the patient. I do believe that it is the patient who should indicate if death is desirable and non-voluntary euthanasia should not be practised. The other person involved is the medical staff member performing euthanasia and not everybody would want to be involved because of their existing values that contravene beliefs that euthanasia is the same as letting a person die.

Justice demands that dying patients have equal rights to care. Justice also reflects policy at a societal level and this may serve to limit autonomy. According to Kay, (1996) it may be a moot point whether the courts act in an individual's best interest or whether they are biased in favour of the community or society as a whole. According to Johnstone, (1999) it is argued that everybody should equally share benefits and burdens in life. In respect to euthanasia, it means that denying patients the right to die in a manner of their choice is to unfairly impose values of others on them and to unfairly limit patient's autonomy, dignity and entitlement to be spared intolerable suffering.

Besides the four principles that form the basis for ethical decision-making, we also seem to adhere to the principle of vitalism⁷ in Western societies such as New Zealand. This is a largely understated value we live with and vitalism is of such significance that we literally presume its worth and understanding in our existence. Vitalism underpins the moral imperative for health professionals: to care for a person is to hold life precious and ought to be preserved (Rogers & Niven, 1996). This principle is applied when patients are offered invasive and aggressive treatments. There are times that treatment appears inappropriate or is rejected by the patient and arguments, such as those outlined in section 2.3.1 in support of euthanasia, are being brought forward.

2.3.1 Arguments for and against the practice of euthanasia

The main arguments in support of euthanasia fall under four main categories (Johnstone, 1999) and relate to the principles of autonomy, non-maleficence, beneficence, and justice as discussed above.

1. Arguments to support individual autonomy and the right to choose. Given the right to die, this means that others should not interfere and, in some instances, assist a person to die.
2. Arguments to support the right to die to maintain dignity (non-maleficence). Advances in medical technology can prolong a person's life. Its methods are not always humane and can undermine a person's sense of self-worth and self esteem.
3. Arguments to support a reduction of suffering (beneficence). Suffering is generally regarded as morally unacceptable and modern medicine cannot relieve all suffering.
4. Arguments to support justice and the demand to be treated fairly. To deny patients the right to choose death is to violate these patients' autonomy, dignity and the option of being spared intolerable suffering are to treat them unfairly.

⁷ See glossary

The main arguments against euthanasia are as follows and are based on the same principles that are used to support euthanasia namely; autonomy, non-maleficence, beneficence, and justice (Johnstone, 1999).

1. Autonomy does not impose a moral duty on healthcare professionals to comply with a patient's wishes for euthanasia.
2. A person's dignity might also mean that 'everything possible be done' which means that compassionate care is provided.
3. Suffering is not a medical problem but a part of life which may give purpose and meaning to life.
4. Justice means that patients should have the right to prolonging treatment even when treatment is considered futile or their lives have poor quality.

More specific arguments against euthanasia include the sanctity of life doctrine, which is related to the principle of vitalism and means that not even intolerable suffering justifies taking a life. Another argument is the possibility of misdiagnosis and, since euthanasia is not reversible, a mistake can not be undone; for example, people with a spinal cord injury may be cured in future with new advances in medicine. Other arguments are as follow: a risk of abuse and euthanasia practised by unscrupulous people, euthanasia not being required since patients are already having 'good deaths', discrimination since some lives are treated as less worthy than others, the patient requesting death by euthanasia not making an appropriate choice, the slippery slope argument that states that we decline our moral standards and that once we compromise one standard such as protecting life, we compromise all standards pertaining to life and human wellbeing (Johnstone, 1999).

Euthanasia is illegal in New Zealand although it might be ethically right because of the suffering an individual has to endure. Besides the above mentioned ethical principles that guide decision-making there are the legal boundaries by which individuals have to abide. Ethics and law overlap but are nevertheless quite distinct from one another.

2.4 Legal issues

An argument in support of legalising euthanasia is that it would formalise current practice. McCall Smith (1976) remarked,

The law may ultimately be called upon to define what is acceptable practice on the part of the professions but it tends to do so on the basis of what the professions themselves suggest. The law then looks for guidance to professional consensus, while the professions naturally look to the law for a statement of what they can or can not do. McCall Smith (1976, p.122)

An example of this is the case of ‘baby L’ as discussed on page 35. In this case, withdrawal of treatment was opposed by the parents of the baby and the case was taken to court. The justice system ruled in favour of the medical profession. It was considered ‘best practice’ to withdraw treatment which means that this was to benefit the baby. It was also common and considered acceptable practice that was adhered to, so the justice system looked to the medical profession as to what was considered best practice and ruled accordingly.

Under this argument healthcare professionals can have conscientious objections, and indeed this is a legal recognition of personal morality. Most healthcare professionals do not work in areas where they are confronted with these issues on a daily basis. For instance, healthcare professionals against abortion practices normally do not seek a job in an abortion clinic. There are very few health professionals belonging to Jehovah’s Witness, administering blood transfusions as this would put them in a position where they are confronted with doing things against their belief.

It is interesting, in view of the previous statements, that some healthcare professionals are neither for nor against euthanasia but practice it regardless; “My personal opinion regarding euthanasia is not relevant, I do not know if it is a good or a bad thing.I do not judge it as good or bad, I want to know whether somebody has made a well considered decision” (Stuy, 2003, p.58).

This medical practitioner went on to state that the process to come to the conclusion that euthanasia was the best option was important and, whether it was a good process, without duress and voluntarily, indicating that autonomy of the patient was an important consideration. This medical practitioner also stated that she had practiced euthanasia ten times and feels that she is doing something good for the patient. Despite the feeling of doing something special and good, adhering to the principle of beneficence, it is stated that she normally does not sleep well the night before euthanasia is being practised even though there is no other suitable solution. (Stuy, 2003).

Jaeger (2001) and Doane (2002) would agree with the above comments and that patients should not be dependent on the personal moral disposition of the healthcare professionals. Healthcare professionals have to decide what to do when their personal and professional inclinations clash and they have to look for guidance. The most obvious sources are professional codes of conduct and ethics.

In most countries, euthanasia is straightforward in a strict legal sense because it is against the law. Health professionals in many countries can call upon the law to justify their actions and refuse to assist. However, a clear legal position does not make the ethical dilemma go away. Emotionally the healthcare professional may feel that the patient has been let down because there is nothing that can be done to improve quality of life and hospice care may not be sufficient to alleviate all the problems. Abiding by the law may even go against the personal morality of the healthcare professional in situations where nothing can be done for the patient who is suffering, since palliative care may not be sufficient.

Since November 1990, euthanasia was practised and condoned but not legalised in the Netherlands (<http://www.euthanasia.org/dutch.html>). Prosecution was unlikely if a doctor complied with the non-prosecution agreement between the Dutch Ministry of Justice and the Dutch Medical Association. These guidelines were based on the criteria set out in the decisions relating to when a doctor can successfully invoke, in the defence of his/her actions, that death was the best option for the patient. Some of the safeguards (see Appendix A, article 2) were

that the patient had to repeatedly request euthanasia, be terminally ill, be of sound mind and competent to make the decision, the request had to be in writing and a second opinion had to be sought from another doctor who is impartial (not involved in the treatment of the patient).

In the Netherlands, euthanasia has been legal since late 2000. The social context for legalising euthanasia is important. Before euthanasia was legalised, it was practised for 10 years and one could argue that the guidelines during this time were 'trialled' and considered satisfactory. Another consideration is that most of the euthanasia is performed by general practitioners in the Netherlands. General practitioners normally do know their patients and the family well and are quite often perceived by the family as a family friend. The general practitioner is, therefore, often in a good position to judge the situation of the patient and whether euthanasia is voluntary and not under duress. Although there is not a well-developed hospice system, the palliative care is very much under the control of the general practitioner, who makes house calls and prescribes pain relief, and other healthcare workers who deliver palliative care at home. The Dutch healthcare system appears to facilitate euthanasia free from coercion or abuse (Otlowski, 1997). There is a comprehensive medical insurance system covering comprehensive care. The medical profession is not commercially inclined and there are no financial incentives for healthcare workers or hospitals to terminate patient's lives (Cohen, 1990). Healthcare workers, especially doctors, are generally perceived to have integrity (Aycke and Smook, 1990). This means that the context in which euthanasia is legalised is potentially free of abuse.

A clear distinction between euthanasia and assisted suicide (section 2.2) has to be made. The latter is legal in Switzerland and everybody, even foreigners, can ask for it. There are organizations such as Dignitas who will assist the person in the process. One has to be assessed by a medical practitioner and, when the person is considered of sound mind, medication is prescribed to them, such as a lethal dose of barbiturates. The individual has to be physically able to take the medication in which case death ensues within hours (60 Minutes, 2003). The state of Oregon has a similar set up. The Death with Dignity Act allows for the

prescribing and supplying of medication to end life but not for the physician to administer the drugs. Suicide is not against the law but 'advising or assisting' is in many countries, such as New Zealand (Deveraux, 2001). However, suicide is still socially stigmatised and, therefore, not perceived as an option by some patients.

The legal situation pertaining to the practice of euthanasia, assisted suicide and suicide differs between countries. Australia's Northern Territory was the region closest to New Zealand to legalise the practice of euthanasia although this legislation was later overruled. New Zealand has not followed suit. However, in New Zealand, end-of-life decisions are made that do involve the courts. Society's values are expressed with lenient sentences in cases of 'mercy killings' and some of these issues concentrating on the New Zealand situation are discussed in section 2.5.

2.5 The New Zealand situation

Values and opinions do not develop in a vacuum and, in this section, some of the practices and issues regarding euthanasia in New Zealand, which may have had an impact on opinions of the participants in this study, are discussed. Specific end-of-life situations that have been discussed in the New Zealand media such as euthanasia, mercy killing, allowing dying and futile care are also covered in this section.

The country closest to New Zealand is Australia and this is where euthanasia was legalised for a short time. On September, 22, 1996, Dr. Peter Nitschke, in Australia's Northern Territory practised euthanasia after a bill was passed to practice euthanasia. Despite polls showing that 75% of Australians approved of euthanasia the federal parliament overruled the legislation. Some individuals believe that there is not a need to follow in Australia's footsteps and legalise euthanasia since the existing regime in New Zealand is working for the majority of patients.

It would be interesting to find out if participants in this study perceive, whether or not, there is a need for euthanasia. There appears to be interest for legislation of euthanasia, especially among older and sick people in the practice of suicide (Deveraux, 2001). Dr. Nitschke is at present involved in giving lectures in Australia and New Zealand on how to commit the act of suicide and is careful not to contravene the law by stating that he is not involved in “advising or assisting” (Deveraux, 2001). However, committing suicide is not an option open to every individual and some people require assistance.

That there may be a need for the practice of euthanasia is indicated by the statistics of a recent survey. In September 2002, a marketing mail survey was sent to one thousand New Zealanders and the results of this survey showed that more than 70% of New Zealanders supported assisted suicide, provided that a medical practitioner gave the assistance (Gendall, 2003).

The problem with this survey was that the terms “euthanasia” and “assisted suicide” were used interchangeably and, therefore, the result may not have reflected the true opinion of the population. As discussed before, assisted suicide necessarily implies that the person is conscious and able to self-administer and euthanasia does not. “Assisted suicide has the convenience of a directly expressed preference by the person who has elected to die” (Bailey, 2003, p. 30).

According to Ansley, (2003, p. 19) “The big question is, do we change important societal values, attitudes and ethical precepts for a few individual cases?” This statement indicates that we are acting in accordance with the value system of the majority of people. I personally question whether this statement is correct in view of the statistical evidence of people supporting euthanasia. Research and frequent publications regarding the topic of euthanasia indicate that there is a debate going on as well as a ground swell for the practice of euthanasia (Bailey, 2003; 60 minutes, 2003; Mitchell & Owens, 2003). Whether the problem pertains to a few individual cases is also questionable since there is no evidence available that this is the case. The writer’s study explores the views and ethical considerations of a small sample of the general population and health

professionals and the findings of this study may or may not support the claims made by Ansley, Bailey, 60 Minutes and Mitchell & Owens.

In a healthcare setting, orders or directives pertaining to treatment are sometimes given that hasten death. It is not officially called euthanasia because of legal implications and, as discussed before, it is a matter of perception as to what euthanasia constitutes. However, there are instructions such as 'not for resuscitation' or for 'nursing care only' which means that certain treatments are withheld. One can question whether withdrawing or withholding treatment, an acceptable practice in New Zealand, actually differs from active or passive euthanasia. According to Griffiths *et al.*, (1998) there is no moral difference, only an emotional difference between killing and withholding futile medical treatment; therefore, there should not be a legal difference. However, in New Zealand courts, withdrawing or withholding treatment have not been judged to constitute euthanasia.

Medical practitioners have had far less difficulty accepting that patients are allowed to refuse treatment than get involved in active or passive euthanasia; for example, chronic renal patients not going ahead with available treatment is offered as a real choice in New Zealand. The perception in these cases, according to Parker, (2001) is that the disease kills the patient and not the physician.

There are difficulties inherent in the present situation in New Zealand and possibly other countries. Because practising euthanasia is illegal, it is likely to be performed covertly, leaving little opportunity for consultation, regulation and obtaining informed consent. Decisions are more likely to be made on the basis of the participating doctor's own conscience and willingness to take risks rather than the patient's request. Some doctors may be more willing than others to provide euthanasia; thereby causing potential injustice to some patients. In light of the paternalistic nature of the medical profession, euthanasia may result on the basis of what the doctor perceives to be in the patient's best interest but without the consent. This is contrary to the fundamental principle of self-determination and autonomy.

It is preferable to have euthanasia legalised if the practice already exists since safeguards can be implemented. Legalisation would promote open discussion of the issues. Doctors would very likely comply with the legal requirements to practice euthanasia rather than take the risk of being involved in a criminal activity. Euthanasia would be an option for all patients under certain circumstances subject only to the doctor to decline to practice euthanasia.

An international study of health professionals found that 87% accepted the idea of passive euthanasia while 21% accepted the idea of active euthanasia. According to Darbyshire, (1987) out of this group of health professionals who accepted euthanasia, 21% claimed to have participated in active euthanasia and 58% claimed to have participated in acts of passive euthanasia. Reasons for accepting euthanasia may be the more complex health issues that health professionals encounter with sometimes no positive outcome or cure. According to Darbyshire (1987):

The past 20 years have seen a comparative explosion in discussion related to death and dying. These discussions have been provoked by technological advances and by related changes in clinical practice. Concepts, which were, previously clear have now been rendered more complex and confusing. Almost inevitably, the technological sophistication which can enable life to be prolonged has thrown up vexing dilemmas as to whether or when this should be done (Darbyshire, 1987, p.27)

Probably due to the circumstances described by Darbyshire, a considerable number of health professionals claim to have been involved in euthanasia in New Zealand. According to Mitchell & Owens (2003):

Eleven hundred (88%) of doctors reported attending a death in the past 12 months, and 693 (63%) had made a medical decision that could hasten death. In 39 (5.6%) cases, death was attributed to actions consistent with physician assisted suicide or euthanasia.Our figures

could be an underestimate of the number of physician assisted deaths as the phrasing of the question asked only about the last death attended. The fact that euthanasia is illegal in New Zealand could also have contributed to the low response rate of 48% (Mitchell & Owens, 2003, p. 202-203).

Some euthanasia cases have been well discussed in the media in New Zealand (Ansley, 2003; Boland, 2003; Haden, 1998; Martin, 2002; Martin, 1998). Although euthanasia is not legal in New Zealand, there have been cases of 'mercy killing' and withdrawal of treatments. Some of these cases are discussed in relation to ethical principle, legal and medically accepted practice in New Zealand. The Martin case was repeatedly in the news at the time of writing this study.

2.5.1 Euthanasia- the Martin case

Martin (2002) wrote a personal account of her mother dying and her attempt to shorten her mother's life. Martin, a registered nurse residing in Australia at the time her mother became ill, came to Wanganui to be with her mother who was dying of cancer. In an attempt to alleviate her mother's suffering, Martin administered a high dose of morphine and also put a pillow on her mother's face. It became apparent during the post-mortem examination that Martin's mother had died or died at the time the pillow was put on her face and, therefore, did not die of suffocation. However high levels of morphine were found, indicating an overdose of the drug. According to Martin, the investigating police officer advised her not to talk about what happened. Martin did not heed the advice of the police and published a book outlining the suffering of her mother and her part in trying to bring about the death of her mother. Martin was charged by the police and will have a legal trial in the near future. Martin states:

I know of 20 cases now where, if the exact details were known, they'd end up in exactly the same situation I am in. The thing is, without legislation we're going to have continuing cases like mine where people are put on trial as murderers. We're just trying to do our best according

to heartfelt wishes of people we love in desperate situations (quoted in Ansley, 2003, p. 20)

Martin was charged with attempted murder because, at present, euthanasia is not permitted in New Zealand. The New Zealand Crimes Act (1961) states:

No-one has a right to consent to the infliction of death upon himself; and if any such person is killed the fact that he gave such consent shall not affect the criminal responsibility of any person who is party to the killing (New Zealand Crimes Act, 1961).

At the time of writing this study, the trial has not yet taken place. It may be that public opinion and circumstances surrounding the death of Martin's mother lead to a lenient sentence as was the case with Janine Albury Thompson.

2.5.2 Mercy killing- the Janine Albury Thompson case

In the case of Janine Albury Thompson killing her daughter, the media labelled it as "killing out of love is not manslaughter but compassion" (Haden, 1998). Janine Albury Thompson encouraged her daughter Casey to jump off a bridge and, when the daughter did not comply, she strangled Casey. In this case Janine Albury Thompson was sentenced to four years in prison for killing her daughter who was severely handicapped. The view from the media was that, " she gave her a good a death as she could contrive as an alternative to years of suffering" (Haden, 1998) and that the judge was too harsh with the sentence.

The perception was that the daughter had a poor quality of life. Many view the notion of quality of life as central to making of life and death decisions. The problem is that the term 'quality of life' is not easily defined and there are very different views and definitions (Johnstone, 1999). For example, a common goal may be 'comfort' for an individual. From a nurse's perspective it may mean pain

relief at all cost but from the patient's point of view it may mean a certain level of discomfort because being mentally alert is more important.

The term "quality of life" can be used to describe a situation. For example, when a person has pain, the situation requires evaluation; whether or not the pain is very severe, and whether or not a quality of life can be morally judged; for example with an evaluative statement such as the pain is so severe that life is not worth living. From a moral point of view, it is only the person whose life is in question who can decide if their quality of life makes life worth living.

In the case of Janine Albury Thompson, healthcare workers did not consider her daughter as having a poor quality of life. Healthcare workers, taking care of the daughter, did not perceive that the daughter was suffering. The daughter was incapable of living an independent life, needed a lot of attention and care and showed difficult behaviour. Healthcare workers, in charge of looking after the daughter, raised issues such as high stress levels and feelings that the mother was not coping with her daughter. There was no full time care available for the daughter. If more healthcare had been available to assist the family in caring for their child, then the incident might not have happened. Janine Albury Thompson had turned to welfare agencies but was unable to get sufficient assistance in caring for her daughter, Casey. Sufficient care should be given or be available to patients and their family so euthanasia is not seen as the only way out. Strictly speaking Janine Albury Thompson did not perform euthanasia but a "mercy killing" according to the media. The term "mercy killing" is used, at times, interchangeably with the term "euthanasia" but it differs because of the context in which the killing finds place as Glick (1992) explains:

Mercy killing is not the same as voluntary active euthanasia since many killings are combined without patients request or consent- typically an elderly husband shoots his terminally ill and unconscious or Alzheimer's disease stricken wife. But the cases almost always exhibit wrenching long- term suffering and sacrifice and financial ruin... They evoke sympathy for both the killer and victim and perpetuate interest in the legalisation [sic] of voluntary active euthanasia, which some believe

might eliminate the compelling need that desperate people feel for killing their hopelessly ill spouses (Glick, 1992, pp. 81-82).

Due to the fact that there was no intolerable suffering on the part of the victim in the Janine Albury Thompson, it could be argued that there was no “mercy killing” but murder. It was Janine Albury Thompson herself who was suffering and not coping with the situation, not her daughter. The insufficient help available in the New Zealand healthcare system, to meet the needs of caretakers and parents of severely disabled individuals, creates circumstances where people such as Janine Albury Thompson committing acts they would not do normally. The sentence and the early parole Janine Albury Thompson received reflect these sentiments. Although, in this particular case, I feel that the healthcare system has failed to supply sufficient healthcare which was clearly indicated by Casey’s mother, who was not coping with the existing situation, and the system could be viewed being as guilty as the mother in Casey’s death.

The funding for healthcare makes the whole case not only an ethical problem but also a political problem. The issue of funding sometimes plays a part in futile treatment, such as the case with baby L discussed below, but this was not a consideration in the care for Casey, the daughter of Janine Albury Thompson.

2.5.3 Allowing to die- the baby L case

At times, our traditional assumptions about beneficence-based practice may be questioned and hastening death may promote the interest of the patient concerned better than prolonging life or allow dying. The case of ‘baby L’ is an example of this. In September 1998, in New Zealand, ‘baby L’ suffered from an incurable syndrome that was not compatible with life. The baby was kept alive with life support, which constituted futile treatment. The parents could not bring themselves to grant approval to have the life support turned off. The withdrawal of treatment would result in death of the baby girl. The Auckland Hospital Board took the case to court to get approval to withdraw treatment and the approval was granted by the courts (Martin, 1998).

