

**AN ANALYSIS OF PATIENTS' AWARENESS AND ATTITUDE
CONCERNING END OF LIFE ISSUES**

A DESSERTATION SUBMITTED TO THE :
FACULTY OF COMMUNITY AND DEVELOPMENT DISCIPLINES
SCHOOL OF NURSING
THE UNIVERSITY OF NATAL, DURBAN

IN PARTIAL FULFILLMENT OF A

MASTERS IN CRITICAL CARE AND TRAUMA (MCUR)

BY

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FEBRUARY 2002

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DECLARATION

I BATHINI PURITY KHANYILE DECLARE THAT “ **AN ANALYSIS OF PATIENT’S AWARENESS AND ATTITUDE TOWARDS END OF LIFE DECISIONS**” IS MY ORIGINAL WORK. I HAVE GIVEN FULL ACKNOWLEDGEMENTS OF THE RESOURCES REFERRED TO IN THIS TEXT.

THIS WORK HAS NOT BEEN SUBMITTED BEFORE FOR ANY DEGREE AND EXAMINATION IN ANY UNIVERSITY.

Purity Khanyile

22/02/02

(ii)

DEDICATION

**THIS WORK IS DEDICATED TO MY LATE FATHER
MR KENNETH KHANYILE WHO INSTILLED THE
CULTURE OF LEARNING IN MY FAMILY, AND
WHO WAS A SOURCE OF INSPIRATION TO ME**

ABSTRACT

AN ANALYSIS OF PATIENTS' AWARENESS AND ATTITUDES CONCERNING END OF LIFE DECISIONS.

This study was conducted using a qualitative descriptive approach. It was based on an analysis that was done to determine awareness and attitude of patients in end of life issues. The semi-structured interviews were conducted for data collection. A sample of ten patients, five inpatient and five outpatient, was purposively chosen. Permission was obtained from the hospital superintendent and heads of departments, and also consent from patients, for the study.

Data was analyzed, using the NVIVO program, a computer software, for data coding, and a conceptual model for categorization. From the findings, the researcher concluded that poor communication causes lack of knowledge in patients, which in turn limits the capacity for decision making in patients. The researcher also noted that participants were not aware of their autonomy in decision-making.

(iii)

ACKNOWLEDGEMENTS

- I would like to thank the Almighty GOD for giving me the courage to go on, when I lost hope and determination, HE gave me new strength.
- My gratitude is extended to Mrs. B. Ncama and Mrs. B. Bhengu, my Supervisors, who were patient, encouraging and always willing to share their Expertise with me. Their guidance will always be viewed with respect and appreciation.
- I would like to thank the superintendent and the staff of King Edward VIII Hospital, for giving me the permission and opportunity to conduct this study.
- A special thanks goes to the patients who participated in this study. Their Co-operation made a huge contribution towards this study. Without them, this study would not have been successful.
- A very special thank you goes to my dearest friend Thandi Shabalala for her encouragement and support throughout the course.
- My gratitude is extended to ICU especially Vuyi Mjoli and Trauma staff for their words of encouragement and support.
- My heartfelt gratitude goes to Dumezweni for his understanding, support and encouragement when I needed it most.
- To my family, Amanda, Mthokozisi, Busi and her husband, and Baba-Nani I thank you for your support and encouragement.
- To my very special son Owethu, for your love and understanding, when I could not spend enough time with you, because of my studies. Your sacrifice would always mean a lot to me.

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CHAPTER I

INTRODUCTION TO THE STUDY

1.1. BACKGROUND OF THE STUDY

Patients right has recently emerged as an important focus area in health care. This is evidenced by the adoption of patients' right charters in most health care settings including South Africa. Wlody (1997) wrote that nursing is based on respect for persons, an ethic of care, and belief in the autonomy of the individual patients, beneficence, justice and advocacy for patients. Particularly, the principle of autonomy emphasizes the patient's right to refuse treatment, to the extent permitted by the law, and the patient's right to be informed of the medical consequences of his or her action (The American Hospital Association, 1973). The importance of recognizing and respecting patient's choices is emphasized by the nursing code of ethics. The cornerstone of all nursing practices originates from the nursing code of ethics, which prescribes nursing practices based on the human dignity and uniqueness of the patient, unrestricted by social or economic considerations, personal attributes or the nature of the health problem (South African Nursing Council, 1994). The importance of a patient's right remains unchanged even though nursing is going through a process of evolution where new technological developments are affecting every aspect of nursing practices.