“Courts have generally left doctors the principal responsibility for deciding what to do. Doctors are entitled to refuse patients treatment if ‘best practice’ suggest this would be in the patient’s best interest” (Jowell *et al.* 2001, p.166). This means that, for example, “when permanently and wholly unconscious, non voluntary euthanasia may be legally available” (Jowell *et al.* 2001, p.166). In the case of ‘baby L’, it may be debatable whether the action of turning off the life support constitutes euthanasia. The action of turning off life support is, in the case of ‘baby L’, not necessarily hastening death but is more a case of ‘allowing to die’. Zalberg and Buchanan (1997) argue:

If appropriate examination and investigation suggest that nothing can be done to bring about the patient’s recovery, that life-support system must ultimately be turned off. This is not euthanasia in either the practical or moral sense – health care professions cannot do the impossible. This is the clinical reality apparently not appreciated by those philosophers who continue to argue that the withdrawal of life- sustaining treatment is the moral equivalent of euthanasia (Zalberg and Buchanan, 1997, p. 151).

A request for voluntary active euthanasia goes beyond what health professionals generally would regard as part of their practice. However when dealing with the terminally ill in considerable pain, or the severely disabled, such as baby L, drawing boundaries is far harder to do. If you hasten death by administering opiates then you move from the realms of “letting die” to active euthanasia. Roman Catholic theologians and philosophers have a doctrine that attempts to deal with this. It is the doctrine of the double bind effect. This distinguishes between what we do and what we intend to do or intend the outcome to be. As part of palliative care, in the terminally ill with severe pain, the pain relief, given with the intention to relieve pain and not kill the individual, would not make us responsible for the second effect (killing the individual) even if it was foreseen. “This principle may be criticised for being ‘doctor-centred, not ‘patient-centred’, because the doctor alone determines the intent, and being open to very wide interpretation” (Macleod, 2002, p37). The double effect argument may not solve the dilemma but it may help us to cope with it (Thompson *et al.*, 2000).

Allowing to die may be in the best interest of some patients and constitute 'best practice'. There is a difference between allowing to die and futile care where the treatment can extend the person's life and increase the quality of life as is the case of Rau Williams discussed below.

2.5.4 Futile care- the Rau Williams case

There are situations where it is not only terminal illness and severe pain that are reasons for euthanasia but also diminished quality of life. For instance, euthanasia is thought to be an option for those people with motor neuron disease, which is a degenerative disease where muscle tissue is wasting away until death follows due to breathing problems (Boland, 2003). Besides health issues, there is also consideration given to the limited amount of resources and "health dollars" available. There is no funding for futile treatment, for example, it would be considered futile to resuscitate a patient with an advanced stage of cancer. Because of the limited resources, there is a directive not to practice futile treatment in clinical settings (Warner *et al.*, 2001; Shah & Lloyd-Williams, 2003).

This also applies to New Zealand Hospital Boards who have been instructed not to deliver "futile" care and, since there is no allowance for "futile" care some patient's do not get the treatment they request. Jaeger (2003, p.4) states, "When decisions about allocation of resources are made according to utilitarian cost-benefit rationale, what is 'good' for the economic efficiency of a hospital is not necessarily perceived as 'good' by the patient". This means that, in practice, some patients do not get all possible treatments available since the outcome does not constitute a cure or promotion of reasonable quality of life. For example, individuals with only brain activity but no other physical capabilities or patients with no brain activity or brain death might possibly be taken off life support. The futility of the treatment might be established, but it may be more difficult to establish the futility of the life concerned, and whether or not the individual concerned finds that there is little quality of life.

The notion of “futility of treatment” and also eligibility of treatment could be questioned. For example, medical practitioners have established guidelines for eligibility for haemodialysis to treat renal failure. Guidelines at present differ markedly from the guidelines of 30 years ago. An individual, according to some guidelines, has to be able to dialyse independently. If not able to dialyse independently then the individual might be considered unsuitable for treatment even though parents or partners could and would administer the treatment which would have been acceptable under old guidelines such was the case with Rau Williams. Rau Williams was not considered suitable for treatment of end stage renal failure and died after his family made two unsuccessful attempts to have the decision overturned by the courts.

The public opinion was that Rau Williams was abandoned by the health care system (Johnson, 1998). It appears that guidelines are there to make the dollar stretch further. More sophisticated treatments are becoming available but, on the other hand, these resources are being made available only to some sections of the population (Hamel *et al.*, 1999). Decisions on the distribution of health resources are entirely the domain of the medical profession (Mitchell, 2002). This means that patients do not always have choices regarding treatment. However, by making their opinion known in advance, patients can determine whether to undergo treatment or not.

2.6 Advance directives (living wills)

Written or advance directives make it possible for individuals to indicate in advance that they wish their lives terminated, if they find themselves experiencing unbearable suffering with no prospect of improvement, in circumstances which render them incapable of expressing their wishes personally.

The option to treat or not to treat is not always discussed with the patient or relatives, which makes withdrawal of treatment involuntary passive euthanasia;

for example, when, as a healthcare professional working in a busy emergency department, an incident occurs where a comatose diabetic teenager arrived in the emergency apartment. Everybody works hard to save his life until the medical notes with this patient's medical history arrives. Because of the frequent problems this individual has in controlling his diabetes, it could be decided to withdraw treatment on the grounds that this patient was not coping with his health problem and, in fact, it may have been a suicide attempt. According to Jowell *et al.* (2001) there is philosophically no difference in withdrawing life saving treatment or not offering it. No data are available as to whether the general population agrees to these decisions to withdraw treatment and under which circumstances. It is certainly of interest that medical staff can come to different conclusions regarding treatment or no treatment when confronted with the same case.

As in the scenario described above, the patient would be incompetent⁸ to make a decision due to the fact he was comatose. According to Eisemann & Richter, (1999) there are an increasing proportion of incompetent patients in the industrialised western countries. To maintain autonomy under all circumstances, an individual can use advance directives which can be used to allow individuals to express and document their treatment preferences at the time they are competent⁹ and to inform health professionals how they want to be treated in case of incompetency (Eisemann & Richter, 1999). There are elderly people who express fears of an overzealous use of life sustaining procedures when they are severely ill. For instance, an individual with motor neuron disease states:

I know if I do nothing I will have a terrible end. Even with all the palliative care, they are not able to give the quality of care I want. Struggling for breath, even with oxygen, is not a finish of life I would like. (Boland, 2003, p.A7).

⁸ See Glossary

⁹ See Glossary

Eisemann and Richter (1999) used a questionnaire survey and found that there is unfamiliarity with advance directives and the general public has to be educated regarding this issue. An advance directive would maintain autonomy and deal with the fear of over treatment and possible prolonged suffering which is related to the principle of non-maleficence.

An advance directive might not be a total solution to a problem. Research suggests that even when there are clear guidelines for euthanasia, such as in the Netherlands, not all cases are reported and some doctors admitted to shortening the lives of patients outside agreed criteria, (Gillon, 1999). This means that competent patients were not always asked their opinion and their life shortened anyway without their permission. According to Cuperus-Bosma, *et al.*,(1999) medical officers involved in euthanasia cases without explicit approval of the patient were generally not prosecuted. The lack of prosecution may be because health professionals often practice within the value system of society.

Health professionals are taught the existing legal requirements, ethical rules and principles pertaining to healthcare and the values inherent in these subjects.

2.7 Education of ethics to health professionals

Education can help in the understanding of ethical principles and rules. As a health professional and educator, I am particularly interested in the area of ethics and the teaching of ethical principles. At present, arguments, such as ‘we can not afford to keep everybody alive,’ permeate the health sector. As a healthcare professional in clinical practice, it is important to take ethical principles into account when encountering ethical dilemmas such as autonomy, self-determination and withdrawal of treatment, and not just the economic state of the nation. Warner *et al.* (2001) raise a number of issues outlining the pressures put on health professionals in medical care.

The professional identities and ethics of the next generation of physicians are now being shaped in an extraordinary, potentially distressing milieu. New medical care systems that place greater value on the health of populations and on financial considerations than on the treatment of individuals have given rise to unprecedented ethical problems in end-of-life care. Some have even speculated that tomorrow's physicians will experience increasing pressure to consider death as an economically advantageous practice. (Warner *et al.*, 2001. p.4).

Ethical issues facing health professionals in clinical settings are complex. In situations involving patients' requests for euthanasia, 'do-not-resuscitate' orders, termination of life support or extraordinary treatments, health professionals are confronted with their own value systems and the patient's rights, the family's expectations and rights, and the law of the land. A knowledge base of legal issues, ethical principles and moral views is imperative for making appropriate decisions.

It is important that, as educators of future health professionals, we teach basic ethical principles and make them relevant to students embarking on a career as a health professional. There is extensive information in the literature regarding ethics, morals, legal issues and personal opinions related to the topic of euthanasia (Doane, 2002; Johnstone, 1999; Nolan & Markert, 2002). However, there appears to be little research available on how an opinion is formed by health professionals. Health professionals are taught ethical principles and legal issues as part of their education. Health professionals with the same educational background, at times, have opposing views. So how do they actually use their knowledge regarding legal and ethical issues to make clinical judgements and which principles do they adhere to? Equally so, how do lay people form their personal opinions, and which knowledge and beliefs do they use as a basis for their decision? This study's aim is to explore the knowledge base, views and ethical considerations of the people partaking in this study. Furthermore, differences in views, knowledge base and ethical considerations between both groups will be examined.

2.7.1 Education in context

Healthcare professionals, by and large, enjoy the trust of society. It is widely assumed that they will operate according to the values of the society they serve. Health care professionals are taught ethical principles and values. On the whole, the professional values and moral standing of healthcare workers probably do reflect those of society. In reality, it is not so clear-cut but, in a democratic society, it may be reasonable to make this assumption. Society and professions are made up of individuals and among individuals there will be differences in opinion regarding ethical issues. An individual may hold a view that is at odds with most of society; a healthcare professional may be out of step with the moral views of the profession. Healthcare professionals can become caught up at a professional as well as personal level in ethical problems encountered in their practice. In this study, the writer will explore the views about ethical issues, such as the practice of euthanasia, of health professionals, and whether these views are based on what they have been taught or personal experience. Where there is a division of opinion, it will not necessarily be a split with the patient asking for a service such as euthanasia, and the healthcare professional striving to uphold society's values. It is sometimes more complicated than that and moral and ethical choices will be influenced by both professional and personal considerations. This implies that healthcare professionals are capable of taking a 'minority' view and go against the general or legal opinion of society and against common practice of their profession. This study will explore differences (if any) in educational background and views, about euthanasia, between health professionals and the participants of the general population, and whether or not the views of both groups are congruent. Morality and moral discourse are part of living and, as Anderson (1990) puts it:

We see our interpersonal relationships as collaborative efforts in constructing values. We see education as, among other things, training in the skills of moral reasoning – morality not merely handed down but learned and created and re-created out of experience. And when there is conflict about that, as there inevitably will be, we accept the conflict also

as an arena for expressing and creating values...(Anderson, 1990, pp.258-59).

This statement may explain the role of education and also why health professionals at times are involved in euthanasia. This may not be legal but it may be ethically right and it may also reflect the values of society. Jowell *et al.* (2001) state that there is strong evidence from surveys among medical practitioners that euthanasia is a widespread practice.

The opinion of medical practitioners and whether they have practiced euthanasia has been researched by Baume (1998) who surveyed medical practitioners and Kitchener and Jorm (1999) who surveyed registered nurses. These surveys relate to health professionals in Australia. Kitchener and Jorm (1999) found that, among registered nurses, most were in favour of euthanasia, especially if it was legalised. Sixty percent of nurses did indicate that they were in favour of being involved in the process of euthanasia and 44 % as a witness. Most nurses did not want to perform the euthanasia themselves. Baume (1998) examined the open-ended responses for themes. It came to the fore in this survey that medical practitioners did rate some ethical principles not very highly- namely, autonomy was found important by less than 20% of the participants involved in this study and 8% of the participants found the issue of autonomy totally irrelevant. Consensual decision-making was found more important in the Netherlands where euthanasia is presently practised and the Northern Territory where euthanasia was practised (Otlowski, 1997).

According to Darbyshire, (1987) 58% of medical practitioners in the United States claimed to have practiced euthanasia and, according to Mitchell & Owens, (2003) 63% of New Zealand medical practitioners were involved in end-of-life decisions. Despite this high percentage, euthanasia is not taught to health professionals as a separate topic in tertiary educational institutions at present. When liaising with colleagues from other tertiary educational institutions in New Zealand, it became evident that the education of ethics and/or euthanasia, to health professionals in a degree programme, is most of the time part of a mandatory paper on ethics, professionalism or social studies. Education is

context dependent and sometimes the topic is covered in more depth as new developments occur. For example, when euthanasia was practiced but not legalised yet in the Netherlands, there were no support systems in place for medical practitioners. Since the practice is legalised, it has become part of the curriculum in educational settings and also post graduate courses have been developed to deal with this new development. “I have learned a lot through talks and postgraduate courses, also the law has changed and brings more clarity” (Stuy, 2003, p58). This Dutch medical practitioner has practised euthanasia and learned since her training as a medical practitioner about the practice of euthanasia. This indicates that educational practices are constantly changing.

2.7.2 Research on teaching practices pertaining to ethics

Educators are responsible for imparting knowledge to healthcare workers. There is an increasing amount of literature relating to ethics, which testifies to the growth and interest in this area (Nolan & Markert, 2002). Education of ethical issues especially euthanasia and the way to impart knowledge, is discussed in this section.

A study by Warner *et al.* (2001) discussed some of the educational practices in place, such as the use of hypothetical scenarios, and what may be required for the effective teaching of ethical principles so medical students can apply them. Overall, it appeared that there were issues with the teaching of ethical concepts and applying them to what medical students encountered in the clinical setting where they practice. Encountering the different attitudes of medical practitioners in clinical practice may influence ethical development more than education and, furthermore, education and attitudes encountered in clinical practice may not be congruent. “Influences on the ethical development of physicians are poorly understood, and many express concern that the process of socialization in medical training continues to engender cynicism and ‘merely the appearance of professionalism,’” (Warner *et al.* 2001, p.660). However, Jaeger (2001) states that theoretical principles and rules can be tyrannical and only those who make

equitable allowances for individual differences have a proper feel for the deeper demands of ethics. This requires an individual to be able to remain open to differences in other people's experiences and this may not always happen. Such observations have led some educators to believe that some medical practitioners do not meet ethical standards.

Warner *et al.* (2001) explored medical students' views on euthanasia. This study showed that students in Oregon, where physician assisted suicide was decriminalised, show more reluctance than their peers in other states to be involved in euthanasia. It is clear from the above mentioned statement by Warner *et al.* (2001) that the teaching of bioethical theories, concepts and prominent ethical issues, such as euthanasia, does not lead automatically to the application and use of the theories and practices. According to Myser *et al.*, (1995, p.97) "We recognize that there is some controversy about the principle-based approach to clinical ethics, not the least of which concerns the difficulties in conceptualising the relationship between ethical theory and clinical practice". Doane (2002) agrees and stated:

(a) the ethical dilemmas that typically arise from medical-technological advances (e.g. euthanasia), (b) learning and using supposedly neutral, culture-free principles rationally and logically to analyse the dilemmas, and (c) reaching a value-free 'right' answer.....A theory, principle or rule cannot tell one how to act in any specific case, and danger of an over emphasis on rational principles is that they divorce people from their own identities and thereby risk destroying the motivation to be moral (Doane, 2002, p.522).

The nature of moral sensitivity is a philosophical stance as much as a social and political problem since individuals have to take into account the legal and ethical issues as well as the socio-political situation, such as funding for healthcare and policies, such as not to deliver futile care.

According to Warner *et al.*, (2001) it appears that students are much influenced in the decision making process by personal and religious beliefs. This statement

was also reflected by Myser *et al.*, (1995, p.102) who indicate in their findings that it was difficult for students to make ethical decisions and recognise them as such. Students found that, “The grounds for clinical ethical decisions were no more than shared values or socio-cultural customs and therefore ethical reasoning was not useful”. However, Myser *et al.*, (1995) stated that ethical reasoning and decision-making may be thought of as a professional skill and found it is as relevant to efficient clinical practice as the biomedical sciences.

Until students have developed ethical reasoning as a professional skill, their opinions and decisions may be influenced by their personal beliefs and existing knowledge base, developed outside the education system, as is the case with the general population.

There are opinion polls (Gendall, 2003) regarding lay people’s opinions whether they are for or against euthanasia but there is not much data available indicating on which ethical principle(s) their opinions are based. There is even no data available on where and how the general population gained knowledge pertaining to euthanasia. In this section, I want to explore some of the learning that may well have had an impact on the development of a knowledge base pertaining to the practice of euthanasia.

Euthanasia is a concept that needs to be viewed by paying attention to the society in which the person lives. In New Zealand, the practice of euthanasia is very topical and appears in the news on a regular basis (Ansley, 2003; 60 Minutes, 2003; Bailey, 2003; Boland, 2003; Deveraux, 2001; Haden, 1998; Martin, 2002). Therefore, it is a subject that can easily be explored if an individual is interested in the topic. An individual can also learn about the topic by ‘accident’ via newspapers and TV programmes because the person is confronted with the topic via these media. The topic of euthanasia can also come up in discussions about religious values with parents or others and/or in an educational setting.

Other ways of learning, such as non-intentional learning, are also context dependent. Individuals learn about euthanasia by, for example, reading articles

in a magazine, newspaper or viewing the news on television. This will only happen if the topic is relevant or topical for society at that particular time.

2.7.3 Knowledge and learning

Learning is defined as gaining knowledge by studying (Collins, 1999). In this section, different modes of acquiring knowledge are discussed. There are several different ways to gain knowledge and one way is by means of the scientific method. Gaining knowledge by way of the scientific method is using systematic procedures of investigation which are public, shared by others and can be tested again and checked for reliability. The knowledge gained by the scientific method has been proven to be 'correct' or 'true' although further investigations may bring new and refuting evidence. Science is mostly focused on something that can be observed, an object or behaviour, or a phenomenon such as euthanasia. The practice of euthanasia, the rules and the need, can be examined and analysed according to ethical guidelines and legal definitions. It has formed an object or phenomenon to study. Husserl (1962) believes in subject-object duality, stating that the person is considered as the subject. The individual is trying to make sense of the environment and things in the external world which constitutes the object, and that the truth lies in the object. According to these beliefs, subjective feelings and values of an individual on a topic, such as euthanasia, are of little value.

However, Heidegger, (1962) rejects the notion of subject-object duality. The person exists as 'being in the world', whereby the person's past experiences and cultural contexts are already integrated into their experience to become part of their existence, without separation of subject-object. Warner *et al.* (2001) confirm this, stating that students report that religious beliefs and strong personal philosophy influence attitudes towards clinical care practices and that it is important to not intrude or change students' perspectives but it is critical to discuss values and perceptions so that they are integrated into the framework of students' increasingly sophisticated clinical understanding. A student can learn to judge new situations and ethical problems from this framework. Learning can

take place in different settings. In general terms, formal learning finds place in an educational institution and informal learning outside the boundaries of an educational setting.

2.7.3.1 Informal learning

There are various ways in which individuals can learn and in a variety of settings. Informal learning happens as part of life and most of our learning finds place by experiencing life. We learn to walk, talk, interpret events and to acquire many skills by just living and most of our learning takes place outside educational institutions. In this section, some of the ways that informal learning occurs, such as phenomenology, vicarious learning, learning from authority, experience and empathy, are discussed.

Science often does not examine the experience of the event or phenomenon. According to Boddy, (1985) phenomenology or the notion of 'lived experience' can be examined, such as the experiences of the participants partaking in this study and their feelings on end-of-life decisions. These experiences do not necessarily give 'objective' knowledge since personal experience relates to perceptual or subjective knowing. It is the only source of self-knowledge and knowledge of most phenomena, such as experiences of pain or pleasure.

Vicarious experience, through the process of empathy, is as close as one can get to experiencing someone else's emotions (Boddy, 1985). In relation to the topic of euthanasia, this way of learning may be applicable to individuals confronted with a patient or relative who is terminally ill.

Knowing by authority involves deferring to the sources of knowledge rather than the manner in which it was generated (Boddy, 1985). This means that some individuals adhere to what has been taught by an authority (for example the church) and that euthanasia should not be practised.

Rogers (1961) states that learning by experience is learning from the highest authority and he claims that the most critical test is experience. The thoughts of somebody else or oneself are as authorised as one's own experience. Mak and Elwyn (2003) confirm that experience does have a place in research from a phenomenological point of view, focusing on the 'what' and 'how' and, from a hermeneutic point of view, interpreting the 'why'. Meaning is constituted in our everyday experience and, therefore, it is often taken for granted or presumed as self-evident. Mak and Elwyn (2003) collected data from patients' perspectives on euthanasia and why these patients requested the practice of euthanasia, since the patients were considered the experts on the phenomenon of euthanasia. The result of Mak and Elwyn's study shows that the interpretation of experiences are very personal and different for each individual, depending on variables such as religious background, personal values, suffering involved and available support system.

All the ways of learning mentioned above are informal. There is also a place for formal learning and this learning most of the time takes place in educational settings.

2.7.3.2 Formal education and learning

An issue that many of those commentating on informal learning do not seem to make is a distinction between learning and education. "Learning can be seen as a product or a thing - a memory or understanding; or as a process - a form of thinking" (Coffield, 2000). Education is perceived to be a setting or environment where learning is encouraged and fostered and where there is a commitment to certain values such as respect for knowledge and truth.

In our society, formal education and learning are required to obtain, for example, diplomas and degrees which are important in our society since they are designed to ensure that there is a knowledge base present and may protect the general public from injury. For example, qualified electricians are acknowledged to have certain skills and knowledge base and are able to install electricity in houses in a

safe way. For health professionals, education means the learning and acquisition of new manual skills so that they can be safely practiced on patients while also developing critical thinking skills and theoretical knowledge so that problems encountered in a clinical setting can be solved appropriately. Educational institutions are responsible for ensuring that students with a certain qualification have an adequate knowledge base to protect the general public and maintain the standing of the qualification. However, formal education should entail more than the acquisition of skills and knowledge; according to Leadbeater (2000) education should foster a desire to learn.

According to Leadbeater, (2000) informal learning means that learning has found place without an educational institution or formality.

We must move away from a view of education as a rite of passage involving the acquisition of enough knowledge and qualifications to acquire an adult station in life. The point of education should not be to inculcate a body of knowledge but to develop capabilities: the basic ones of literacy and numeracy as well as the capability to act responsibly towards others, to take initiative and to work creatively and collaboratively. The most important capability, and the one which traditional education is worst at creating is the ability to carry on learning. Too much schooling kills off a desire to learn....Schools and universities should become more like hubs of learning, within the community. More learning needs to be done at home, in offices and kitchens, in the contexts where knowledge is deployed to solve problems and add value to people's lives (Leadbeater, 2000, p. 111-112).

However, in our society the focus of learning remains on formal provision, qualifications and accountability (Coffield, 2000). There is some doubt as to whether the notion of informal learning is the best way forward. "Within much that is written and said about the area, learning and education are confused: and there is an over concern with institutional setting or sponsorship as against process and content" (Coffield, 2000).

It is a challenge for educational institutions to impart knowledge and skills in an interesting and relevant way to students. It is even more of a challenge to impart values and critical thinking skills such as the teaching of ethical principles, outlined in section 2.3, in such a way that students can apply the knowledge in a clinical setting.

2.7.3.3 Knowledge and values

Individuals base their views and decisions in life often on knowledge and values; this also pertains to the practice of euthanasia. De Roeck (1979) describes several ways of processing values and norms of society. As an individual we can say 'yes' or 'no' to general rules and norms of society. When we say 'yes' to norms and values we do belong to a group and we may feel accepted. When we say 'no' it may make the individual stand out, giving a feeling of being different or negative. We can sit on the fence and not have a clear opinion or not want to share it out of fear of non-acceptance. Cultural differences may play a role in the acceptance of general rules and norms of society.

Culture is a complex concept. There are numerous definitions of culture, even anthropologists do not agree about how culture should be defined, interpreted and analysed. It is clear that culture plays a fundamental role in shaping people's values, beliefs, perceptions and knowledge about the world within we live, that it influences people's behaviour and generally gives logic and meaning to a whole way of life in that world, and that it ultimately provides a 'blueprint' for their (human) survival in that world (Kanitsaki 1992, p.5). There is a link between culture and people's moral values, beliefs, perceptions and knowledge of what constitutes morally right and wrong conduct. For example, the concept of autonomy reflects the dominant cultural values of the individualised western society. For individuals holding the same beliefs and values, there is no problem or conflict. However, according to Johnstone, (1999, p. 148) "autonomy is not in all cultures valued in the same way and communication with the family rather

than the individual patient might be culturally appropriate such as in the case of 'traditional' or non-western cultures".

We do have to coexist with the different belief and value systems. Rogers (1961, p.13) states, "Our society has a need for fundamental knowledge and a competent approach in respect to the prevention and the solution of conflict management in interpersonal relationships". Learning appears to be an important part in this. According to Rogers, (1961) facts can bring truth, and every little fact can bring us closer to the truth. Learning is defined as a new orientation in thinking, perception and understanding of an old concept incorporating new facts and values (Rogers, 1961).

Awareness or being conscious of ethical principles, such as the principle of vitalism, that we seem to adhere to in Western society such as New Zealand, does not always occur. We literally presume its worth and understanding in our existence and may not be conscious of doing so. This tacit knowledge does influence people's value systems and may provide a basis for the way we interact with others or react to situations. Eraut (2000) has identified six different types of situations in which tacit knowledge may be gained or used:

- knowledge acquired by implicit learning of which the knower is unaware;
- knowledge constructed from the aggregation of episodes in long term memory;
- knowledge inferred by observers to be capable of representation as implicit theories of action, personal constructs, schemas, etc;
- knowledge that enables rapid, intuitive understanding or response;
- knowledge entailed in transferring knowledge from one situation to another;
- knowledge embedded in taken-for-granted activities, perceptions and norms (Eraut, 2000, p. 28).

The above-mentioned ways of gaining knowledge can be applied to health professionals and the general population. Individuals process new information and some information is more readily integrated in the existing knowledge base than other information.

2.8 Summary

In summary, this chapter has covered a range of issues regarding end-of-life situations nationally and internationally and the practice of euthanasia. It is apparent that views on euthanasia differ and that the practice of euthanasia is legalised in the Netherlands and that assisted suicide is available in Oregon and Switzerland. Terminology to discuss the different situations was used interchangeably and this leads to the question: "Can you define/explain what euthanasia is?" It was of interest to the writer whether individuals had a good knowledge base and were able to define the practice. Clearly there is a 'gap' in the literature; little research has been done as to whether people can define euthanasia; we may be discussing a different concept if people define it differently. The New Zealand situation and several cases where withdrawal of treatment was applied were discussed. This led to asking the question: "When is euthanasia an option?" Ethical issues and ethical principles that help guide in decision making in end-of-life situations were discussed. Legal issues and educational issues in general and in particular pertaining to health professionals were discussed. This led to the question: "Which values, ethical and legal issues should be taken into consideration?" It became apparent that, although there are theories about informal learning which may apply to learning about a topic such as euthanasia, there is no research as to how the general population gained a knowledge base pertaining to this topic, and which forms of informal learning applied. Therefore, descriptive data about how the general population gained knowledge regarding bioethical issues and euthanasia in particular are non-existent. This study endeavours to fill this gap.

Chapter 3

Methodology

The method for this study is qualitative. Qualitative data describes or represents people, actions, views and feelings, the meanings and interpretations given to events in social life (Kumar, 1999; Cohen & Manion, 1990). Euthanasia is a phenomenon that people are confronted with in newspapers or encounter in their own personal lives. The great strength of qualitative research is in the study of motivations and other connections between factors. Qualitative research examines the way people redefine situations until the situation makes sense, is acceptable or comfortable for the individual concerned. In this study, participants were interviewed and shared their opinions and views on the topic of euthanasia. It was apparent in the overview on euthanasia, in Chapter 2 that not everybody is comfortable with the practice of euthanasia and that views on the topic differ widely. To understand a situation or phenomenon such as euthanasia, different levels of knowledge are required, such as outlined below.

The first layer of knowledge is from descriptive data outlining the context or situation and can be found in the literature; for example, what is happening in New Zealand and elsewhere regarding euthanasia and can be found in the previous chapter. The second layer is the cognitive layer and participants are asked their perceptions of what is happening regarding euthanasia. The next layer is the normative layer. This study is primarily designed to examine what health professionals and the general population know/or understand about euthanasia, their opinions, how they derive their opinions and what should happen. The fourth layer is the explanatory layer and educational theory (Chapter 2, section 2.7) is used to explain what is happening regarding the forming of an opinion regarding euthanasia. The data are analysed in a way that seeks to explain how education is embedded in a context. The second and third layers of knowledge are related to the aims described below.

The aims of this study were to:

- Examine the difference in knowledge base between two small groups of health professionals and the general population regarding euthanasia.
- Find out how participants are educated regarding ethics and euthanasia in particular.
- Explore the viewpoints, feelings, and ethical considerations that the members of the two small groups of general population and health professionals regard as important to the topic of euthanasia and their attitude and views on the practice of euthanasia.

When applicable, meanings and interpretations given to events, contradictions between attitudes and behaviour, how conflicting attitudes and motivations are resolved and particular choices made, were explored in the study. Qualitative research is well suited to gaining an understanding of views and values on a topic such as euthanasia in a certain context. It was also the most appropriate way to conduct this study since it was the best way to achieve the aims for this study. With a quantitative approach the writer would not have achieved an understanding of the views and opinions of the participants. Interviewing participants partaking in this study in private, the writer was able to establish a rapport with the participants so that information was forthcoming. Because the study was designed to compare two groups, there is some quantitative data analysis as well to support the differences between the groups of participants.

3.1 Methodology

If methods refer to techniques and procedures during the data gathering process, the aim of methodology is to describe and analyse these methods to help us understand the process itself (Cohen & Manion, 1990). This study aimed to capture the insights of individuals from a variety of backgrounds and this was

achieved by interviewing each participant. The methodology used in this study is based on Yedidia & MacGregor (2001) since it appeared the most appropriate for investigating people's opinions and feelings concerning a very emotive and controversial topic such as euthanasia. Equally so, an ethnographic technique of interviewing and inductive, qualitative approach to analysis is used to examine the opinions of a variety of people. This strategy does, not by its very nature, adopt the preconceptions of the investigator and was used in this research study.

An interview, with one open-ended question regarding existing understanding and knowledge base, was proposed. Since euthanasia is a sensitive and controversial topic, this approach gave the participants the option to share as much or as little information as they wanted. It avoided bias and 'leading' the participant in a particular direction. Only one interviewer was used to prevent bias in the interviews. Interview on an individual basis was best suited for this topic as it gave the participant the option to share personal and sensitive information that might not be volunteered in a group of strangers who might or might not share the same opinion and or experiences.

According to Cohen & Manion (1990) open-ended questions have the following advantages: to be flexible, establish rapport, encourage cooperation and it may provide richness in data that may not have occurred if only closed-ended questions were posed and allowed the interviewer to make a truer assessment of what the participant really believed. The in depth interviews with the participants varied in duration from 40 minutes to two hours.

The interviews were audio taped, transcribed verbatim and subjected to inductive analysis using standard qualitative techniques: multiple readings of the transcript to identify themes, coding of the transcript by themes, examining how themes relate to each other and to the central theme of the study. Passages from the interview transcripts that typify views and opinions regarding a theme are presented in order to permit the participants to speak for themselves. The transcribed passages are presented in italics for ease of reading (codes used to protect confidentiality).

An interview stating an open-ended question, “What is your knowledge and/or understanding of euthanasia?” was used. In most cases, data obtained from the interview would provide all the information required. However, a pilot study trialling the open-ended question showed that not all data wanted were consistently volunteered. That is, some participants volunteered a lot of information while others gave limited information and some information volunteered was not relevant to the aims of the study. Therefore, it was anticipated that, with one open-ended question, not all data would be obtained from each participant and closed-ended questions were incorporated in the interview when deemed necessary to obtain data required. The following questions were asked if not all information required was volunteered:

- 1) Should euthanasia be practised and/or legalized in New Zealand?
- 2) When is euthanasia an option in your opinion?
- 3) Which values, ethical and legal issues should be taken into consideration?
- 4) Where did you gain knowledge regarding euthanasia?
- 5) Have you had any experience with euthanasia?
- 6) Have you lost somebody you were close to due to illness?

Answers to the above questions would give the writer the information that was sought. The questions were structured so that the participant could elaborate on the answer(s) and volunteer as much information as he/she was willing to give. For example, participants could elaborate and explain in response to question 1) why or why not euthanasia should be practised and/or legalized.

3.1.1 Data analysis

The data were analysed using a coding system. First, content analysis was performed by sifting through the data to find a particular response according to the identified themes and the responses were colour coded. Themes investigated were:

- 1) Can the participant define/explain what euthanasia is?
- 2) What criteria would they use to decide whether euthanasia is acceptable or not acceptable, how have they formed an opinion?

- 3) Ethical considerations such as the principle of vitalism, autonomy, non-maleficence, beneficence, fairness or justice, and legal or moral/value issues.
- 4) How has the participant gained knowledge in this field and has formed an opinion eg by experience, education, publications, propaganda etc.
- 5) Themes may emerge from the analysis.

The themes were anticipated and also emerged from a number of sources such as the literature search and aims of this study. The themes are related to the questions outlined in section 3.1. From the data further themes emerged. It is clear from Chapter 2 (section 2.2) that there are different interpretations of the term euthanasia and this issue was examined as well.

Sometimes more than one response was given and the process was repeated until no new responses were discovered. Because of the use of an open-ended question, participants' volunteered information not related to the identified themes. When several participants gave a particular response it became a recurrent theme and a new category or theme was developed.

The data were analysed and the results from the health professional group and general population group were compared. At times, when the data showed a difference or the life or work experience may have made an impact on the data, a distinction was made between three groups; namely the general population, the health professionals who have experience with life and death situations and the randomly chosen health professionals.

3.1.2 Validity

To assure validity, transcripts were presented to the participants to permit the person interviewed to check for themselves on the transcriptions from the interviews. According to Kumar, (1999, p.138) face validity is, "the judgement that an instrument is measuring what it is supposed to is primarily based upon the link between the questions and the objective of the study." Content validity

is the adequate representation of the issues to be researched in the questions. According to Edwards, (1986, p.156) “validity is concerned with ensuring that the ideas and propositions which emerge from a study are well-grounded in, and soundly reasoned from, a reliable data base”. The researcher always wishes the participants to be forthcoming with information without distortion or difficulty. To create an environment where participants would feel free to share views, on a sensitive topic such as euthanasia, interviews were held on a one to one basis in the comfort of the participant’s home. The open-ended question gave data not required but was basically there to ‘set the scene’, to give the participant the opportunity to share opinions on the issue and give a ‘richness of data’ that otherwise might not have been obtained. The closed-ended questions ensured that there was completeness in the data obtained from the participants. Due to the fact that the participants were known to the researcher, “there is the danger that information may have some bias” (Edwards, 1986). The writer is aware of this and remained alert to this possibility throughout the study.

External validity, which is concerned with the ideas generated in a study being able to be understood, is an important issue. The researcher must seek to portray the participants’ reality. External validity, in effect, must be assessed largely on the degree to which description portrays this reality and is relevant and true to the participants (Edwards, 1986).

Interviews with consecutive participants were analysed and yielded theoretical saturation, which means that when the data were analysed no new themes emerged. The qualitative method, by virtue of the density of data collection and the inductive style of analysis is designed to maximize validity.

3.1.3 Reliability

The reliability of the research tool refers to the consistency and stability. Therefore; “a scale or test is reliable to the extent that repeat measurements made by it under constant conditions will give the same result” (Moser & Kalton

1989 p.353). However, in social science a research instrument is not always 100 percent reliable.

Qualitative studies seek to understand the interplay among variables which exist in a natural context. In determining the reliability the researcher must provide detail in which the study was developed, the part of the researcher and the ways in which the data were gathered and processed (Edwards, 1986). This detail is the key to obtaining a high level of reliability which can be hindered by biases or other influences (Edwards, 1986). To ensure reliability, a pilot study to test the open-ended question took place involving 18 participants and several factors influencing reliability were taken into account when data were collected. Because the open-ended question did not yield all the data the researcher was seeking, some closed ended questions were developed, and these were to be used only in cases where the participant did not volunteer the information that was sought. This process resulted in interview questions being the same, the physical setting was the same in that participants were interviewed in their own homes at a time suitable for them to ensure an environment that was comfortable to volunteer information and all participants were interviewed by the same person to prevent bias of the researcher. All data were tape recorded and word-processed verbatim.

A concern which arises from the notion of generalisability, discussed in section 3.1.4, is the issue of replicability of a study (Edwards, 1986). The use of questions, type and number of participants and interview setting in this study can be replicated. However, in this study, replicability is not an important feature because human beings are not always static in behaviour, views and attitudes. When measuring opinions, views and attitudes, respondents may give different responses depending on their mood, the nature of the interaction (eg. a repeat interview may give a different response due to the change in interaction) and opinions and attitudes may change due to a variety of factors such as life experiences or the regression effect (eg. some participants may feel that they were too negative or positive in the initial interview). If this happened then the opportunity for the participant to be re-interviewed was made available. One

participant made use of this opportunity and wanted to discuss issues on a further occasion.

3.1.4 Generalisability

A feature of quantitative research is the degree to which findings can be generalised from the sample to the general population. However, in this qualitative study, the generalisability of results from the sample population to the general population is not possible. This is due to the fact that the sample size was very small, and, therefore, not representative of the general population and the health professionals in New Zealand.

Generalisability, therefore, was less of a concern for this study than it would have been had a quantitative approach been taken. As mentioned before, there is no data available about how the general population gained knowledge regarding a number of bioethical issues, and this study endeavours to fill this gap. Therefore, the writer is concerned with the participants' knowledge base, experiences and views, and accurate description of these for the reader.

3.2 The participants

Two groups of participants were selected. The rationale was to investigate difference(s) (if there were any) in attitude towards euthanasia between health professionals and the general population, and compare the rationales given between the two groups for the opinions and views.

3.2.1 Selection of participants

In total 14 participants were involved in the actual research project. All participants indicated that they were more than willing to be involved and partake in the research project. Seven participants were from the 'general

population' and not working as a health professional or related to the health sector. Seven participants were working in the health sector. Two of the seven health professionals were employed in a hospice and were caring for terminally ill patients on a regular basis. The other health professionals worked in a variety of settings, two as medical practitioners and three participants as nurses, see Table 3.1 below.

Statements made by the health professionals, who participated, are indicated by an H and a number. These health professionals differ in religious and cultural background as well as in work experience, from a new nursing graduate (H2) to persons with approximately 40 years work experience (H6, H7). Two participants are medical practitioners. The age range for this group is approximately 22 (H2) to 80 (H1) years old. Table 3.1 provides more individual detail about the participants in the health professional group.

Table 3.1: Data pertaining to healthcare professionals

Participant	Sources of knowledge	Experience with dying	Profession
H1	Work	professional & personal	Health professional
H2	education	professional	Health professional
H3	education	professional	Health professional
H4	education, reading, teaching, work	professional & personal	Health professional
H5	education	professional	Health professional
H6	work	professional & personal	Health professional
H7	work, discussions	professional & personal	Health professional

Participants were selected from a group of people known to the researcher in and outside the health sector. The aim in using different groups was to gain knowledge of a range of perspectives on the topic of euthanasia. Some health professionals were selected for working in or having experience with end-of-life situations. This was done to cater for any possible differences between health professionals with experience in this area and health professionals without experience in this area. Table 3.2, below contains data pertaining to participants from the general population group.

Table 3.2: Data pertaining to the general population

Participant	Sources of knowledge	Experience with dying	Profession
G1	work, education, animal ethics advisory committee, television	personal and with volunteer work	Technician, & Volunteer work
G2	education	personal and professional	Minister & Volunteer work
G3	nil/reading	personal	Educator
G4	discussion, television	personal	Student
G5	work, television	personal and volunteer work	Volunteer work
G6	personal, discussion, newspaper	personal	Educator
G7	nil/reading	personal	Artist

Statements made by the general public group, who participated, are indicated by a G and a number. The main characteristics of the participants belonging to this group are outlined in Table 3.2. The participants differed in age from approximately 16 (G4) – 69 (G2) years of age, religious background, and work and life experience.

There was a mix in gender, age, different religious and cultural background, and life experience in the group of 14 participants. It is useful that there are differences between the participants since it added to the differences in opinions and insight in the topic. These differences may have contributed to and been reflected in the responses to the question posed in the interview. It was anticipated that, if the person did not want to participate, another name was going to be drawn; however, nobody refused to participate. The initial approach took place by phone or face-to-face contact. All the participants approached agreed to participate. An information sheet (Appendix B) was given to participants stating the purpose of the interview and research project.

3.2.2 Consent

Consent was obtained from each participant. Informed consent in this context means that the participants were aware of the type of information being sought, the purpose it would be put to, what was involved (Appendix C).

3.2.3 Wellbeing of participants

The participants had to be aware of the topic, and the type of information sought, so that they were able to decide whether or not they wanted to participate. There was a possibility that participants underestimated their emotional status and the opportunity to withdraw at any time was given.

Since the topic can be very emotive, it was anticipated that participants might want to vent views and 'be heard'. This can be therapeutic and beneficial. Participants who had lost a loved one may have had unresolved issues; these might have come to the fore along with feelings of loss, inability to cope and grief, which had to be dealt with in a sensitive way. These issues were not brought up by the research and as such the research itself was not causing the harm. However, if issues arose then counselling by a professional counsellor would be made available.

3.2.4 Confidentiality

The information obtained was dealt with in a way that the individual participants could not be recognised, by not revealing too many personal details from the descriptions in the research. The data was locked in a secure place and stored in accordance with Massey University Policy. The interview was transcribed by the writer and viewed by the participant and the opportunity to withdraw at this stage was also available.

3.3 Problems and limitations of the study

Firstly, one major limitation of this study was the sample size. Because of the small sample size, a total of fourteen participants, the results are not representative of the general population, or the whole group of health professionals.

Secondly, a bias might have occurred in the data since, for this study, no participants declined to partake in the study. It may be that the individuals who were not willing to partake in the study have a certain view that will now not be represented. On the other hand, it is possible that some people who were interviewed might have had quite strongly developed views.