Brody (1983) states that new technology has given rise to new moral problems. For example, the ability of medical science to prolong life artificially does not ensure an

acceptable quality of life. Questions therefore arise as to: When does life end? When should life end? Should people be allowed to refuse life sustaining medical treatment? These questions bring the issue of euthanasia into focus. The word 'euthanasia' comes from Greek, and it stands for 'good death'. The Concise Oxford dictionary (10th Ed., 1999) defines euthanasia as 'the painless killing of a patient suffering from an incurable disease or in an irreversible coma. It has been used increasingly in the past century to designate all forms of allowing death to set in or actively bring it about, whether one's own or another's and whether the death is voluntary or against the wishes of the subject (Dworkins, Frey, and Bok, 1998).

This broad concept of euthanasia has created controversy in the medical scene. Medical Practitioners experience difficulty when decision making concerning end of life issues, has to be made. Case studies of the ethical dilemma surrounding the quality of life and the right to die were conducted in Scotland. They revealed that mercy killing would remain unacceptable, but assisting individuals to end their lives might be a proposition for the future (Mc Cormack, 1998).

Studies had revealed that in some countries there is no clarity as to what practices are acceptable regarding the issue of euthanasia. Griffiths (1999) used a phenomenological method in the United Kingdom to explore the value of personal autonomy in issues of consent. It was concluded that in the reality of practice, covertly, physician assisted suicide and voluntary euthanasia do take place despite the forbidding legal system. Another survey conducted by Hayden (1999) on doctors in the University of Alabama,

revealed that 34% of physicians admit to continuing treatment despite patient or proxy's wishes. In other instances a patient's life is prolonged for organ donation, which is clearly in contrast with the principle of beneficence, which requires that one must promote the well being of patients (Kinney, 1988).

1.2. PROBLEM STATEMENT

The dawning of the democratic era demanded transparency and empowerment of the people. People seek knowledge and understanding of all concepts that affect their everyday life. Advances in knowledge, however, still do not balance the debilitating effect of diseases and injury. Many people continue to live with life threatening conditions like HIV and AIDS. Other people lead lifestyles of a high-risk nature, like taking alcohol and driving, or engaging in sports like diving. Such people need to be always prepared for the worst in life.

In the researchers' observation and experience in hospital shows that, many of these patients arrive unconscious, and the method of their treatment is to keep them sedated. This makes them unable to verbalize their opinions regarding choices of treatment. As a result it is important to conduct research about patients' awareness and attitudes towards end of life issues.

1.3 OBJECTIVES OF THE STUDY

1. This study seeks to explore the level of awareness and knowledge about end of life decisions
2. It seeks to determine individual attitudes towards decision making in end of life issues.
3. It seeks to explore factors influencing decision- making in end of life issues.

1.4. RESEARCH QUESTION

1. What do patients know about end of life issues?
2. What are patients' attitudes concerning end of life decisions?
3. What are the factors that influence patient's decision-making concerning end of life issues?

1.5 SIGNIFICANCE OF THE STUDY

In the medical circles end of life decisions are still a debated issue, approached with uncertainty and caution. The aim of this study is to bring the patient's or client's opinion into the debate about end of life issues. Open communication could facilitate decision-making and thus prevent the unnecessary process of artificial ventilation and other life saving measures. This study is aimed at exploring individual attitudes towards this matter, and establishing whether they are aware of their autonomy in decision-making. The result of this study could enable some people like the participants to be prepared for their end of life. The study will also sensitize health personnel to be prepared to discuss such issue according to their clients' expectations, for example, in such a way

that they could remove guilt feelings from families, who are faced with deciding about the end of life of a loved one.

1.6. DEFINITION OF TERMS

1.6.1. End of life decision refers to circumstances when patients who are faced with terminal or life threatening conditions have to decide on the type of treatment they prefer. Options of treatment considered may even include treatment termination (Buchanan, 1993)

1.6.2. Living will is an expression of the patient's right to refuse specific medical treatment. It is an advanced directive instructing the doctors not to employ heroic measures to prolong the patient's life (Buchanan, 1993).

1.6.3. Physician assisted suicide is the intentional act of providing the means (lethal injection, pills, weapon or mechanical device) for a person to end his or her own life (Wlody, 1997).