Thirdly, data might not be representative of the different cultural groups existing in New Zealand. The participants partaking in this study are from different ethnic cultures, most of the participants are New Zealand born, and some participants have a Polynesian or European heritage. However, not all existing cultures in New Zealand are represented.

Concepts, such as quality of life, are, for some western cultures, strongly defined by being independent of others, but in some cultures being independent of others may not be an issue. It is important to be aware that participants had different views on issues such as autonomy, quality of life and euthanasia. In our multi cultural society not all participants included in the research project belong to the same cultural group and not all do adhere to western values, and this is reflected in the data obtained from participants. Again, the sample size would lead to cultural bias in relation to euthanasia because not many cultures were represented in the sample.

3.4 Ethical approval

The writer followed the process adopted by the Adult Education Group-Wellington Campus at that time:

- A brief proposal for a research/study project is brought to the Adult Education Group meeting by the thesis coordinator.
- Supervisors were selected and after meeting on several occasions over a period of time I completed my thesis proposal.
- The thesis proposal was read by the thesis paper coordinator, and the supervisors allocated to supervise the researcher, for comment.
- A meeting was held with the researcher, the supervisors and the thesis coordinator. The proposal was fully discussed and it was decided that a Massey University Human Ethics Committee (MUHEC) application was not required. The reason for this decision was that the participants were outside the university and from the researcher's personal network. Hindsight suggests that MUHEC ethical approval would have been

appropriate. However, the researcher, her supervisor and the thesis coordinator are confident that the study was conducted with due consideration of ethical issues and with the best of intent. The participants were not interviewed in any capacity of their employment, whatever that may have been at the time.

- Regular meetings took place about the development, and the ethics of the thesis until the thesis was ready for submission. Awareness of the public debate on the topic of euthanasia was very high; hence ethical issues surrounding the thesis were discussed on a regular basis and written about throughout the thesis.
- The usual practice of signing off the thesis as being ethically sound was done by the first supervisor.

At every step of the way during this study the writer strived to be ethically sound and protect the interest and wellbeing of the participants. Information pertaining to this study was given to participants, consent from participants was obtained, and the researcher sternly endeavoured to use the views of the participants and adhere to the methodology to ensure reliability and validity. The above described process adhered to, at the time of this study, by the Adult Education group at Wellington, has been altered, and all research projects with human participants require ethical approval by the Massey University Ethics Committee, or signing off through the low risk process.

The writer was unable to identify any obligations under the Treaty of Waitangi that required particular attention in this study.

3.5 Ethical issues pertaining to the researcher

My personal involvement in euthanasia, having experienced the practice as a family member, when my father passed away and, as a health professional, when working as a Registered Nurse, involved in “withdrawal of treatment”; it might influence participants in their answering the interview question if they knew my

background. Participants were not advised of my background, it did not appear to be appropriate to bring it up as an issue, since it could cause participants to feel inhibited in expressing their own views. Six participants were aware of my background. When approaching participants aware of my background it did not appear to be an inhibiting factor in their participation and volunteering information. This may be due to the fact that the euthanasia and withdrawal of treatment did not feature as a new or recent event.

For this project, I did not foresee involvement in euthanasia and withdrawal of treatment to be a major problem since there was awareness of possible bias. It was anticipated that bias would be detected or recognised by reflecting on the content of the interviews and becoming aware of the issues. Because of the interest in the topic and my own existing ideas and value system, (for example adhering strongly to the principle of autonomy) there had to be awareness of my own value system to prevent bias creeping in. In all cases interviewees were given the transcriptions (section 3.1, p.55) to read to ensure that what they had said was transcribed accurately. The open-ended and the closed-ended questions provided the only direction for the project and prevented guidance from the researcher to occur.

The challenge was to represent the views and knowledge base of the participants fairly and, therefore, a strict coding system for analysing data and correct reporting of findings was adhered to. The adherence to a strict coding system prevented bias occurring.

Chapter 4

Results

The participants, involved in this study, consisted of a small group of health professionals employed in general areas of healthcare and palliative care, and a small number of individuals of the general population. An open-ended question of “What is your knowledge or understanding about euthanasia?” was used for collection of data. If sufficient information was not volunteered, closed-ended questions, as outlined in on page 57 were posed. The questions were designed to obtain data regarding the knowledge base, attitudes and ethical principles relating to the practice of euthanasia. Not all the data transcribed could be used; two participants declined some of the data to be included in the analysis.

In this chapter, the results were analysed with the themes outlined on pages 57-58 in mind. However, more themes emerged during the analysis and this is reflected in the data below. Although the reader can find the outline of this chapter in the Table of Contents, a brief overview is given below for the benefit of the reader. The results of this project are as followed. Section 4.1 to 4.6 provides the results of the analyses of the themes. Section 4.1 examines the knowledge base regarding euthanasia. When analysing the data regarding the first theme “What is the definition/ understanding of euthanasia?” both themes emerged. The ability to define euthanasia is discussed in section 4.1 and the ability to explain what constitutes euthanasia was discussed in section 4.2. The second theme, relating to whether euthanasia is acceptable, is presented in section 4.3. The theme was rephrased as a heading for this section since what came to the fore were two different issues, namely, whether euthanasia was acceptable and whether or not it should be legalised. In this section the ethical principle of autonomy is discussed in relation to the decision whether or not to practice euthanasia. The third theme, in section 4.4, pertains to values, ethical and legal issues that should be taken into consideration. One of the ethical

principles found important by participants is the principle of autonomy. The fourth theme is discussed in section 4.5, and relates to knowledge and personal experience of the participants. Section 4.6 represents results related to a new theme that emerged from this study, termed 'suffering and spirituality'.

4.1 Definition of euthanasia

The first theme relates to the ability to define and explain the practice of euthanasia. In this section, the results, with regards to the definition of euthanasia, are described. In section 4.2 statements, regarding the understanding of euthanasia as a phenomenon, are described. There are clear definitions of euthanasia as discussed in section 2.1 and the glossary. For the purpose of this research project, active voluntary euthanasia is taken as the correct definition. Active voluntary euthanasia is defined as dying on a voluntary basis, while terminally ill or suffering an incurable disease, due to administration of lethal drugs by another person.

Out of the 14 participants for this project, seven of them gave correct definitions, four of them gave an incorrect definition that had nothing in common with the term euthanasia, and three participants gave a definition that was partially correct and fell in between the two extremes mentioned (Table 4.1). Table 4.1 shows that five of the seven health professionals, and two of the seven participants from the general population group, gave a correct definition for euthanasia. This shows that five of the health professionals interviewed define euthanasia correctly although only two of the general population group gave a correct response. Only two participants from the health professional group gave a partially correct definition of euthanasia whereas, in the general population, two of the seven participants provided a partially correct definition of euthanasia, and three of the seven participants gave an incorrect definition of euthanasia.

Table 4.1: Number of participants from the health professional and general population providing a correct, partially correct or incorrect definition of euthanasia.

Group	Correct definition	Partially correct definition	Incorrect definition
G	2	2	3
H	5	1	1

The following statements do not necessarily contain all the information that constituted a correct definition of euthanasia such as “death on a voluntary basis while suffering a terminal illness or incurable disease by active means such as a lethal injection, by a medical practitioner” (Johnstone, 1999), but have or imply most of the criteria for a correct definition of euthanasia.

In the general public group the following statements were volunteered; the Greek definition of euthanasia is

A gentle death (G2).

Have a doctor to give an injection that kills (G4).

Among the health professionals there was a range of definitions offered as follows

The person concerned must want it to happen and the individuals responsible carrying out the procedure must be medical practitioners and it has to be carried out rightly, objectively and satisfactorily (H1).

A gentle death,... a drug assisted death by medical practitioners (H7).

A doctor assisting or helping the person who wishes to die to do so (H5).

Deliberate termination of life by pharmacological means consented to by the patient and not in breach of law (H3).

Euthanasia is when a person whom is terminally ill makes the decision to end their life and does so with the help of medical professionals and lethal chemicals (H2).

Partially correct statements were as follows

To help with drugs to die in a painless way (G5).

Die with dignity and self determination (G6).

And hasten death with chemical means (H4).

Although G5 and H7 provide similar definitions, the difference was that participant G5 did not indicate that a medical practitioner administered the drugs.

Some participants gave a definition or opinion that was not considered correct. For instance,

It is a consideration of suffering (G7).

It happens on an informal basis, my mother was given morphine when she was ill and after that she lost consciousness (G1).

G1 also states that

I would agree to euthanasia if people could do it themselves (G1).

Strictly speaking, this last statement is not a definition but a reflection of how the participant perceives euthanasia.

Two participants gave statements that were not definitions at all

What would the definition be (H6).

The only knowledge I have got would fill the left hand perforated corner of a postage stamp (G3).

4.2 Understanding and knowledge of euthanasia

Though some participants were not able to define euthanasia very well, they all expressed an understanding¹⁰ and some knowledge¹¹ of the topic. The opinions were very personal, as opposed to the definition, which is more to clarify the meaning of the term. When participants explained their understanding more value laden statements were made such as

It is wrong to take a life, no matter what condition it is in (G7).

It is a fine line when you give a drug to make a patient pain free but is going to hasten death (H4).

I think it is a gentle way to die from a terminal condition (H7).

You do not use pain relief to kill but to give comfort (H6).

My mother was given morphine for pain relief and she lost consciousness, a sort of passive euthanasia, the will to live was not there and she was in no condition to give consent to anything any more (G1).

H2 and H6 have worked in an area where withdrawal of treatment was practised but did not discuss this practice during the interview. H6 did discuss experiences

¹⁰ See glossary

¹¹ See glossary

within her family and community. Participants H2 and H6 worked in the same area as participant H7 who has talked extensively about the practice of withdrawal of treatment during the interview. H6 works at present in the community and H2 has only worked for a few years in the area where H7 is practising as a health professional. As mentioned before, H7 talked extensively about end-of-life situations and withdrawal of treatment, while H2, although working in the same area as H7, did not mention having experiences with withdrawal of treatment. The difference between H2 and H7 may be due to the length of employment and, therefore, less experience with withdrawal of treatment for participant H2, or the difference may indicate a lack of insight in clinical situations. All of the other health professionals acknowledged the practice of euthanasia. Three of the general population participants perceived that euthanasia was practised, although two participants mentioned that it would not be called euthanasia but 'giving pain relief'. The following information was shared.

Life support equipment gets switched off (G5).

The very ill have been given more morphine to ease the way (G5).

She (referring to the patient) was never going to recover from that stroke and he (referring to the general practitioner visiting the patient) gave her morphine, and not too long after she died (H7).

An awareness of end-of-life situations that may not be without suffering or complications leads to the question whether or not euthanasia is considered an option.

4.3 Should euthanasia be practised and/ or legalised in New Zealand?

The second theme "What criteria are to be used to decide whether euthanasia is acceptable or not and how is an opinion formed?" is presented in this section. A distinction is made whether participants would like to see euthanasia legalised,

or whether the practice of euthanasia is acceptable, and why. Opinions of participants varied. Some participants were for the practise of euthanasia, but not for legalisation, and wished the status quo to remain, that is, pain relief can be given even if it shortens life. The practice of giving pain relief with the intent to relieve pain, even if it shortens life, is not considered euthanasia in New Zealand.

In Table 4.2 the number of participants for or against legislation of euthanasia, and the practice of euthanasia are shown. Out of the 14 participants for this project, nine are pro euthanasia itself, and seven are pro legislation of euthanasia. Out of the 14 participants three are against euthanasia, and two are neither pro nor against euthanasia, whereas, 12 of all participants are against legislation of euthanasia. Table 4.2 shows that four of the seven health professionals, and five of the seven participants from the general population group, are pro euthanasia. From the health professional group, two participants are against euthanasia, whereas in the general population one participant is against euthanasia. In both, the general population and the health professional group, six of the seven participants are against legislation of euthanasia.

Table 4.2: Opinions for or against the practice of euthanasia and of legislation of euthanasia

Participants	Legislation			Euthanasia		
	For	Against	Neither	For	Against	Neither
G	1	6	0	5	1	1
H	1	6	0	4	2	1

Opinions differed regarding the question whether or not euthanasia should be practised. This is shown by the following statements,

I do actually think it is being practised....., there is a lot of merit in the idea of euthanasia being legalised (H7).

It is called giving pain relief (G2).

We have to show mercy when people are suffering (H1).

One participant stated that euthanasia itself was not the issue but that people should debate it

*I have no problem with it (referring to euthanasia) from a moral point of view provided that there has been thorough consultation, thorough consideration, **everybody truly honestly** (emphasis by participant), without any fear of recrimination are able to discuss and let their feelings be known (G6).*

The participant felt that a discussion on a national scale was warranted to get clarity on the subject of euthanasia, and, whether as a nation New Zealand would consider euthanasia as an option.

I have an objection to fundamentalist principles and an imposition of people's own patterning onto other people (G6).

This statement made by G6 relates to autonomy and appears to be an important consideration among the participants

You can not obtain consent because it is not legal (G2).

It seems unfair to tell people what to do (G4).

I do think that we need some legislation in New Zealand that covers it and gives choice because I do think it is a fundamental choice (G3).

These statements related to the ethical principle of autonomy.

Of the total number of participants in this study three were against euthanasia (Table 4.2). The following statements qualify the opinions against euthanasia

If life is cut short before their natural time and my feeling is that there is unfinished business that may well come into another life, I think they have the right if they could perform the euthanasia on themselves (G1).

The ability to cause death by euthanasia to one's self does indicate suicide or assisted death, but is not an option for patients that are not able to do so, and as such, it does not comply with the definition of euthanasia.

*There is a possibility **always** (emphasis by participant), to come to appreciate what it is to have a life (G7).*

My belief is we do not have to use euthanasia (H6).

Two participants were neither for nor against euthanasia (Table 4.2). G6 stated that the whole issue regarding euthanasia had to be discussed on a national level and H3 stated "*I am not (pro euthanasia), as I am yet to hear the debate for or against*" (H3).

All participants who indicated they were for euthanasia were not necessarily for legalisation. One participant would like the status quo to remain,

I think it is not unreasonable but I have this concern about it, that it is a slippery slope. In principle it is a good concept and I think the current system although it is not legal it does sort of happen, but it is not legal and that puts some constraints on what people can actually do (H5).

Several participants indicated that once euthanasia was legalised it would be more open to abuse

People may abuse the right (H5).

Once it is legal it is open to abuse by unscrupulous people (H4).

If it were to be legalised controls have to be in place (G5).

If it becomes legal it can be abused (G1, H5).

Even a participant for legalising euthanasia because, in their opinion, “*it is practiced anyway*” (H7) stated that safety regulations have to be in place.

4.4 Values, ethical and legal issues that should be taken into consideration

This section is related to the third theme (page 58) and examines which ethical principles the participants, in their opinion regarding the practice of euthanasia, have taken into account. Most answers supplied were in the context of a terminal illness, extreme suffering, and no treatment available to reverse the situation.

Autonomy is at the forefront of the considerations. In the context of this study, autonomy (see section 2.3) is defined as being able to self determine how to die, or being able to choose for or against euthanasia.

A person must be willing and wanting (H1).

Leave people to self determine (H3)

A person's consent is involved (G2).

Some disease processes were considered ‘grey areas’. Suffering and decreased quality of life were acknowledged as a good or acceptable reason to choose for euthanasia. However, if the disease process affected the individual’s ability to make a competent decision, such as with mental illness, depression and Alzheimer’s disease, the decision to opt for euthanasia was not considered acceptable. The decision to choose for euthanasia when suffering any kind of mental disorder may not be the right one for the individual since it was taken at a time that mental functioning was impaired (H5, G1).

Advance directives were mentioned but perceived to have some problems associated with them if the decision was made when the person was depressed or has some treatable condition. Participant H3 voiced some concerns about patients without a mental illness, and the possible effect a physical illness, may have on mental functioning;

It may be argued that an advance directive is always necessary and one should be in a 'relatively' well state to make such a significant and irreversible decision. However where advance directives are concerned, how does one truly know how or what one will feel at the time that one has specified the advance directive should take effect? (H3).

Suffering was acknowledged but the option of euthanasia and the use of advance directives was not favoured by the participants in this study if the suffering was not physical and caused by a mental illness

Since it is irreversible and treatment with medication might have changed the person and their view (G1).

Or as in the case of Alzheimer's disease

Their mental functioning is not clear (H5).

It gets trickier when people are cognitively impaired (H4).

Dignity, and a reduction of suffering/non-maleficence, is a serious consideration when the cause is physical

When prolonging life is causing unnecessary suffering (H4).

People can die a happy death (G4).

Suffering produces blessing, there is truth in that but it is also a weak argument (G2).

Avoid unnecessary and pointless suffering (H1).

Suffering is not always well defined. In the context of euthanasia pain and loss of functioning comes to the fore. H3 states

There has to be a benchmark, like not being able to self care (H3).

The suffering when losing independence is due to a person's loss of dignity, self worth and self-esteem. The criteria for euthanasia such as 'not being able to self care', or being independent, may be culturally defined. In Western society, where the focus is on self-determination and independence, these criteria may well be valid, since it reflects the values of society. Patients who lose their independence may well feel that they are a burden; this feeling may constitute suffering. Patients not coping with a loss of independence, since their sense of self worth and dignity depends on it, may also be suffering.

All participants, except one, wanted safety issues in place, related to the principles of non-maleficence and beneficence. The participant who did not make an indication that safety issues were important (H6) indicated euthanasia not to be an option under any circumstance. The safety issues to be considered were as follows

Consent from the patient (G2) (H7) (H4).

*Awareness that people performing euthanasia become desensitised,
informed consent (G1).*

Responsible people who are either friends, family and also medical representation in place to ensure that it (euthanasia) was carried out rightly, objectively and satisfactorily, action must be safeguarded against corruption or false ideas of beneficiaries (H1).

The government should have people to assess or police regarding quality of life and terminal illness (G4).

Euthanasia should not be used against individuals with certain conditions or disabilities, these groups of individuals have the same human rights as everybody else (G3).

You cannot ask or demand euthanasia to be performed (G3).

It should be initiated by the person who wants to have the euthanasia (G3).

The people who had to perform euthanasia were also taken into consideration

You can also not demand euthanasia being performed by health professionals when it is against their belief system (G3).

The value of the medical profession in relation to euthanasia is important, since participants (G4, H3) stated that medical practitioners were preferred (as opposed to other health professionals) to perform the action. However, medical practitioners were not indicated the most important in the decision making process, as opposed to the performing of euthanasia

You have to decide who decides, I do not believe that the medical profession are God (G2).

Ideally with support people on board (H3).

Participants stated that the medical profession might not be the right profession to be involved in the decision making process at all because euthanasia could be abused, and the profession is not beyond reproach

Other health professionals putting peer pressure on and that happens, ... I think that there are bad eggs in every barrel (G1).

Participant G1 was referring to a situation in a clinical setting where bedspace was required and euthanasia could be practised on patients to make bedspace available.

Some are in medicine because it is a good way of making money (G2).

During the interview, participant G2 indicated that some doctors would ask money for practicing euthanasia, and focus on making the practicing of euthanasia a lucrative business. Participant G2 had recent experience with health professionals and informed consent in a hospital setting and perceived signing a consent form to be no safe guard

I was asked to read three pages and give my consent, I didn't understand what I was signing (G2).

These statements indicate that there was a perception that some health professionals might not adhere to professional and ethical principles.

4.5 Sources of knowledge and personal experience

This section relates to the fourth theme and some of the information is incorporated in Tables 3.1 and 3.2 (section 3.2.1, p.62 and p.63 respectively) containing information regarding health professionals and the general population respectively.

From the health professional group, three participants (H2, H4, H5) received education, specifically pertaining to euthanasia, or indicated that the topic was covered as part of another course. Most of the health professionals also claimed to have had some experience with the practice of euthanasia which in the New Zealand context means passive euthanasia or withdrawal of treatment. Of the general population group, two participants (G1 and G2) received education regarding euthanasia and participant G1 indicated that she was involved in the practice of euthanasia on animals.

Knowledge, pertaining to the topic of euthanasia, was obtained from different sources. One of the medical officers stated during the interview not to remember what was taught exactly during medical training regarding ethical issues but did recall that case studies were discussed and

Looking at the social context (H5).

This participant stated that euthanasia as a topic was never discussed and the reason given that it was not legal and, therefore, not considered an issue or a requirement to include it as a topic in the curriculum.

One health professional (H3) thought that the topic must have been discussed as part of their education but could not recall this. One health professional (H7) stated

I think it was so far out a concept that it was not talked about (G7).

This participant has been a health professional for a considerable time. Euthanasia may well have been a topic that was not specifically discussed at the time of educating health professionals when this participant entered the profession. One health professional stated that she definitely was taught ethics, and the topic of euthanasia, during a masters paper in ethics (H4); this participant also taught the topic 'ethics'.

All health professionals in this group, except one (the new graduate), had personal experience of some sort with euthanasia, and gained knowledge this way. However, participant H6, did not discuss experiences in relation to end-of-life situations in an hospital setting. Personal experience in all cases influenced forming an opinion about euthanasia.

The 'general population' group stated a greater variety of sources where knowledge was gained compared with the health professionals. Most participants stated that knowledge was gained from talking to other people,

reading newspapers and magazine articles, and, to a lesser extent, television programmes.

The youngest participant had a sick grandmother, and the topic was discussed between him and his mother (G4). Two participants stated that their knowledge was negligible and gained from magazines (G3, G7). One participant was involved in passive euthanasia, and also gained knowledge from discussions with other people and what is published in newspapers (G6). Three participants gained knowledge from the previously mentioned sources such as newspapers, but also from ethics being taught in a philosophy course, being involved in animal ethics and practising euthanasia on animals, being involved in a theology course and doing volunteer work for an organization that helps people (G1, G2, G5). These participants (G1, G2, G5) also had personal experience with dying family members.

4.6 Suffering and spirituality

A theme that emerged from the data was that of spirituality. One participant defined spirituality as

Making sense out of life (G3).

Several participants expressed that, before euthanasia is an option, the spiritual side of the person requesting euthanasia should be taken care of.

All participants stated suffering as a consideration. Most of the time, suffering was considered a reason for euthanasia. If the participant was not for euthanasia then measures to alleviate suffering and pain were very important considerations, and pain relief to alleviate symptoms, even if they might shorten the life span, were considered appropriate. Most of the time suffering was associated with pain, but other consideration such as loss of independence and loneliness were also mentioned.

Some participants stated that suffering was acceptable in a certain context.

The goal in life is to be happy, what a load of rubbish (G3).

This participant defined loss of dignity and suffering as

My valuing of life as a human being is what I can contribute, if I can no longer contribute ...I do not want to be here.....In terms of spirituality, and I define that as to what gives meaning to your life, we should care (G3).

This participant attended to parents who needed a lot of care and recognised that

People can become a burden (G3).

However, this participant does not want to be a burden since it is not congruent with the participants' spiritual beliefs.

Being a burden does not mean that people have no value. As one participant pointed out

It is awful that we have this emphasis on being useful, my mother was useful in her own way by being the matriarch (G1).

This participant's mother had declining health and felt a burden to her family. Participant G1 states that suffering may not be a bad thing

You can grow and learn"... "from a Buddhist point of view all things are Suffering (G1).

That suffering may be of use and may have positive outcomes is a view shared by another participant.

We think that suffering of any sort is bad, showing unhappiness is a big

no no (G7).

This participant explains that in our society suffering is misunderstood in its function.

When you look at the news it is all about unhappiness and it is just based on a misunderstanding which means that people immediately think it is wrong and feel victims. We are all playing the victim if we are not careful and then there will be nobody who takes responsibility. I see little kids and it completely stunts a certain growth that is natural in a creative sense of their potential (G7).

This participant views life as important, and explains that there are different views on life, and growth is possible in different situations

*There is a possibility **always** (emphasis by participant) I think for someone with a degree of consciousness to appreciate what it is to have a life, be alive in a different light (G7).*

4.7 Summary

In this chapter results were examined. The knowledge base and ability of participants to define euthanasia are discussed. All participants showed some understanding and knowledge pertaining to euthanasia; this was not depending on being able to supply a correct definition.

Opinions differed on whether or not euthanasia should be practised and/or legalised. Participants talked about the practice of euthanasia. All participants recognised the complexity of issues surrounding euthanasia. Some participants in their thinking were pro euthanasia in certain circumstances. Only two participants were for legislation of euthanasia. All participants indicated that safety issues were important. Participants obtained information from a variety of sources such as discussions, newspapers, formal education and life experience. Views on life were discussed and spirituality emerged as a theme.

The data are discussed further in Chapter 5.

Chapter 5

Discussion of the data

In this chapter, the data analysed in Chapter 4 are discussed. The sections in this chapter follow the themes as outlined on pp. 57-58 and these sections are discussed in the same order as in Chapter 4. In section 5.1, the definition of euthanasia is discussed, the sources of knowledge pertaining to the topic of euthanasia and perceptions as to what euthanasia constitutes.

Section 5.2 discusses the participants' understanding on the topic of euthanasia and 5.3 discusses whether euthanasia should be practised and/ or legalised in New Zealand and some of the concerns raised by the participants in this study.

Section 5.4 relates to the third theme and examines the ethical principles that participants feel should be taken into consideration, along with other issues that have been expressed by participants and deemed important and relevant to the practice of euthanasia.

In section 5.5, the sources of knowledge regarding euthanasia are discussed, as are the impact of education, experience in end-of-life situations, informal learning and tacit knowledge.

In section 5.6, the issue of suffering and spirituality is further explored.

5.1. Definition of euthanasia; differences between the participants representing the health professionals and the general population group

Euthanasia is clearly defined in the glossary and discussed in Chapter 2, section 2.2. For the purpose of this study, the correct definition for active voluntary euthanasia is adhered to; namely, "death on a voluntary basis while suffering a

terminal illness or incurable disease by active means such as a lethal injection, by a medical practitioner” (Johnstone, 1995). It was not always clear from the definitions supplied whether one was talking about passive euthanasia, active euthanasia, voluntary or involuntary euthanasia. G1 made the following statement

I would agree with euthanasia if the patient could do it themselves (G1).

This indicates that for this participant the terms “euthanasia” and “assisted suicide” are the same. The participants are not alone in using an incorrect definition. As Bailey (2003) points out, surveys have made incorrect conclusions and do not always adhere to the definition of euthanasia. For example “assisted suicide,” whereby the patient is able to medicate or take appropriate action, and “euthanasia,” where the medical staff perform the task of administering medication and the patient does not necessarily have to be able to do this, have been used interchangeably in the media and by researchers while they have different meanings.

More participants from the general population supplied less clear definitions of euthanasia compared with the participants representing the healthcare professionals. Most of the definitions given by the healthcare professionals indicated active euthanasia with the use of medication. The difference between both groups may be due to the familiarity in terminology in that the topic may be raised more often among certain groups of individuals than others. For instance, the topic of euthanasia is regularly discussed in medical and nursing journals which health professionals read although most participants did not mention journals as a source of knowledge nor discussions with peers (Table 3.1, section 3.2.1). Education and work were the sources that were mentioned most, with four participants from the health professional group gaining knowledge from work related situations and four participants acquiring knowledge from education.

5.1.1. Definitions of euthanasia; sources of knowledge

Only one of the participants in the health professional group mentioned reading or literature as a source of knowledge and four participants of this group mentioned education as a source of knowledge. However, three participants in the general population group mentioned reading as a source of knowledge. Participants G3 and G7 mentioned during the interview that they did not know anything about the topic of euthanasia and their reading as a source of knowledge indicated that this was how they heard about the topic of euthanasia as opposed to reading to seek further understanding regarding the topic of euthanasia. Two participants from the general population group mentioned education and work as a source of knowledge (Table 3.2, section 3.2.1). A greater variety of sources were mentioned in this group as a source of knowledge such as TV and discussion (two participants), personal experience (one participant) and reading (three participants). With the exception of one participant, (H4) none of the participants who mentioned education stated reading as a source of knowledge. It may be that the participants take reading for granted as a source of knowledge, whether it is in the newspapers, magazines or medical and nursing journals.

Despite the use of more sources by the general population group, in the acquisition of knowledge pertaining to euthanasia, fewer participants gave a correct definition compared with participants from the health professional group. Some sources may not have given correct information such as TV programmes and newspapers, since incorrect definitions are used and terms such as ‘mercy killing’, ‘assisted suicide’ and ‘euthanasia’ are used interchangeably by reporters, and these sources are mentioned by the participants from the general population as a source of knowledge (Bailey, 2003). However, more health professionals have had ethics as part of their education and the topic may have been covered in this context with correct definitions supplied. Also, four health professionals mentioned work, compared with two participants in the general population group, as a source of knowledge. Experience may also have a big impact on a person’s knowledge base and perception as to what constitutes

euthanasia. As discussed in the following section, the perceptions differ depending on the experience of the participant.

5.1.2 Perceptions on what constitutes euthanasia

Mitchell, (2002) states that the perception of what constitutes euthanasia for health professionals is dependent on whether or not the health professional was involved in practising euthanasia as discussed in Chapter 2, section 2.2. For instance, the health professionals (H7, H4), who were practising withdrawal of treatment and other measures that shorten life, perceived these measures as a form of passive euthanasia. The health practitioners, who were not practising withdrawal of treatment or other measures that could possibly shorten life, did not share this view. Participant H6 and H2 did not share their hospital experiences where there was withdrawal of treatment. Both participants had working experience in an area where withdrawal of treatment was practised. Participant H2 was a recent graduate and was able to state a correct definition of euthanasia; however, it may be that H2 did not perceive the practice of withdrawal of treatment as passive euthanasia or even as an ethical issue. Since withdrawal of treatment is legal in New Zealand, it may not have represented an issue at all for this participant, just another new experience that was encountered in the working environment. According to Thompson *et al.*, (2000)

The newcomer has no stock responses or repertoire of skills to deal with these new encounters....The new recruits tend therefore to adopt the ways of nursing they see around them. This can be said to be due, in part, to their lack of alternatives and, in part, to the efficiency of the socialisation process (Thompson *et al.*, 2000, p.31).

Participant H6 worked in the community at the time of interview. This participant has worked in a clinical setting where withdrawal of treatment was practised; however, this was not discussed during the interview. Participant H6 was not able to state a correct definition of euthanasia, and related the topic of euthanasia to experiences with family members who were terminally ill with

cancer, although this participant had worked for some time in an acute clinical setting where withdrawal of treatment was practiced.

As discussed in Chapter 2, section 2.2, there are several definitions of euthanasia (Johnstone, 1999). The perception of what euthanasia is differed between participants.

No I do not believe we practice euthanasia on our patients, whether a patient would have lived perhaps longer had a nurse not administered medication, who knows (H3).

My belief is that we have to make sure that our loved one's do not feel pain, and that is not euthanasia to me (H6).

Another participant defined the action of giving a lot of pain relief as

Walking a fine line and the difference is whether the objective of giving the drug is to cause death or relieving pain (H4).

Participants H3 and H6 were less inclined to define administering pain relief as euthanasia than participant H4. Normally, pain relief is not defined as euthanasia; however, pain can be so severe that large amounts of pain relief need to be administered. If the intent is to alleviate pain, when administering pain relief, it is not considered euthanasia even when the medication dosage is so high that it may shorten life, according to the doctrine of double effect (Johnstone, 1999). Participants H3 and H6 were very strongly of the opinion that administering pain relief does not constitute euthanasia. It may be that these participants had negative views pertaining to the practice of euthanasia, and did not want to be associated with the practice. Participant H3 has stated that their mind was not made up either for or against the practice of euthanasia and this may explain the reluctance to view administering large doses of pain relief as euthanasia.

Not all participants shared the view that administering pain relief was not tantamount to euthanasia.

Giving pain relief is a euphemism for euthanasia (G2).

She got morphine and the will to live then was not there (G1).

G1 did not share the view that administering pain relief is tantamount to euthanasia although it may be a contributing factor when the patient, in this case a friend of the participant was slowly dying of cancer. Because of the patient having young children there was a strong will to live. Participant G1 observed that, once morphine had to be administered for intolerable pain this patient lost her fighting spirit although there was still the desire to live and to be there for her children. Participant G1 was of the opinion that, in this context, administering pain relief is not related to euthanasia. However, this participant perceived the same act, that of giving pain relief when it pertained to her severely ill mother, as passive euthanasia (section 4.2, p.73). While participant G2 perceives the administration of high doses of pain relief as practising euthanasia, for participant G1 it is very much dependent on the situation. This demonstrates that, depending on the situation, the participant may or may not view the same action as practising euthanasia. According to Benner and Wrubel, (1989) such interpretations of situations result from a developed perceptual skill in a historical context and is called experience. The participant is interpreting a seemingly similar situation as different and, according to Thompson *et al.*, (2000) this indicates a moral development or moral experience.

Mitchell, (2002, p.iii) states that, “those who had performed euthanasia portrayed this action as the ‘ultimate commitment’ to the patient, no other option being seen as meeting the patients’ need”. H4 and H7 have expressed feelings that euthanasia has a place in end-of-life decisions, and that it be used for the benefit of the person who wants to die. Stuy (2003) claims that there is a place for euthanasia and that it is important that correct procedures are followed, to ensure that the patients’ wishes are complied with. For H7 it would be a commitment to care for a patient, as expressed by the statement,

I try to be there for them, how I would cope I do not know (H7).

Some participants, representing the general population, have a perception of or experience with the health system in not meeting patients' need, and, therefore they view euthanasia differently and in a more negative light compared with participants from the health professional group.

Participant G2 made the statements

The medical profession are not God and There are rotten apples in every barrel (G2).

G2 is expressing doubt as to the good intentions and "ultimate commitment" of health professionals. This participant mentioned, during the interview, that they were admitted to hospital and had to sign a consent form while not understanding it. This experience did not produce trust in health professionals. This participant expressed feelings of being vulnerable as a patient. Participant G2 also expressed the opinion that administering pain relief, at times, equated to passive non-voluntary euthanasia; furthermore, that some doctors do this out of compassion whereas some do it because they are not committed to their patients. There appears to be a fear or mistrust of health professionals. These sentiments might be fuelled by stories in the newspapers of the health care system not coping with the increasing cost of the growing older population and expensive treatments. Some rationalisation has to occur, and this is happening, as illustrated by the Ray Williams and the Janine Albury Thompson case (Johnson; 1998, Haden; 1998). However, it may make the general population doubtful as to whether or not they can trust health professionals.

Findings by Mitchell & Owens (2003,) as discussed in section 2.5 (pp.31-32), showed that medical practitioners in New Zealand were involved in administering medication to hasten the dying process and that 5.6% of medical practitioners were involved in actions that were consistent with the practice of

euthanasia. The definition of the term euthanasia used by Mitchell & Owens (2003) is the same as the definition for “active euthanasia” in this study. These findings confirm the ideas of the participants, of the general population group, that euthanasia is happening. However, it is not clear whether or not the actions of these medical practitioners were out of compassion and in compliance with the wishes of the patient, making it difficult to determine if there are grounds for mistrusting the medical profession. Baume, (1998) stated, as discussed in section 2.7.1, that only 20% of medical practitioners, partaking in the study, found consensual decision-making important and 8% of the medical practitioners found the ethical issue of autonomy totally irrelevant. These findings do indicate that it is possible that not all medical practitioners act in the interest and with consent of their patients.

5.2 Understanding and knowledge of euthanasia

Knowledge can either be gained from life and practical experiences or from reading, listening, or being taught about a subject. There are a variety of sources from which participants have gleaned information from about euthanasia. In this section, some cases, related to healthcare practises, and what they meant to the participants in this study, are discussed.

Most participants felt very certain that their view on euthanasia was the correct view. As discussed in sections 4.3 and 5.1, the opinion as to whether or not certain actions were viewed as being consistent with euthanasia was dependent on the situation. Participants also expressed views whether or not euthanasia was acceptable, and under which circumstances it was acceptable. All participants gave a rationale for their way of thinking.

One participant (H3) expressed doubts as to their own knowledge base, and would like more discussion, debate and research in the area of end-of-life decisions in a hospice setting. Both participants involved in hospice work (H3, H4), indicated that open discussion about the topic of euthanasia is not always possible. It appears that the participant with the most experience came to terms

with that and felt very comfortable working in the hospice area. Experience presents an individual with knowledge that is generalizable across many situations, so that a specific situation is readily interpretable (Benner & Wrubel, 1989). Eraut, (2000) as discussed in section 2.7.3.3., identifies this knowledge as tacit knowledge which can be used for transferring knowledge from one situation to another. Therefore, experience may be helpful in coping with complex situations, as encountered in a hospice setting. It may also be that other factors played a role, such as education. Formal education leads to acquisition of skills and knowledge and, according to Leadbetter, (2000) should foster a desire to learn, and this acquisition of knowledge should enable individuals to cope with certain situations. Participant H4 has studied and taught the subject of euthanasia, and has extensive work experience in hospice work. The hospice where participant H4 was employed was more involved in educating staff and the general public, more than the other hospice where participant H3 is employed. H4 stated,

Any organization has their philosophy (H4).

H4 explained that there were differences among health organizations in terms of their aims with regard to health care, education of staff and the general public, and end-of-life care. The end-of-life care provided in a hospice is normally not driven by technology and medical interventions. However, there is also less treatment available that could be called “futile care”, which could be withdrawn from the patient. Generally, hospices try to avoid the impression that euthanasia is being practiced, whether it is passive or active euthanasia, since it could have a negative effect on the trust the general public has in hospice care. To build an environment of trust is important for the delivery of end-of-life care in a hospice. According to Thompson *et al.*, (2000) in the case of hospice care, universal prescriptions to situations are neither possible nor appropriate but that something may need to be done where a patient has outlived his/her death.

One participant questioned the meaning of life (that is, the value we place on life) and raised important issues such as a need for all people to have knowledge about the practice of euthanasia. However, knowledge and understanding did not

necessarily lead to a point of view participants felt comfortable with. For example, participant H3 who had experience working in health care settings, such as critical care areas and a hospice, had a good understanding of what euthanasia meant but had many questions surrounding ethical issues in relation to euthanasia and healthcare worker's knowledge of ethical issues. A question raised by this participant, was

Are healthcare workers needs for knowledge in this area respected?

(H3).

This participant had not yet formed an opinion 'for' or 'against' euthanasia. An increased knowledge base may be of help and would make this participant feel more comfortable with the care that is provided, at present, in a hospice setting. Participant H3 had worked in intensive care areas where a lot of practice is "evidence based", meaning it is based on research findings. This is not the case with some of the practices in a hospice setting, which made this participant question whether or not 'best practice' actually takes place. As discussed in section 2.7.3, (Warner *et al.*, 2001; Heidegger; 1962) past experiences do become part of a person's existence, and strong beliefs and personal philosophy influence attitudes towards clinical practice. Participant H3, has previous experience in a different area of health care and this has influenced the participants' views, as expressed by the statement that practice should be 'evidence based'.

H3 has many questions regarding the practice in the hospice where this participant is employed,

*Although I consider the **science** (emphasis by participant) of nursing needs development in the institution that I work, I am confident that the **art** (emphasis by participant) of nursing is practised competently, by this statement I mean, the intention to reduce suffering and optimise comfort is attempted via nursing practices, but, we do not participate in research nor are we actively enquiring into the research of others (H3).*

As in relation to end-of-life care, this participant is confident that everything possible is done to make patients comfortable, and the need for euthanasia non-existent. However, participant H3 is questioning the legality of some of the practices regarding the administration of medication and also whether or not the way medication is administered hastens death and could be perceived to be consistent with euthanasia.

H3 reported the following findings,

When a patient dies directly after a stat (immediately given) dose of medication to control symptoms of pain and or restlessness it is viewed as counterproductive to draw a correlation between the medication and the death. When you remove the stimulus of pain a patient will convert back to their 'true' state and this may be an irreversible unresponsive state, the patient's awake state is purely pain driven. I hear myself reassure patients with this information, although, no evidence of its validity through literature as yet has been offered via the institution. Nurses are simply told that the timing of the death is related to the disease process and unrelated in any way to medication administration. At times medications are administered on an as required basis, although they are charted PRN four hourly (as required four hourly), but in actual fact may have been given three hourly at the nurses discretion. These actions are supported by the medical staff, who are satisfied for nurses to administer medication in this manner, however do not amend their charting to legally cover nurses actions should these actions be scrutinized at a future point in time. I feel that my competency in my nursing practice would 'grow' if I were in an environment that had the strength of character to question its own practice (H3).

As discussed before, the doctrine of double effect, whereby pain relief can be administered with the intent to relieve pain, even if hastening death is the outcome, is legal in New Zealand (Johnstone, 1999). It may be that the philosophy and aims of a hospice are to care for individuals at the end-of-life. Such a hospice also has a caring attitude towards its staff and makes counselling

available to staff who need this service. It was not part of the culture or philosophy of the hospice where participant H3 is employed, to put a lot of effort into educating their staff and to partake in research or even to evaluate their own practice. The issues raised, pertaining to drug administration by participant H3, could easily be examined and, if there is a correlation with drug administration and hastening death, then current practice could be reviewed and policies could be altered. However, it may be that, if the findings of such research indicate that there is hastening of death, and practice is altered, healthcare professionals caring for patients that may be suffering, have lost a means to alleviate pain and thus care for these patients. Fears of such findings may be prohibiting the undertaking of this sort of research.

Some participants, such as G1, perceived the delivery of pain relief in the context of her terminally ill mother as passive euthanasia, since the mother lost consciousness and there was no apparent will to live. Participant G5 expressed that withdrawal of treatment equated to passive euthanasia. This is technically correct but, as discussed previously, not everybody shares this view (discussed in Chapter 2, section 2.2).

This study has demonstrated that the participants had a knowledge and understanding of the practice of euthanasia. Participants in this study, who are healthcare professionals, were critical of the healthcare practices in New Zealand, and had their patient's interests at heart.

5.3 Should euthanasia be practised and or legalised in New Zealand?

Chapter 4, Table 4.2 (page 75) illustrates that two participants were neither for nor against the practice of euthanasia, three participants were against and the remaining nine participants were for the practice of euthanasia. However, only two participants were for legalisation of euthanasia. Not legalising the practice of euthanasia means that consent from the patient cannot be obtained.

When expressing whether or not euthanasia should be practiced, strong feelings came up, and were expressed in a stance either for or against the practice of euthanasia. H6 stated that administering pain relief does not constitute euthanasia, and thus, there is no need for the practice of euthanasia. It was important for this participant that people shared the same view. H6 had encountered family members not wanting to go on living when battling with a terminal illness and found that this was not a good attitude. Participant H6 felt that family members had to take care of one another and also accept this care. G5 also had strong feelings on the subject, and felt that the value of a life should never be underestimated, and that taking a life was not acceptable practice.