1.6.4. Autonomy is the freedom to make decisions about one's own body without coercion or interference from others. It is the freedom of choice or self-determination that can be experienced in all human life events (Kinney, 1988).

1.6.5. Quality of life is the value that can be attached to an individual's life and it involved the making of decisions for the treatment of seriously deformed persons or

newborns, victims of severe injury, terminal illness or advanced age. It involves decisions based on what is best for the individual patient and not the avoidance of a burden to the family or to society (Rachels, 1986).

1.6.6. Patient in this study means, a person who has suffered a life threatening condition, who has been through the intensive care unit, has been subjected to extraordinary care, and who is mentally competent to make informed decisions about his or her life.

1.6.7. Extra ordinary care in this study means intubation and artificial ventilation, invasive monitoring, dialysis, surgical intervention.

1.6.8. Ordinary treatment refers to basic nursing care; bathing, ensuring safety and comfort and pain relief.

1.6.9. Euthanasia is the practice of ending a person's life in order to release the person from incurable, intolerable suffering, or undignified death (Beauchamp, 2000).

1.6.10. Step-down unit in this study refers to a ward, which provides high care to patients who are transferred out of the intensive care unit.

1.6.11. Outpatient department in this study refers to the casualty section of the hospital where treatment is rendered to clients with minor ailments or injuries.

1.6.12. Awareness refers to consciousness or knowledge of any matter (Concise Oxford Dictionary, 10th ed., 1999)

1.7. CONCLUSION

This chapter gives an overview of the course that this study has taken. At the beginning the researcher gives a motivation for the conducting of the study by outlining the background and stating the identified problem, which prompted this study. The significance of the study is discussed after the purpose of the study. In the next chapter the researcher reviews the literature relevant to this study.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter gives an overview of the literature reviewed in this study. The researcher has addressed all the important issues that affect end of life issues. Studies pertaining to end of life decisions were reviewed. A philosophical view of different perspectives is given towards the end of this chapter.

2.2. THE DISTINCTION BETWEEN KILLING AND LETTING DIE

In recent years there has been a considerable discussion about this issue, but, it has not yet been resolved. To the effect that Thompson (1999) wrote that in the medical context, a doctor killing a patient is different from a doctor letting the patient die, in the sense that killing the patient is always morally impermissible, whereas letting the patient die is morally permissible. This distinction is sometimes taken further. If a person fails to perform an action that could prevent evil consequences, he or she is seen as morally less blameworthy than he or she would be if he or she performed an action that resulted in the same evil consequences (Johnson, 1993). This is referred to as the acts and omissions doctrine, Johnson (1993) cited the British Medical Association Handbook of Medical Ethics, which described the doctrine as follows; “ The failure to perform an act that would prevent negative consequences is morally better than to perform an act that would result in identical consequences.” (Johnson, 1993, p 636). This whole issue is

complicated by the dilemma that arises when doctors, who are expected to preserve lives, are faced with situations where patient's quality of life is so poor that should he live, he would be in a permanent vegetative state. Weithman (1999) states that in those cases 'terminal weaning' is the best course of action. This implies that the physicians withdraw ventilation to cause death. This is often accompanied by the administration of opiates in large doses. Weithman (1999) alleges that these drugs cause death through respiratory depression. Therefore the above action is clearly intended to cause death. In another view Johnson (1993) argues that it is permissible to withhold or withdraw extraordinary or disproportionate means of life support. The patient's perspective will be discussed in the next section.

2.3. THE RIGHT TO CHOOSE

Chronic intractable pain and incurable illness are usually the dominant features of a poor quality of life. There is, however, an associated aspect of hatred of dependence and helplessness, which is felt by terminally ill patients (Mc Cormack, 1998). These are the patients who need the right to choose treatment. The passage of the 1991 Self Determination Act reinforced the value of the patient's autonomy (Wlody, 1997). The intention of this legislation was to guarantee an active role and voice for patients in the health care system. It requires health facilities to inform all patients of their right to refuse any treatment, to provide information to patients about advanced directives and to facilitate the execution of an advanced directive by patients who so desire. This could be done in two forms. One is the living will, in which the desire to avoid extraordinary care should the patient become hopelessly ill is indicated. The second option is the durable