Not all participants were against the practice of euthanasia. All participants wanted the same outcome, which is congruent with the principle of beneficence; namely, not inflicting harm and promoting good. This ethical principle was used as an argument both for and against the practice of euthanasia. Some participants, such as H6 and G7, are against euthanasia, because, in their view it is the wrong thing to do and both participants have expressed views that life itself is valuable and important and, as such, adhering to the principle of vitalism, as discussed in section 2.3, p. 23. Other participants, such as H1, H4, H5 and H7, could see merit of euthanasia being practised under certain circumstances.

Participants envisaged controls in place to protect people against the inappropriate use of euthanasia once legalised. Legalisation could avoid the use of involuntary euthanasia. As a participant pointed out,

Euthanasia is at present called giving pain relief (G2).

Participants differed in opinion as to what constitutes euthanasia. Some participants viewed giving pain relief to control the symptoms of pain as a type of euthanasia, for example,

It does happen but simply because there is enough pain relief given but it is never acknowledged (H4).

However, some do not, for example,

We do not need euthanasia if we keep our loved one's pain free (H6).

G4 stated that with euthanasia

You can die a happy death (G4).

Alternatively, suffering might be inflicted upon the individual, as well as the family, if other avenues to kill one self are explored. One participant alluded to this by making the following statement

It must be horrible for the families of people who kill themselves and it is messy, obviously kind of gruesome, if you do not have the right means (G4).

This opinion is shared by others. An individual suffering motor neuron disease, and contemplating suicide, stated that drowning, since a child could find you, or placing oneself in front of a train which would be gruesome for the train driver, are not good ways to commit suicide (Boland, 2003).

The answers, supplied by the participants, came with qualifying statements. One participant (H7) stated that euthanasia was an option, especially if they are a burden to others. This participant also viewed it as an option for others in certain circumstances. As a health professional, this participant, would not mind being involved in euthanasia,

I could stand back and not be emotionally involved (H7).

However, this participant also stated

It is hard to reconcile preserving life, and balance that with taking life (H7).

This is an indication of the complexity of the issue. As a health professional, H7 is mostly involved in preserving life, and care and resources are made available to achieve a good outcome and prognosis for a patient. There are circumstances where, despite good care and medical technology, a positive outcome could not be achieved, and in these circumstances, H7 indicated that euthanasia could be an option. However, in a healthcare setting, where the goals are to achieve a positive outcome, it takes a different mindset to cut a life short. It is difficult for health professionals to fit the practice of euthanasia in their paradigm according to participant H7.

Preserving life is part of a health professional's job and vitalism is part of the ethical principles applied. The merit of legalisation of euthanasia, according to H7 is in the reduction of suffering. It might be difficult to reconcile both values, that is vitalism versus euthanasia, as illustrated in the comment,

I think as a health professional if somebody really wanted me to be there, I think I would try to be there for them. Just how I would cope I do not know (H7).

This participant suffered the loss of a spouse and a year later the loss of a son. The dying process was very stressful for the son as well as the family. Memories of the death of the partner and son make this participant (H7) doubt their own ability to cope, both during the event and after, with a situation where euthanasia was practiced.

As a health professional, participant H7 was involved in some cases where treatment was withdrawn. In these circumstances, there is the argument for active voluntary euthanasia,

Perhaps we ought to bite the bullet and face up to it (H7).

But also against,

They took him off (life support) and he kept on going... that introduces

an element of doubt (H7).

The above mentioned examples of ethical issues encountered in clinical practice, by participant H7, make it clear that a principle based approach to clinical ethics can be controversial (Myser *et al.*, 1995). As discussed, in section 2.7.2, p.45, Doane (2002) states that overemphasis on rational principles, rules and theories can cause the destruction of the motivation to be moral.

This participant was referring to a case where life support was withdrawn, on the basis of the baby not progressing, and the baby survived without any aid, and appears to be growing up as a healthy child. In the above described case there was withdrawal of treatment, (defined as passive euthanasia but not considered euthanasia under New Zealand law) with the envisaged outcome that the baby was going to die. There is also the problem that the baby might sustain injury or damage from the withdrawal of treatment. For example, lack of oxygen if lungs are immature and, therefore, possible brain damage. That there was a good outcome, in this case, is more good luck than good management. All elements of doubt should be dealt with and excluded before passive or active euthanasia is contemplated. If euthanasia were practiced only in cases where the patient is suffering a terminal illness or intolerable suffering due to an incurable disease, there would be less doubt as to the appropriateness of the practice of euthanasia. However, if the practice of euthanasia were to be practiced in other circumstances, the element of suffering and quality of life should weigh heavily. In the writer's opinion, where there is any level of doubt, then health professionals should err on the side of caution, in the application of passive euthanasia, as illustrated in the above example.

The fear of making the wrong decision in regard to the health status was also expressed by lay people, for example,

*I want to be sure that **absolutely** (emphasis by participant) every avenue had been exhausted, that health professionals would consult outside their realm, field and areas (G1).*

This participant also felt that experienced medical practitioners, as opposed to young and inexperienced medical practitioners, should be involved in end-of-life decisions as a safety precaution against making mistakes. Implicit in this is the concern that medical practitioners are not always meticulous in weighing all possibilities before arriving at a final decision about withdrawal of treatment. However, this is not always the case, as illustrated by the following comments,

Euthanasia should not be inappropriate, things that might actually help them (referring to patients) have to be offered first....Only for terminal illness, not just cancer and with strict controls (H5),

Euthanasia should only be for the benefit for the person it is given to (H4).

The for and against arguments and rule bound moral western philosophy, as outlined by Johnstone (1995) in Chapter 2, section 2.1, is very black and white, whereas the views of the participants in this study are more subtle in interpretation. The position taken by the participants either in support of, or against euthanasia, appear to be very dependent on the context. One participant was for legalisation,

I do support euthanasia...especially if there are safe guards in place... I think a lot of education and a lot of legal work is necessary (H4).

However, in the context of working in a hospice setting this participant held a different view,

This is not a view (being for euthanasia and legalisation of euthanasia) shared by the organization where I work. It does happen but simply because there is enough pain relief given but it (euthanasia) is never acknowledged, no. Patients will ask for it and be told 'I am sorry but we are here to help you to have the maximum quality of life and control of your symptoms but not to actually hasten death'. If the public did have

*the perception that it was practiced some people might not want to come.
So I think it is a healthy decision (H4).*

All of the above statements relate to safeguarding the patient who wants euthanasia and focus on the value of life and the ethical principle of protection against harm. Harm, as discussed in section 2.2, refers to unwanted treatment, and pain and suffering. The patient does not have to suffer because the medication will be given to alleviate symptoms. If symptoms are not totally under control, the medication can be increased. Participant H4 is referring to this practice as euthanasia but, in New Zealand, increasing doses of medication does not constitute euthanasia, even if it shortens life, if the intent is to alleviate pain.

The action of administering medication, to relieve symptoms in the context of being terminally ill, is adhering to the ethical principle of preventing harm and promoting good.

As indicated by the responses in Chapter 4, section 4.5, participants in this study consider the principle of autonomy very important and patients should be given the opportunity to decide whether or not they want euthanasia. However, most participants were not for legalisation of euthanasia. The reason for this is that legislation is not viewed as a safeguard against the safe practice of euthanasia, and protecting the interests of citizens. This may be a correct presumption since the legal system does not protect patients from (involuntary) passive euthanasia, or withdrawal of treatment (legal in New Zealand), being practised at present. As mentioned before, participants have the perception that, once euthanasia is legalised, it is more open to abuse. There is a catch here, in that, if euthanasia is not legalised, it cannot be openly discussed with patients, family members and healthcare workers. Discussions happen covertly if at all, and communication might not be clear and can be open to interpretation. This may lead to incorrect decisions being made regarding end-of-life situations. As discussed before, in section 2.7.1 and section 5.1.2, there are medical practitioners who find

consensual decision making unimportant and, therefore, would not necessarily abide by the patient's wishes (Baume, 1998).

Although the ethical principle of autonomy was very strongly advocated by the participants in this study, and appears to feature strongly in the philosophy of western culture, not legalising euthanasia makes it difficult for individuals to indicate what their wishes are in end-of-life situations. This is because medical practitioners would not like to implicate themselves by discussing a practice that is illegal and informed consent can not be obtained for the same reason.

The statement of participant G6, that society as a whole should discuss the topic of euthanasia, refers to a readiness of society as a whole. This opinion is shared by Mitchell (quoted by Ansley, 2003, p. 19), "until we start telling our loved ones what we really want, start incorporating death into our lives, we have absolutely no right to bring some sort of physician-assisted death. It would be like putting someone from kindergarten behind the wheel of a BMW". However, it is difficult to get a national discussion when the Death with Dignity Bill, 2003 did not get passed. It means that the discussion is finding place mainly in the media and is mostly in terms of for or against the practice of euthanasia. These relatively superficial discussions do not approach the subject with enough depth or discrimination to fully inform people of the issues. Therefore, they do not encourage the level of discussion advocated by Mitchell (2003).

From this study, it was revealed that nine participants were for the practice of euthanasia and three participants were against. However, it was not totally black and white, with some participants wanting more discussion and more information. None of the responses to the question(s) were a simple yes or no, and participants qualified their responses and explained that there had to be safeguards in place to protect everybody involved; namely, patients, family and healthcare workers. This is about the values, ethical and legal issues that need to be taken into consideration and which are now discussed in section 5.4.

5.4 Values, ethical and legal issues that should be taken into consideration

This section discusses section 4.5 in the previous chapter, related to the third theme (p. 58), which examines ethical principles in relation to the practice of euthanasia.

A question which needs careful consideration is, “Who actually makes the decision pertaining to the practice of euthanasia?” Autonomy of the patient was considered very important, as discussed in section 5.3. Some participants mentioned advance directives. H3 stated,

Is it morally wrong that as health care providers we should question a patient's right to action their advanced directive at a time that they have stipulated, or is it ethically wrong not to question the directive at this time? (H3).

Several participants expressed that possibly a team, consisting of among others a social worker, psychologist, clergyman, should be involved, or at least more than one person, to serve the person who requested the euthanasia. Autonomy was considered important and participants felt that the medical profession or health care workers might not take this ethical principle into account sufficiently during the decision making process.

Some mistrust was expressed about the level of commitment of the medical profession to abide by the wishes of the patient and, thus, to serve them as they would like. This may be justified. Mitchell, (2002) stated that doctors were more likely to judge a situation from a status quo point of view which means maintaining the situation as it is. This may mean that patients requesting euthanasia will not receive euthanasia and patients requesting treatment may not receive it since treatment can be denied if considered futile. In either case, the patient may not get what they perceive to be in their best interest, with the medical practitioner holding the power in the decision making process.

Obtaining informed consent is one of the safety considerations mentioned (G2). This participant stated,

Obtaining informed consent is absolutely necessary for the safe practice of euthanasia (G2).

It should be noted that medical practitioners in countries where euthanasia is legalised have more consultation with their patients and the option of euthanasia can be openly discussed (Mitchell, 2002). Medical practitioners are not obliged to perform euthanasia. It is important that medical practitioners do not have to act against their own value and belief system, and maintain their autonomy over the decision to practice euthanasia. Participant G1 stated, when referring to the practice of euthanasia,

It takes its toll (G1).

Participant G1 was involved in culling animals, which were excess to requirements, and found that practicing euthanasia was associated with negative feelings. G5 and G1 also stated that practicing euthanasia must be a difficult thing to do and suggest that, if the patient can administer drugs to him/herself, then that should be the preferred option. This means that participants G5 and G1 were in support of physician assisted suicide which at present is not a legal option in New Zealand and also not an option for patients who can not take medication any more.

Whether or not a universal benchmark can be set, regarding quality of life and suffering, is debatable. It is very subjective and dependent on the situation. As one health professional pointed out, suffering and quality of life had to be qualified in some way, before euthanasia is considered as an option, and suggested that not being able to self-care be a benchmark. However, a younger participant (G4) indicated that euthanasia was not an option if there was somebody to look after this participant

I am a very active person, if I could not move but still had my family to

look after me I would be happy (G4).

Maybe self-care is not as important, when still dependent on parents to a large extent, than it is for individuals who have lived an independent life for many years.

Many factors play a role when considering euthanasia, such as gradual decline of health where individuals have been able to adjust to the changed circumstances, or a crisis situation where adjusting to the altered situation has not occurred. Participant H6 stated that the family should care for the patient or arrange care. It may be a difference in cultural perspective, but independence and autonomy did not feature in the considerations of this participant. When discussing a family member who was terminally ill, this participant expressed feelings of dismay when that family member was not willing to do everything in his/her power to prolong life. Family involvement and taking care of each other, by either financial or physical means, was considered important. Alleviation of suffering, by means of administering pain relief, was also considered important, and, if pain relief would interfere in some way with the duration of life, this participant did not consider it euthanasia.

Participant G3 mentioned that euthanasia should not be used in cases of individuals with disabilities. Participant G3 has a friend with a disability and is relaying this friend's views on the practice of euthanasia. The argument put forward by G3 was that individuals with a disability should not be discriminated against and have equal rights to healthcare. However, it is difficult to put all disabilities under one heading since there are a number of disabilities with a varying impact on the quality of life and independence a person can achieve. For instance, a person who is deaf or blind has more chances of leading a normal life than an individual with Duchenne muscular dystrophy whose quality of life will go downhill during their lifetime and who is likely to die at a young age.

According to participant G1, the problem with euthanasia is that, once euthanasia is performed, there is no way back. Even when the patient has chosen

for euthanasia and a time suitable for them, some participants have doubts as to whether or not it is the right thing to do. G1 stated,

Working in the area of depression and individuals with thoughts about suicide I have experienced individuals who changed their minds, and I think once you are at a certain stage with euthanasia you can't change your mind (G1).

Technically, a person can change their minds up to the very last second. However, it is possible that a decision is made during life which an individual later regrets and then has to live with the decision. In the case of euthanasia, you can not make the deed undone but neither can you regret it.

Johnstone (1999) covers a comprehensive range of issues related to euthanasia. In my study, the range is less comprehensive. However, it appears that, although the number of participants in this study was small, there is sufficient knowledge base among the participants to reveal important issues regarding the decision making process. Some of the issues raised by participants were as follows:

- Who should be involved in the decision-making?
- Who should perform the euthanasia and under which conditions?
- Which individuals should be considered for euthanasia and under which conditions?
- Protection of health professionals so they do not have to perform euthanasia if it is against their value and belief system.
- Protection of the individuals against inappropriate use of euthanasia. The consideration that euthanasia should be considered and discussed on a national basis, so that, as a nation, a decision can be made in a democratic way.

This leads to the consideration of sources of knowledge, which are discussed in the next section.

5.5 Sources of knowledge

In this study, two groups of participants were compared on the basis of their sources of knowledge about the practice of euthanasia. A higher percentage of participants belonging to the health professional group were able to give a correct definition of euthanasia (Table 4.1, section 4.1, p. 71). Also, a higher percentage of participants in this group had some kind of experience with end-of-life decisions, such as withdrawal of treatment, or euthanasia itself, as in the case of participant H7, or had the topic covered as part of their education.

Experience in clinical practice, along with a sound theoretical education, provide greater opportunities to learn and give more detailed knowledge about a topic such as euthanasia compared with informal learning. In this section, the topic of education and learning is explored. However, informal and formal learning appeared to be relevant to the acquisition of knowledge and this is also discussed in this section.

5.5.1 Learning through education and experience

Participants gained knowledge from a variety of sources. Health professionals, depending on age, had been taught ethics and/or the topic of euthanasia, or had some personal experience with euthanasia (Table 3.1, section 3.2.1, p.62). In the past, the education system did not cover the topic of euthanasia at all because it was not relevant to society and health professionals. As participant H7, a nurse with considerable years experience, stated,

It was so far out a concept that it was simply not talked about. We were probably considered too young anyway, I do not know if it was ever discussed in that sense that we ever had any lectures on it (H7).

Educational practices have changed and this is reflected in curriculum changes. One participant, H2, a nursing graduate with two years experience, stated,

Euthanasia was discussed in a paper on ethics which was considered important for development in becoming a professional health practitioner. Case studies were presented and we had to work in groups to tease out the issues and our responsibilities and report back to the class (H2).

The statements of participant H2 and H7 reflect the changes in the curriculum and the changes in society's expectations of health professionals. Health professionals are expected to protect and promote the interests of the general public in their policy development, allocation of resources and decision making in a clinical setting, based on data and best interest of the patient. The following statement implies that there was a paternalistic approach to teaching and that the lecturers knew best as to what had to be taught and how it was taught.

We were probably considered too young (H7).

There was little or no expectation that students developed critical thinking and analysing skills. It might also have reflected the expectations of society towards health professionals, in that nurses were viewed as helping the medical staff and that nursing was not a profession in its own right. The teaching approach itself may have reflected a paternalistic or more authoritarian view.

Participant H7 remembers receiving lectures only, which implies a 'passive' way of learning, while H2 received lectures with general information, and was expected to take an active approach to learning with the case study presentations. There was also the expectation inherent in the latter approach that students learned to analyse, develop some critical thinking and be able to apply what was presented in the lectures. Skills such as analysing, critical thinking and applying new theories and knowledge, to a variation of settings, are expected of health professionals today. As previously discussed (section 2.7.2, p.46), Myser *et al.* (1995) was of the opinion that ethical reasoning is a professional skill. Myser *et al.* (1995) and Warner *et al.* (2001) were of the opinion that case based or scenario based presentations of ethical issues is the best way to learn to distinguish between ethical issues and social or legal issues.

Case based learning provides an optimal context for students to learn the key skills of clarifying and prioritising the values inherent in clinical decisions. Such values include maintaining standards of care, preserving autonomy, enhancing quality of life, alleviating suffering, and acting honestly and faithfully amongst others (Warner *et al.*, 2001, p.665).

Warner *et al.*, (2001) as discussed in section 2.7.2, state that the teaching of theories and ethical concepts does not lead automatically to the application of the theories and concepts. Furthermore, even though the case based learning approach aimed to make a direct link between ethical knowledge and clinical practice, this approach did lead to some problems. According to Myser *et al.*, (1995) students did have difficulties with making distinctions between the legal, social and ethical issues and difficulties with determining the 'quality of life' of the person presented in the case scenario. Students made appeals to personal values, attitudes and feelings as a means for resolving complex ethical issues, which may have lead to inadequacies in relation to the management of complex clinical ethical issues. According to Warner *et al.*, (2001) the problem with case based scenarios is that it does not measure clinical behaviours. Clinical behaviours can only be captured by observational or interview studies. This may be reflected in the response of participant H2, who stated to have no experience with euthanasia in a direct or indirect manner. However, this participant was working in the same area as participant H7, who came across several cases where passive euthanasia or withdrawal of treatment, was practiced. This difference between both participants may be partially due to the difference in years of experience. However, according to H7, euthanasia and withdrawal of treatment, are very relevant issues as reflected in the following statement,

Yes, it (euthanasia) happens, I think because it (referring to euthanasia) is so near to happening that perhaps we ought to bite the bullet and face up to it (H7).

It begs the question whether certain clinical scenarios are perceived as passive euthanasia, or withdrawal of treatment, by relatively inexperienced health professionals. This study is not extensive enough to draw conclusions on this

issue but it may need further exploration. There is evidence that students feel that theory does not reflect what is practised and that the theory offered does not serve them in clinical areas (Thompson *et al.*, 2000). This view is confirmed by Myser *et al.* (1995) who states that students struggle to apply knowledge of ethical principles and confuse it with other issues such as personal values and legal issues. Furthermore, the socialization process of health professionals merely leads to the appearance of professionalism but can engender cynicism and/or feelings of inadequacy (Warner *et al.*, 2001; Thompson *et al.*, 2000). For example, participant H2 does not perceive the withdrawal of treatment to represent an ethical issue since it is not an illegal act and, therefore, not a problem. The more experienced participants in my study did acknowledge the ethical issues encountered in their practice, even though the issue did not represent a legal or personal problem.

Participant G1 learned theory and the skills to practice euthanasia some time ago,

I went to the Christchurch School of Philosophy and later to the Wellington School of Philosophy, and learned about ethics. I also learned a bit about ethics from my animal nursing technology course and also from working as a laboratory technician with laboratory animals (G1).

For this participant, euthanasia is not an academic concept since it was practiced on animals. Learning extended to techniques on how best to practice euthanasia, which drugs to use, body size and relationship to medication, and different physical and chemical methods of euthanasia. Participant G1 indicated mixed feelings about the practice of euthanasia

Practising euthanasia on animals that are ill gives you a good feeling. Practising euthanasia on animals or culling them because they are excess to requirements does not feel good, it takes its toll (G1).

It may be that health professionals gained knowledge from other sources besides education and experience. These sources may not have had the same impact or importance and therefore, have not been mentioned. For instance, participant H2 stated that ethics was part of her education and that euthanasia was among the topics discussed. Students were divided in small groups and presented with a case scenario that had to be analysed and presented to the whole group. There is no doubt in my mind that reading about the topic, and discussing it among members of the group, was part of the preparation for the presentation. However, the prescribed textbook which covered the topic of euthanasia, the library resources, and discussions with fellow students, were never mentioned as a source of knowledge.

Although there is a lot of information on euthanasia on websites, not one participant has mentioned it as a source of knowledge. It did surprise me since recent graduates, such as participant H2 (undergraduate degree) and participant H4 (masters degree), would have been encouraged during their education to use knowledge from a variety of sources and both are familiar with computers.

Participant H4 was the only participant mentioning to have read about euthanasia for interest. This participant has easy access to a library with relevant information at work. As mentioned earlier, this participant also learned about euthanasia while enrolled in a paper on ethics and taught the subject as part of an undergraduate paper in a tertiary institution. With the exception of participant H4, not one participant indicated to have used a library as a source to find out more about the topic of euthanasia.

Participant H3 stated that there was a need to further education within the hospice setting and indicated that the hospice should provide education. From what was disclosed during the interview with this participant, I feel this expectation may not be fulfilled, and education regarding euthanasia may not eventuate. This particular hospice provides employees with counselling and support, to help employees cope with difficult situations and end-of-life issues, but the topic of euthanasia appeared to be taboo.

Besides education and experience, there are various other ways of learning such as informal learning.

5.5.2 Informal learning

Various ways of informal learning are discussed in section 2.7.3.1. Some participants in this study gained knowledge about euthanasia by means of informal learning.

Several of the participants have expressed knowledge gained from vicarious experience, (section 2.7.3.1, p.48) such as empathy with others. For example, participant G3 relays feelings on the subject of euthanasia, from talking with a friend with a disability.

It may be that participants G7 and H6 are against the practice of euthanasia and, because of their religious beliefs, take the sanctity of life issue as paramount. This is an example of knowing by authority, in this case the authority is the church or religion (section 2.7.3.1, p.48).

Rogers, (1961) states that learning from experience is learning from the highest order. Participants, interviewed for this study, had their own experiences relating to euthanasia or other life events from which they took meaning. This ‘meaning’ or sense gained from these experiences was applied to life and death situations and the practice of euthanasia.

For instance, participant H4, who worked in a hospice setting and had extensive experience in dealing with patients who were terminally ill stated,

Obviously some people’s religious beliefs are going to intrude, I am a Christian and it (referring to euthanasia) does not offend me. I think legally it needs to be very carefully done. I think in theory I would not have been for euthanasia but in practice I can see the huge advantages. I

can also see that some people I am nursing would actually choose for euthanasia if they had a choice. I have seen so many cases where euthanasia would have been very helpful (H4).

This statement reflects an opinion based on life experience and interactions with other people. This participant was very aware of the authoritarian knowledge of the church. However, the sharing of experiences with others has given this participant insight into what it means to be terminally ill and a different view on what euthanasia can mean to a sick individual. It is a powerful way of learning.

Informal learning is a life long process by which an individual acquires knowledge, skills and insights from experiences encountered in everyday life, be it at work, at home or from interactions with family and friends, from travel, reading material or watching television. There is no set curriculum, and attention can be focused on a number of things and issues, important to that individual, at any given time. For example, G1 gained insight into the difference between situations where it felt good killing animals, and when it felt inappropriate to do so.

Participant H7 mentioned discussing the topic of euthanasia with colleagues. For this particular participant it meant sharing personal experiences with a colleague in similar circumstances. The general population gained knowledge (Table 3.1, section 3.2.1, p.62) from a diverse range of sources such as: news articles, education, work, personal experience with a relative dying, and talking with others. Context is still an important factor, and different settings will offer different resources and interest. For example, an individual on a refugee boat will have different interests and opportunities to learn and interact with the environment than an average New Zealand citizen in the comfort of their own living room. Participant H3 perceived their own working environment as not conducive to learning and stated,

My experience working in palliative care is that the subject of euthanasia amongst colleagues is viewed as provocative and in conflict with the service we provide. However I have never had an explanation as to why

*this is the case and have yet to find a forum within palliative medicine where I feel safe to pursue the debate. As I work with people who are dying I feel that my professional credibility would risk unjust scrutiny were I to pursue this debate. Are healthcare worker's needs for knowledge in this area **respected** (emphasis by the participant), or is the legitimacy of this knowledge **owned** (emphasis by the participant) by the hierarchy of the healthcare institutions? (H3).*

The environment this participant works in gives opportunities to learn about the dying process, palliative care, and the requirements of terminally ill people who are, at times, suffering. The learning can take place through experience or informal learning. According to Thompson *et al.*, (2000)

The speed with which the new recruits adopt the prevailing mode of nursing has both advantages and disadvantages.The disadvantage is in the newcomer's so readily adopting a 'professional' approach to nursing is, as has already been suggested, that it puts at risk the initial sensitivity, where personal moral values dominated (Thompson *et al.*, 2000, p. 31).

The topic of euthanasia was one of the interests to this participant. Because of the attitude in the workplace, this participant did not feel safe to explore the topic openly. In trying to meet expectations of other staff and superiors, an individual might be compromising their own value system. The need for further (formal) education on this topic is unlikely to occur or be supported by the employer.

Two participants stated that they do not know much about euthanasia (G3, G7). Both participants have mentioned that they had no sources of knowledge but may have read something about euthanasia in the newspaper (Table 3.1, section 3.2..1, p.62). The writer surmised, from the statements of these participants, that the readings from the newspaper, acknowledged as a source of knowledge, did not make a big impact on the knowledge base of the participants.

Despite the claim of not knowing much about euthanasia, participants G3 and G7 have clear ideas regarding whether or not euthanasia should be practiced and under which circumstances. It may be that individuals take on board a lot more information than they realise and form an opinion. Eraut, (2000) defines this type of learning as implicit learning (section 2.7.3.3.). For instance, participant G3 stated that a friend with a disability discussed the topic of euthanasia; however, this was not mentioned as a source of knowledge. Participant G3 discussed the views of the friend during the interview and, as such, has used the information as a source of knowledge. Both participants were also able to apply their existing value system to the practice of euthanasia. Participant G7 was against euthanasia because life was very valuable and suffering could lead to personal growth. Participant G3 could see merit in the practice of euthanasia under circumstances where people have become a burden to their family. Being able to apply existing values to a new situation means that the participants have an understanding of the topic and how it fits in their paradigm.

A difference that may be important is that education is a conscious activity while learning can be but is not necessarily so. This is evident where participants have stated not to know anything about euthanasia but have obviously learned about the issues from a variety of sources, as was the case with participants G3 and G7. Another way of viewing informal learning is as implicit learning or tacit knowledge; knowledge we have but are not aware of or cannot tell.

5.5.3 Tacit knowledge

Individuals are not always aware of knowledge and values. Eraut (2000) identified different types of tacit knowledge as discussed in section 2.7.3.3. Several of these situations are discussed below, and they illustrate how participants have used knowledge and applied it to the topic of euthanasia.

The first situation is about transferring knowledge from one situation to another. G1 states that feelings differed when culling animals that were excess to requirements as opposed to practising euthanasia on animals that were sick.

It takes its toll (G1).

This knowledge is transferred to a situation pertaining to people,

I believe the same thing would happen with doctors and nurses and other practitioners taking the lives of healthy people, but also taking the lives of sick people, although I can see that if they are in severe pain it could give satisfaction as well (G1).

These sentiments are confirmed by the statement of a medical practitioner who practised euthanasia and stated that in the night before the event, she normally does not sleep well and “ I talk about it afterwards with a nurse or other medical practitioner who was closely involved with the patient, I certainly do not go home by myself” (Stuy, 2003, p.58).

Eraut (2000) identifies knowledge constructed from the aggregation of episodes in long-term memory. The following response of participant H7 is an example of this knowledge.

The first time I ever encountered euthanasia, and this is something that very much stuck in my mind, was when I was in London years and years and years ago (H7).

Participant G7 is an example of applying a point of view from one situation to another such as,

Unhappiness or misery can lead to growth, I see little kids protected from that and it completely stunts their growth to when somebody is really suffering I always think that for someone with still a degree of consciousness they may come to appreciate what it is to have a life (G7).

According to Eraut, (2000) knowledge can be transferred from one situation to another.

Another example, of applying knowledge to a different situation, is participant G3 who stated that there was no personal knowledge base, all knowledge regarding euthanasia

Fits on a corner of a postage stamp (G3).

However, this participant has gained knowledge by what Eraut (2000) identifies as implicit learning of which there is no awareness. When analysing the interview, it showed participant G3's knowledge was gained from friends

I have a strong soul mate who believes that people with disabilities have human rights (G3).

This participant went on to discuss that, under certain circumstances, such as individuals with disabilities, some people perceive euthanasia not as an option. Another part of the statement may indicate an intuitive way of knowing,

And I certainly don't know, I get myself really confused about disability, because I acknowledge their human rights in my head but not in my gut (G3).

According to Eraut, (2000) an intuitive understanding or response is an example of tacit knowledge.

The above example also demonstrates that new ideas can be based on different values and that new or different values are not always as easily accepted as a fact if they contradict or oppose existing ideas. Participant G3 did refer to other friends who have children with disabilities and stated,

I have just realised, I have a friend who has got six kids. They are living in poverty. One of the children has disabilities, another child is severely autistic and if this friend and her partner were still together and had another child who had a severe disability I would not question their right to deal with that decision (G3).

Participant G3 acknowledges the rights of people with disabilities and respects the opinion of a friend who has a disability. However, G3 clearly has the view that it is acceptable to intervene in situations, where life would become harsh and unbearable, for people to deal with another disabled child. At an emotional level, G3 is not accommodating the values of the disabled friend who claims that disabled people have rights to life in all situations.

5.6 Suffering and spirituality.

Spirituality¹² was a theme that emerged as the study progressed. Six out of the group of 14 participants discussed the subject, most of the participants did so at length indicating that it meant a lot to them. Five participants of the general population group broached the subject directly and one participant belonging to the health professionals did as well. Only data from participants who raised the subject of spirituality directly are discussed in this section. There were data from other participants that could be interpreted as having a spiritual content but these are not included, as the writer did not wish to over extrapolate. However, this suggests that spirituality may play a significant role in influencing a persons' view of euthanasia. Future studies may wish to explore this further.

Spirituality was used as a term and not every participant defined the term clearly. Most participants used the term "spirituality" in relation to some sort of suffering¹³. For instance, participants G7 and G2 perceive that suffering has the potential to lead to personal growth or blessing. Ethical controversies surrounding the care of the terminally ill are not only at technological level but also at institutional and medical level. Campbell (1992, p.255) stated they should be viewed "as a sign of a deeper crisis of meaning in our culture" and as an indication of how impoverished our society has become in "assessing the significance of suffering, dying and death as part of a whole human life". Suffering is an existential problem involving questions regarding the meaning

¹² See glossary

¹³ See glossary

and purpose of life (Campbell, 1992; Starck & McGovern 1992). Participant G7 stated

They think that suffering is bad and that nobody should suffer, what utter rubbish (G7).

This participant appears to agree with the statement made by Campbell that suffering can contribute to meaning of life and that in our society the meaning of suffering is not well understood.

Participant G7 related spirituality to suffering and why people think that suffering should not occur. This participant felt that suffering, and finding solutions for this suffering, would make people stronger, and make them grow as human beings and equip them with better coping mechanisms. In relation to dying, participant G7 feels that euthanasia might not be a good option to alleviate suffering since life itself has value, and that suffering has the potential to serve an individuals' personal growth. However, participant G2 expressed the opinion that suffering is very overrated and that, from a religious point of view, it produced blessing, but that suffering was not good as an argument against the practice of euthanasia. This participant felt that there was a place for the practice of euthanasia if the patient was suffering intolerably.

Suffering is not always related to pain. In western society, being autonomous and being independent are highly rated, and help in our self-esteem and feeling good about ourselves. A loss of this independence may constitute suffering for the patient involved. Dependency may become burdensome for the dependent and/or the caregivers. Boland, (2003, p. A7) describes an experience of a sufferer of motor neuron disease, who became increasingly dependent, "a company was hired to help look after him, but fired, when it was realised that some of the young girls sent to help were embarrassed about taking him to the toilet." "The very experience of illness, and more fundamentally the process of aging that inevitably culminates in death, not only reveals our shared vulnerability and dependency, but also that we are all subject to some kind of powers beyond our control" (Campbell, 1992, p.270). Individuals in western

society have a lot of control over their lives and seem not very adaptable if they lose that control and become dependent, as discussed by participant G3.

Participant G3 felt that, if people become a burden to others, it does not necessarily mean that euthanasia has to be the option chosen. However, this participant defines spirituality as “*making sense out of life*” (G3) and stated that euthanasia is definitely a possible option if becoming a burden. This participant is a very active person with lots of energy and a disposition of wanting to be of help and to serve others. Not being able to help and serve would diminish meaning to their life. The following statements illustrate this

My valuing of life as a human being is what I can contribute.....if I can no longer contribute I do not want to be here and causing pain and suffering to other people (G3).

In this case the suffering of others brought on by her dependency would be possible grounds for euthanasia, and her personal suffering would not necessarily be physical, but psychological, by knowing that they were a burden.

Participants G1 and G6 relate spirituality to a life hereafter. G1 explained that cutting a natural life short would leave unfinished business that may well come back into the next life. G6 explained that the dying process can be used to prepare you for the next life or “loka”. It is better to be conscious during this process, which means that heavy sedation or pain relief with a sedative effect may not be appropriate. However, if the individual was in severe pain, such that the pain became a major distraction, then the process of being conscious and preparing yourself for the next life would not be possible anyway. In this case pain relief or euthanasia may be an appropriate option. G6 stated that,

If the person involved is very focussed and not concerned with dying and pain then it becomes more bearable and pain relief may not be required. The person may then enter into the dying process fully conscious. (G6).

One participant stated,

My experience working in palliative medicine is that the subject (of euthanasia) amongst colleagues is viewed as provocative and in conflict with the service we provide (H3).

However, there are discussions among staff about patients being prepared and ready to die, so that there is no unfinished business. Participant H3 felt it was important that spiritual matters were dealt with, and in the context of end-of-life decisions, it meant having said goodbye to family with no issues left that had to be sorted or discussed. This participant explained the term “terminal anguish” which means that patients may have unresolved issues and, therefore, are not ready to die. Such patients were, at times, given sedation if there was no way of resolving the issues, so that the feelings of anguish and despair would be diminished.

5.7 Summary

In summary, it appears that individuals were quite capable of forming an opinion about euthanasia, whether or not they have had formal education on the topic of euthanasia. The differences in the definitions supplied by the participants, and how these definitions reflected the ideas the participants had about euthanasia, were discussed. The definitions and perceptions as to what constitutes the practice of euthanasia differ among the participants, and this was related to the source(s) of knowledge. More participants from the group of health professionals came up with a correct definition compared with the group of participants from the general population. From the data in Table 4.1 and Table 4.2, on pages 71 and 75 respectively, it appears that education may have a great influence on this result. Other sources of knowledge, such as newspapers and TV programmes, used terms such as “euthanasia”, “mercy killing” and “assisted suicide” interchangeably; therefore, “educating” the general public incorrectly.

Overall it was useful to have a mix of participants with significant life and work experiences partaking in this study, since it appears that these factors have had

the most influence on the insights of the participants. Based on work and life experience, participants of both groups were able to indicate whether or not there was a place for the practice of euthanasia and in which circumstances. Safety issues relating to the practice of euthanasia were discussed, and participants from both groups were able to contribute to these issues equally.

Participants did not have to be educated or actually 'live the experience' to provide comments in relation to euthanasia. For example, G3 related well to experiences of friends and relatives and used the insight in other people's experiences as part of their knowledge base. It became evident that informal learning was important in gaining a knowledge base about the topic of euthanasia. It is beyond the scope of this study to examine which type of informal learning had the most impact on developing a knowledge base and value system. To gain better understanding of this issue further research is required.

Spirituality emerged as a theme from the data. Suffering and meaning of life were discussed. However, exploration of the factors involved in perceptions of suffering and quality of life is beyond the scope of this study but may warrant further investigation. Participants have indicated that spiritual issues are just as important for them as ethical principles, and that these issues have to be dealt with to ensure there is a "good death".

Chapter 6

Recommendations

This chapter will highlight the important issues pertaining to the practice of euthanasia that came to the fore in the literature search or were mentioned as concerns by the participants in this study. Recommendations that deal with these issues are made in the area of healthcare and education.

6.1 Furthering the debate on euthanasia

In the debate regarding euthanasia, some argue that there is no intrinsic moral difference between active and passive euthanasia, while passive euthanasia is commonly practised. It is argued by Mitchell (in Ansley, 2003) that, rather than seeking to prohibit active voluntary euthanasia, it would be better to bring all life and death decisions out into the open where they can be publicly debated and are open to public scrutiny. However, the acceptance of this argument depends on the acceptance of the view that there is no moral difference between active and passive euthanasia. In view of these arguments it is recommended that:

- Euthanasia should be debated nationally and open to public scrutiny.
- The debate should include issues pertaining to the safe practice of euthanasia.

6.2 Recommendations for education

One of the purposes of this study was to explore the impact of education on the knowledge base pertaining to the topic of euthanasia. Education appeared to be important in acquiring a knowledge base pertaining to ethical issues and the topic of euthanasia. Teaching ethics may be difficult since, according to Myser *et al.*, (1995) students did find it difficult to make distinctions between legal, social and ethical issues.

6.2.1 Recommendations for education of health professionals

Pertaining to education of health professionals it is recommended that:

- Educational institutions should get students to make links between theory and practice. At present there are skills books for nursing students, which focus mainly on manual skills practiced in a clinical setting. These manuals could include recognition of ethical problems encountered in practice and ask the student to discuss them. This might help students focus on more than the acquisition of manual skills.
- Educators should help students make links between theory and practice and help recognise situations where ethical principles are involved by discussing situations occurring in clinical practice during clinical placements.
- Further research should occur on the impact of informal learning on developing a knowledge base and value system.

6.2.2 Recommendations for education of the general public

Pertaining to education for the general population it is recommended that:

- All New Zealand citizens as part of learning ‘life skills’ in secondary schools should be taught about ethical issues.

6.3 Suggestions for future research

Because of the importance of bioethical issues in our lives, it is recommended that ethics and ethical principles be taught to the general population. Informal learning is important since most of our learning during our lives falls in this category. It is recommended that further research is done into the impact of informal learning on the acquisition of knowledge and values. This knowledge may be of help making educators more effective in their endeavours.

It is recommended that:

- The impact of informal learning should be explored especially which type of informal learning, on the acquisition of values and development of a value system.
- The importance of spiritual beliefs, as opposed to ethical principals, should be examined in relation to the practice of euthanasia (and other ethical issues one may encounter).

Chapter 7

Conclusion

Euthanasia is practised overtly and legally in the Netherlands, and according to statistics, covertly in a variety of other countries and New Zealand (Darbyshire, 1987; Mitchell & Owens, 2003). The practice of assisted suicide is legalised in Oregon and Switzerland. Euthanasia is not legalised in New Zealand; however, there is practice of withdrawal of treatment, which, in New Zealand, is not defined as euthanasia.

7.1 Defining euthanasia

This study initially looked at descriptive data pertaining to the topic of euthanasia, education and learning. The term euthanasia is clearly defined, however, perceptions as to what constitutes the practice of euthanasia differ widely. Ethicists and educators make distinctions between practices such as euthanasia, mercy killing, assisted suicide, ‘allowing to die’ and futile care. This study highlighted the end-of-life practices that find place in New Zealand and most of these situations have been discussed in the media. There is an increased awareness of bioethical issues in our society, of which euthanasia is but one. Since education is influenced by the demands and needs of society, health professionals are educated on ethics, ethical principles and end-of-life situations. Researchers and the media use the terms euthanasia, mercy killing and assisted suicide interchangeably, and this misrepresents the practice of, and issues surrounding euthanasia. The general public is informed about end-of-life issues, as described by the media and researchers, and their misrepresentation colours perceptions and views of the practice of euthanasia.

7.2 Research project

A qualitative approach, by means of interview, was used for this study. In total, fourteen participants from the greater Wellington area were involved in the study, namely, seven health professionals and seven participants from the general population. This qualitative research study was designed to capture the knowledge base, insights and values of individuals on the topic of euthanasia. All participants were interviewed and an open-ended question was posed. This method worked well since participants freely volunteered their views, life, and where applicable, work experiences regarding end-of-life situations. The following questions were posed to gain data if this information was not volunteered.

- 1) Should euthanasia be practised and or legalized in New Zealand?
- 2) When is euthanasia an option in your opinion?
- 3) Which values, ethical and legal issues should be taken into consideration?
- 4) Where did you gain knowledge regarding euthanasia?
- 5) Have you had any experience with euthanasia?
- 6) Have you lost somebody you were close to due to illness?

The information gave insight into the value systems, opinions to whether or not the participants were pro euthanasia and why, opinions to whether the practice of euthanasia should be legalised and reasons why, and information as to where the participant gained knowledge regarding the topic.

Part of the methodology was to analyse the interviews with consecutive participants as they occurred until no new themes emerged which meant that theoretical saturation was achieved. Despite different backgrounds, the participants discussed similar issues during their interviews. Participants volunteered a lot of information and, because of the open-ended question, additional information was offered which led to the development of a theme on spirituality. Comparing two groups resulted also in quantitative data showing the differences between the two groups.