power of the health care attorney, which identifies an agent to speak for patients should they become incompetent to make their own health care decisions (Pierce, 1999). Some studies have addressed this issue by looking into advocacy for the right to voluntary death. Young and Ogden (2000) particularly addressed the Human Immunodeficiency Virus and AIDS group. They wrote that a decade ago the AIDS Canadian society argued that incurably ill AIDS patients should be permitted to choose death as their next form of treatment. Lobbying for patients' rights was also carried out by: The British Columbia Persons with HIV and AIDS Society, in 1994, the AIDS Committee of Toronto in 1995, and in Australia, the AIDS Council of New South Wales in 1995. In 1999 an international summit for promoting standards of care for people living with HIV and AIDS produced a position statement, advocating the involvement of persons with HIV and AIDS in the discussion of end of life decisions concerning 'their' bodies including decisions about the manner and timing of death (Young and Ogden, 2000). Furthermore Dworkins, Frey and Bok (1998) states that every competent person has the right to make momentous personal decisions which invoke fundamental religious or philosophical convictions about life's value to him or her self. This principle is held to support a protected right to physician assisted suicide because "Death is for each of us, among the most significant events of life" (Dworkins, Frey and Bok, 1998, p628).

It would be inappropriate not to consider the competency of a person to understand the nature of the decision at hand and to be able to make a reasoned choice based on adequate information including the risk and benefits of different and alternative treatment (Brock, 1999).

Furthermore voluntary choices should be based on the patient's values, not coerced or manipulated to serve someone else's interest or view of what is best for the patient. To emphasize the point of values, Mak and Clinton (1999), in their outcomes research conducted in Hong Kong, to establish patient's desired outcomes in end of life care, remarked that the Hindus and Christians, regard religious devotion as an important element of a good death. Another study by Okuno, Tamura, Tagaya and Davis (1999) conducted in Japan on elderly patients, to investigate factors that influenced decision-making in end of life issues. It showed that traditional values and group belonging influenced decision-making about end of life in elderly people.

2.4. THE POTENTIAL FOR ABUSE

There has been a growing concern that vulnerable persons might be at risk. Brock (1999) has stated that for a doctor to intend a patient's death is wrong when it violates a patient's right not to be killed. This clearly stresses the importance of patient's consent. Young and Ogden (2000) reports that the result of a survey conducted in Canada on nurses working within the HIV and AIDS setting showed that legislation for these practices needs to be established and nurses were wary of the potential for assisted suicide and voluntary euthanasia. Another version of this concern invokes the familiar 'slippery slope' argument (Velleman, 1999), that the proposal for legalizing physician-assisted suicide is only the first step to an ever-expanding practice of killing patients. They fear that weakening of respect for human life will follow. Velleman (1999) also wrote about the practice of relieving pain with lethal doses of morphine, referred to as the principle of

double effect. Velleman (1999) further explained that increasing the dose of morphine, which is known to cause respiratory depression, would not only relieve the pain felt by the patient, but would also cause respiratory arrest and thus death.

To highlight the extent of the concern for potential for abuse Emmanuel (1999) analyzed facts surrounding this issue. He pointed out that in many deaths patients would not be competent to request and consent to euthanasia as 0,2 % patients falls into the group of children under eighteen years. Prior to death, optimal palliative care should be able to relieve pain in all but 5% of patients. Lastly data from HIV patients in New York indicates that 53% of patients with significant pain consider physician-assisted suicide. In conclusion Emmanuel (1999) wrote that this whole issue undermines the integrity of the medical profession, in his study 25% of physicians regretted physician assisted suicide and voluntary euthanasia.

2.5. THE CARE PROVIDERS' VIEW

Several studies have been conducted in South Africa but more in overseas countries about end of life decisions. In these studies researchers are examining the care providers' or health personnel's' views of euthanasia. In some studies it emerges that there is a difference between what is practiced and what is accepted by the law. It seems like, the legal aspect of euthanasia is problematic, as no clear guidelines are available. Tshukutsoane (2000) in Baragwanath hospital in South Africa conducted a survey on nurses to assess how critical care staff perceived withdrawal and withholding of life support, to evaluate the involvement in the decision-making process, and to find solutions

to improve this process. It was concluded that involvement of all caregivers, especially nurses, is an imperative, and 84% of the respondents wanted societal guidelines about end of life decisions.

It seems like the controversy is also evident in overseas countries. Wlody (1997) cited Stevens and Hassans, (1994) research done in Europe, Australia and New Zealand. They administered an instrument to a sample of nurses. Five hundred registered nurses participated in a quantitative study. The purpose was to examine the attitudes and practices of nurses towards the management of death and dying, and euthanasia. According to the findings, 47% of respondents had received request from patients to hasten death by withdrawing treatment. Requests from patients for active euthanasia was received by 37% of nurses. According to Stevens and Hassans, (1994) as cited by Wlody,(1997) 'persistent and unrelievable pain' was the main reason for such requests. About 19% nurses had taken active steps that brought about the death of a patient. Of all the nurses in the study, 82% thought that guidelines for withholding and withdrawal of treatment should be established. Other nurses (60%) were in favor of legalizing of active euthanasia under certain conditions or circumstances.

Wlody, (1997) has studied health personnel (doctors and nurses) from five United States hospitals, surveying their professional views on life sustaining treatment. Almost 47% of all respondents and 70% of the doctors reported that they had acted against their consciences in providing care to the terminally ill patients. In this study it was concluded

that many physicians and nurses were disturbed by the degree to which technological solutions influence care during the final days of a terminal illness and by the under-treatment of pain.

Some factors like cultural issues, and personal attitudes are seen to have an influence in end of life issues. Ekblad, Martilla, and Emilson (2000) conducted a qualitative focus group study in Stockholm on nurses. The purpose was to gather reflections about cultural issues among hospice staff after a seminar in multicultural end of life care. The main finding was to better understand other culture as being important to raise awareness about staff's own culture. It was discovered that open communication is important for cultural awareness and sensitivity. Another study was conducted in Japan by Okuno, Tamura, Tagaya, and Davis (1999) to investigate factors that influenced decision-making in end of life issues. The result of this survey showed that traditional values and group belonging influenced decision-making about end of life in elderly people.

In some cases the care providers' personal attitudes and views interfered with practices in end of life care. Pierce (1999) interviewed nurses and doctors in the United States, who were practicing in the field of oncology. This study dealt with issues associated with the care of dying persons, how health personnel integrated their perspective of science and data with their perspective on persons and personal goals, and how these issues affected the vigor with which they treated terminal patients. The influence of personal views is highlighted in the study by Norberg and Soderberg (1993). They did a phenomenological study in Sweden on nurses and physicians. The aim of the study was the analysis of stories about people in ethically difficult care situations. This analysis involved action

ethics and relationships ethics. They asserted that people could reflect on their choices of action on the effect of their action, and on their relationships to other people. In this study both nurses and doctors commented on too much treatment. Nurses were particularly concerned about problems related to patients and family's wishes, while physicians perceived problems related to quality of life and economic factors.

2.6. THE LEGAL PERSPECTIVE

As laws have evolved, certain forms of euthanasia have been legally accepted like passive euthanasia. In 1999 the USA state of Oregon enacted a law allowing physicians actively to assist patients who wish to end their lives, including assisted suicide, (Beauchamp, 2000).

In South Africa, end of life decisions have been drafted as a bill “ to regulate end of life decisions and to provide for matters incidental thereto “(South African Law Commission, 1996, p78). In chapter three of the bill it is stated that a mentally competent person may refuse treatment. The person must be above the age of eighteen years and of sound mind, competent to refuse any life sustaining medical treatment or the continuation of such treatment with regard to any specific illness from which he or she may be suffering. It should be clear to the medical practitioner under whose care the person who is refusing treatment, that the refusal is based on a free and carefully considered decision, exercising his or her own free will (The South African Law Commission, 1996). The medical practitioner shall give effect to such a person's refusal even though it may cause the death or hastening of the death of such a person. The South African Law Commission (1996)

further states that no medical practitioner is obliged to give effect to a request to assist with the termination of the patient's life. A person who is above the age of eighteen, and of sound mind shall be competent to issue a written directive declaring that if he or she ever suffers from a terminal illness and would as a result be unable to make or communicate decisions concerning his or her medical treatment or its cessation, any medical treatment which he or she may receive should be discontinued and that only palliative care should be administered. This is stated in chapter four of the bill as a directive to the treatment of a terminally ill person.

On the issue of assisted suicide Griffiths, (1999) refers to the elements of the Suicide Act, (1961), section 2. It is stated that: " a person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction, on indictment to imprisonment for a term not exceeding fourteen years..." (