7.2.1 Limitations of the project

One of the limitations of this study was the small sample size. Maybe with a lot more participants, more themes would have emerged. It also means that the results are not representative of the whole population or representative of all the different cultural groups in New Zealand, who may have different perspectives on the practice of euthanasia. For example, in comparison with other research studies, a lesser percentage of participants in this study are for legalisation of the practice of euthanasia.

7.3 Knowledge and education

The participants, partaking in this study, differ in knowledge bases and educational backgrounds. Some participants were educated about ethical issues and the topic of euthanasia and some participants learned about the topic of euthanasia from other sources such as TV, work, reading, teaching, discussions, ethics advisory committee and newspapers (Table 4.1 and Table 4.2).

Difference in education may be the main cause of the difference, in the ability to define the term euthanasia correctly, between the two groups of participants. Educational institutions teach ethical principles to health professionals, to guide in decision making with ethical dilemmas in clinical practice. However, despite being taught ethics, most individuals base their views and decisions on life experience, personal knowledge and values; this also pertains to the practice of euthanasia. This may explain why participants of both groups were equally capable of forming an opinion pertaining to euthanasia. A definition is learned and not value-laden. Decisions and opinions are based on personal values and life experience and, in this area, there is little difference between the two groups of participants.

Educational theory was used to explain what was happening in relation to an individual's knowledge base with respect to euthanasia. How participants gained an understanding of euthanasia and various ways of informal learning were discussed since this appeared to be relevant to the acquisition of knowledge. Tacit knowledge, such as implicit learning, intuitive understanding, and applying knowledge to new situations, as described by Eraut, (2000) was relevant.

The topic of euthanasia is relevant to our lives because of the widespread (Mitchell & Owens, 2003; Shah & Loyd-Williams, 2003; Warner *et al.*, 2001; Johnson, 1998) (covert) practice of euthanasia, which makes it possible to end intolerable suffering in patients with incurable and terminal disease. The study by Mitchell & Owens (2003) suggests that euthanasia occurs, and Johnson (1998) discussed the Ray Williams case, where treatment was withdrawn. Almost all participants partaking in this study knew of somebody who had been very ill, was suffering or had a severe disability and poor quality of life. Some of the participants were aware of cases of withdrawal of treatment. Participants based their opinions about euthanasia on the life situations and experiences they were familiar with. Since ethical issues make part of our life, it is useful to have a knowledge base regarding ethical principles from which an individual can make decisions. Formal learning, such as in an educational institution, ensures that important and relevant topics are covered to prepare health professionals for clinical practice. Recent graduates had ethics as a topic during their education and they were made aware of the possible problems and issues they may encounter in clinical practice. Recommendations, as outlined in Chapter 6, are proposed to ensure that links are made between theory and practice.

7.4 Summary

One definition of euthanasia should be used across everything because the definition of euthanasia influences decisions and perceptions. However, euthanasia should not be studied as a scientific object or phenomenon because it is not in the subject matter that lies the 'truth' but in the person and his/her value

system. This means that the 'truth', with respect to euthanasia, is not represented in all the factual knowledge regarding the topic, but that an individual's subjective feelings, perceptions and value system are of equal or even more value in forming an opinion on the topic of euthanasia.

Since it is apparent, from the descriptive data and the information volunteered by the participants in this study, that euthanasia is practised, albeit covertly, it may be timely to have it brought out in the open and nationally debated. Having euthanasia, with safety issues appropriately addressed, as an option may be desirable in situations where medical technology and interventions are not wanted and/or are not able to alleviate suffering while terminally ill, or suffering an incurable illness. It can be left up to the individual to choose to take this option when it fits in their value system and if it does not pose a dilemma for the person performing the euthanasia.

Postscript

My dad died of cancer. This diagnosis was made four weeks before he passed away. However, he had been sick for at least a year with medical practitioners not able to find what was wrong. Suffering came from social isolation, loss of independence, being unable to take care of one's self, loss of function; as husband, grandfather and contributing human being, loss of self image, the strong belief that mum was too young to stay behind by herself, not being able to be there until the grandchildren were older, the physical pain associated with strong muscle contractions and erosion of tissue due to vomiting of bile and acid stomach content. It was heart rending to see the physical decline of a man who had always been strong, and the mental suffering that went hand in hand with this process. It was very comforting to be able to assist my parents in these last four weeks with practical and moral support, be part of the family in a practical sense, and be able to say goodbye to my dad properly.

Relevance of the practice of euthanasia

Because our family resides in the Netherlands, it was an option to choose euthanasia. However, the option to practice euthanasia was not taken lightly. Discussions about euthanasia took place during the last four weeks of dad's life, during which time dad was assessed by several medical practitioners regarding his physical condition and state of mind. Dad also had to indicate his wishes verbally, as well as in a self written letter. My parents were in agreement about the practice of euthanasia. However, my sister, although respecting dad's wishes, has not come to terms with the practice of euthanasia, for reasons not even clear to herself. It takes strength and resolve from everybody involved to work through issues that were raised at the time, such as, among others, family members disagreeing with dad's decision, opposing views of medical practitioners, limitations of the health care system in delivering sufficient care, inadequate relief of signs and symptoms. Participants share the experience of having to deal with some or all of these issues.

Relevance of the research topic

On return to New Zealand, where the writer resides, a topic for a thesis was discussed with thesis paper coordinator Marg Gilling and thesis supervisor Michelle Knight, Department of Social and Policy Studies in Education at Massey University, Wellington. I was encouraged to choose a topic I was interested in, felt strongly and passionate about and that had relevance to New Zealand society. The practice of euthanasia was discussed in view of the experience with my dad, my nursing practice and the withdrawal of treatment that occurred in that area of health care, and the practice of euthanasia being topical and receiving international and national attention.

It was interesting to delve into publications about the subject of euthanasia. The literature search in this thesis is not exhaustive but does reflect what is happening in New Zealand and internationally at the time of writing the thesis. It made me reflect on the current health care system and whether or not people receive appropriate care. There clearly are cases where there was not enough care available with disastrous results, such as in the Janine Albury Thompson case. The end results of situations people find themselves in, such as the Lesley Martin and Janine Albury Thompson cases, are highlighted in the media, not necessarily the amount of suffering, stress, and deliberations that went on before hand. Deliberations and concerns pertaining to end of life situations are also mentioned by the participants in this study and I endeavoured to obtain their perspectives and concerns about euthanasia and share them with the reader.

Then came the time to investigate people's opinion(s) about euthanasia. I felt privileged that participants were willing to share their thoughts and feelings with me, on a topic they felt was important to New Zealand society, but that also made them reflect on personal experiences, with death of loved ones and/ or patients, and what life, illness, and suffering meant to them.

The participants

All the participants were very willing to share thoughts, opinions and personal experiences, which, at times, were painful. Some participants expressed their appreciation that there was somebody who wanted to listen to their experiences. This listening may not always occur on a topic related to end of life experiences, and, therefore, individuals are not able to share their innermost thoughts and feelings, while there may be a desperate need for this. Feelings of insecurity, inadequacy, being alone, and people being unsupported to deal with a situation, were brought up. None of the participants in this study ever hit the headlines, but their stories are as remarkable as those you read in the media. However, normal life, and dealing with personal experiences of end of life situations, although not for the faint hearted, is taken for granted. However, it does deserve more attention, so that individuals can express themselves and we, as a nation, become more aware of the many variables in people's life and hopefully increase understanding for other people's end of life situation.

After the interviews, the time consuming task of typing the interviews and analysing of the data began. It was important to the researcher to capture the knowledge base of the participants, as well as do justice to the opinions of the participants. It was evident that life experiences had more influence on the forming of an opinion than formal education. Some life experiences had a big impact on the emotional status of the participant, as the death of my dad had on me, and these experiences had to be reflected as well.

It would be great if life experiences and opinions can be shared in a national debate about euthanasia, to increase understanding of end of life decisions, since it is an important area and affects us all.

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Appendices

Appendix A

Upper House of the States General

Parliamentary year 2000-2001 no 137

26 691

Review procedures of termination of life on request and assisted suicide and amendment to the Penal Code (*Wetboek van Strafrecht*) and the Burial and Cremation Act (*Wet op de lijkbezorging*) (Termination of Life on Request and Assisted Suicide (Review Procedures) Act)

Amended legislative proposal 28 November 2000

We Beatrix, by the grace of God, Queen of the Netherlands, Princess of Orange-Nassau, etc., etc. etc.

Greetings to all who shall see or hear these presents! Be it known:

Whereas We have considered that it is desired to include a ground for exemption from criminal liability for the physician who with due observance of the requirements of due care to be laid down by law terminates a life on request or assists in a suicide of another person, and to provide a statutory notification and review procedure;

We, therefore, having heard the Council of State, and in consultation with the States General, have approved and decreed as We hereby approve and decree:

Chapter I. Definitions of Terms

Article 1

For the purposes of this Act:

- a. Our Ministers mean the Ministers of Justice and of Health, Welfare and Sports;
- b. assisted suicide means intentionally assisting in a suicide of another person or procuring for that other person
the means referred to in Article 294 second paragraph second sentence of the Penal Code;
- c. the physician means the physician who according to the notification has terminated a life on request or assisted in a suicide;
- d. the consultant means the physician who has been consulted with respect to the intention by the physician to terminate a life on request or to assist in a suicide;
- e. the providers of care mean the providers of care referred to in Article 446 first paragraph of Book 7 of the Civil Code (*Burgerlijk Wetboek*);
- f. the committee means a regional review committee referred to in Article 3;
- g. the regional inspector means the regional inspector of the Health Care Inspectorate of the Public Health Supervisory Service.

Chapter 11. Requirements of Due Care

Article 2

1. The requirements of due care, referred to in Article 293 second paragraph Penal Code mean

that the physician:

- a. holds the conviction that the request by the patient was voluntary and well-considered,
 - b. holds the conviction that the patient's suffering was lasting and unbearable,
 - c. has informed the patient about the situation he was in and about his prospects,
 - d. and the patient hold the conviction that there was no other reasonable solution for the situation he was in,
 - e. has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a d, and
 - f. has terminated a life or assisted in a suicide with due care.
2. If the patient aged sixteen years or older is no longer capable of expressing his will, but prior to reaching this condition was deemed to have a reasonable understanding of his interests and has made a written statement containing a request for termination of life, the physician may carry out this request. The requirements of due care, referred to in the first paragraph, apply *mutatis mutandis*.
3. If the minor patient has attained an age between sixteen and eighteen years and may be deemed to have a reasonable understanding of his interests, the physician may carry out the patient's request for termination of life or assisted suicide, after the parent or the parents exercising parental authority and/or his guardian have been involved in the decision process.
4. If the minor patient is aged between twelve and sixteen years and may be deemed to have a reasonable understanding of his interests, the physician may carry out the patient's request, provided always that the parent or the parents exercising parental authority and/or his guardian agree with the termination of life or the assisted suicide. The second paragraph applies *mutatis mutandis*.

Chapter III. The Regional Review Committees for Termination of Life on Request and Assisted Suicide.

Paragraph 1: Establishment, composition and appointment

Article 3

1. There are regional committees for the review of notifications of cases of termination of life on request and assistance in a suicide as referred to in Article 293 second paragraph or 294 second paragraph second sentence, respectively, of the Penal Code.
2. A committee is composed of an uneven number of members, including at any rate one legal specialist, also chairman, one physician and one expert on ethical or philosophical issues. The committee also contains deputy members of each of the categories listed in the first sentence.

Article 4

1. The chairman and the members, as well as the deputy members are appointed by Our Ministers for a period of six years. They may be re-appointed one time for another period of six years.
2. A committee has a secretary and one or more deputy secretaries, all legal specialists, appointed by Our Ministers. The secretary has an advisory role in the committee meetings.
3. The secretary may solely be held accountable by the committee for his activities for the committee.

Paragraph 2: Dismissal

Article 5

Our Ministers may at any time dismiss the chairman and the members, as well as the deputy members at their own request.

Article 6

Our Ministers may dismiss the chairman and the members, as well as the deputy members for reasons of unsuitability or incompetence or for other important reasons.

Paragraph 3: Remuneration

'philosophical issues' - in the original text the Dutch word 'zingevingsvraagstukken' is used to describe the discussion on the prerequisites for a meaningful life.

Article 7

The chairman and the members, as well as the deputy members receive a holiday allowance as well as a reimbursement of the travel and accommodation expenses according to the existing government scheme insofar as these expenses are not otherwise reimbursed from the State Funds.

Paragraph 4: Duties and powers

Article 8

1. The committee assesses on the basis of the report referred to in Article 7 second paragraph of the Burial and Cremation Act whether the physician who has terminated a life on request or assisted in a suicide has acted in accordance with the requirements of due care, referred to in Article 2.
2. The committee may request the physician to supplement his report in writing or verbally, where this is necessary for a proper assessment of the physician's actions.
3. The committee may make enquiries at the municipal autopsist, the consultant or the providers of care involved where this is necessary for a proper assessment of the physician's actions.

Article 9

1. The committee informs the physician within six weeks of the receipt of the report referred to in Article 8 first paragraph in writing of its motivated opinion.
2. The committee informs the Board of Procurators General and the regional health care inspector of its opinion:

a. if the committee is of the opinion that the physician has failed to act in accordance with the requirements of due care, referred to in Article 2;

or

b. if a situation occurs as referred to in Article 12, final sentence of the Burial and Cremation Act.

The committee shall inform the physician of this.

3. The term referred to in the first paragraph may be extended one time by a maximum period of six weeks. The committee shall inform the physician of this.
4. The committee may provide a further, verbal explanation on its opinion to the physician. This verbal explanation may take place at the request of the committee or at the request of the physician.

Article 10

The committee is obliged to provide all information to the public prosecutor, at his request, which he may need:

- 1°. for the benefit of the assessment of the physician's actions in the case referred to in Article 9 second paragraph; or
- 2°. for the benefit of a criminal investigation.

The committee shall inform the physician of any provision of information to the public prosecutor.

Paragraph 6: Working method

Article 11

The committee shall ensure the registration of the cases of termination of life or assisted suicide reported for assessment. Further rules on this may be laid down by a ministerial regulation by Our Ministers.

Article 12

1. An opinion is adopted by a simple majority of votes.
2. An opinion may only be adopted by the committee provided all committee members have participated in the vote.

Article 13

At least twice a year, the chairmen of the regional review committees conduct consultations with one another with respect to the working method and the performance of the committees. A representative of the Board of Procurators General and a representative of the Health Care Inspectorate of the Public Health Supervisory Service are invited to attend these consultations.

Paragraph 7: Secrecy and Exemption

Article 14

The members and deputy members of the committee are under an obligation of secrecy to keep confidential any information acquired in the performance of their duties, except where any statutory regulation obliges them to divulge this information or where the necessity to divulge information ensues from their duties.

Article 15

A member of the committee that serves on the committee in the treatment of a case exempts himself and may be challenged if there are facts or circumstances that may affect the impartiality of his opinion.

Article 16

A member, a deputy member and the secretary of the committee refrain from rendering an opinion on the intention by a physician to terminate a life on request or to assist in a suicide.

Paragraph 8: Report

Article 17

1. Not later than 1 April, the committees issue a joint annual report to Our Ministers on the activities of the past calendar year. Our Ministers shall lay down a model for this by means of a ministerial regulation.
2. The report on the activities referred to in the first paragraph shall at any rate include the following:
 - a. the number of reported cases of termination of life on request and assisted suicide on which the committee has rendered an opinion;
 - b. the nature of these cases;
 - c. the opinions and the considerations involved.

Article 18

Annually, at the occasion of the submission of the budget to the States General, Our Ministers shall issue a report with respect to the performance of the committees further to the report on the activities as referred to in Article 17 first paragraph.

Article 19

1. On the recommendation of Our Ministers, rules shall be laid down by order in council regarding the committees with respect to
 - a. their number and their territorial jurisdiction;
 - b. their domicile.
2. Our Ministers may lay down further rules by or pursuant to an order in council regarding the committees with respect to

- a. their size and composition;
- b. their working method and reports.

Chapter IV. Amendments to other Acts

Article 20

The Penal Code shall be amended as follows:

A

Article 293 shall read:

Article 293

1. A person who terminates the life of another person at that other person's express and earnest request is liable to a term of imprisonment of not more than twelve years or a fine of the fifth category.
2. The offence referred to in the first paragraph shall not be punishable if it has been committed by a physician who has met the requirements of due care as referred to in Article 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act and who informs the municipal autopsist of this in accordance with Article 7 second paragraph of the Burial and Cremation Act.

B.

Article 294 shall read:

Article 294

1. A person who intentionally incites another to commit suicide, is liable to a term of imprisonment of not more than three years or a fine of the fourth category, where the suicide ensues.
2. A person who intentionally assist in the suicide of another or procures for that other person the means to commit suicide, is liable to a term of imprisonment of not more than three years or a fine of the fourth category, where the suicide ensues. Article 293 second paragraph applies *mutatis mutandis*.

C

In Article 295, the following is inserted after '293': first paragraph.

D

In Article 422, the following is inserted after '293': first paragraph.

Article 21

The Burial and Cremation Act shall be amended as follows:

A

Article 7 shall read:

Article 7

1. A person who has performed a postmortem shall issue a death certificate if he is convinced that death has occurred as a result of a natural cause.
2. If the death was the result of the application of termination of life on request or assisted suicide as referred to in Article 293 second paragraph or Article 294 second paragraph second sentence, respectively, of the Penal Code, the attending physician shall not issue a death certificate and shall promptly notify the municipal autopsist or one of the municipal autopsists of

the cause of death by completing a form. The physician shall supplement this form with a reasoned report with respect to the due observance of the requirements of due care referred to in Article 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) act.

3. If the attending physician in other cases than referred to in the second paragraph believes that he may not issue a death certificate, he must promptly notify the municipal autopsist or one of the municipal autopsists of this by completing a form.

B

Article 9 shall read:

Article 9

1. The form and the set-up of the models of the death certificate to be issued by the attending physician and by the municipal autopsist shall be laid down by order in council.
2. The form and the set-up of the models of the notification and the report referred to in Article 7 second paragraph, of the notification referred to in Article 7 third paragraph and of the forms referred to in Article 10 first and second paragraph shall be laid down by order in council on the recommendation of Our Minister of Justice and Our Minister of Health, Welfare and Sports.

C

Article 10 shall read:

Article 10

1. If the municipal autopsist is of the opinion that he cannot issue a death certificate, he shall promptly report this to the public prosecutor by completing a form and he (shall promptly notify the registrar of births, deaths and marriages.
2. In the event of a notification as referred to in Article 7 second paragraph and without prejudice to the first paragraph, the municipal autopsist shall promptly report to the regional review committee referred to in Article 3 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act by completing a form. He shall enclose a reasoned report as referred to in Article 7 second paragraph.

D

The following sentence shall be added to Article 12, reading: If the public prosecutor, in the cases referred to in Article 7 second paragraph, is of the opinion that he cannot issue a certificate of no objection against the burial or cremation, he shall promptly inform the municipal autopsist and the regional review committee referred to in Article 3 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act of this.

E

In Article 81, first part, '7, first paragraph' shall be replaced by '7, first and second paragraph'.

Article 22

The General Administrative Law Act (*Algemene wet bestuursrecht*) shall be amended as follows:

At the end of part d of Article 1 :6, the full stop shall be replaced by a semicolon and the following shall be added to the fifth part, reading:

- e. decisions and actions in the implementation of the Termination of Life and Assisted Suicide (Review Procedures) Act.

Chapter V. Final Provisions

Article 23

This Act shall take effect as of a date to be determined by Royal Decree.

Article 24

This Act may be cited as: Termination of Life on Request and Assisted Suicide (Review Procedures) Act.

We hereby order and command that this Act shall be published in the Bulletin of Acts and Decrees and that all ministerial departments, authorities, bodies and officials whom it may concern shall diligently implement it.

Done

The Minister of Justice,

The Minister of Health, Welfare and Sports.

Upper House, parliamentary year 2000-2001, 26 691, no 137

Appendix B

A qualitative investigation about euthanasia and the difference in the knowledge base and decision-making process between lay people and health professionals in the Wellington region.

Information Sheet

The purpose of the study is to find out people's opinion and knowledge base regarding euthanasia and if euthanasia has a place in New Zealand. Participants are asked to answer one question during an interview at a mutually convenient time.

The information obtained will be analysed and used as a partial fulfilment of the requirements for the degree of Masters in Education by Wilma Tielemans. There is a possibility that the findings might be published in a health related journal for the benefit of health professionals.

The information is kept confidential, no names will be mentioned or individuals identified. Data obtained will be destroyed after the finish of the study or if the participant wishes returned to them.

The participants are free to withdraw from the study at any time during participation or refuse to answer any particular questions. The researcher will answer any questions about the study at any time if/when posed by participants. At the end of the study findings will be made available to participants.

If counselling is required after the interview then this service will be made available to the participant.

You can contact me by phone or email.

Phone: 04-3848410 (home) or 04-8012794 ext.6469 (work)

Email: w.tielemans@massey.ac.nz

Wilma Tielemans
31 Waterhouse Drive
Brooklyn
Wellington

Appendix C

A qualitative investigation about euthanasia and the difference in the knowledge base and decision-making process between lay people and health professionals in the Wellington region.

Consent Form

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

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission. (The information will be used only for this research and publications arising from this research project).

I agree/do not agree to the interview being audio taped.

I also understand that I have the right to ask for the audio tape being turned off at any time during the interview.

Signed:

Name:

Date: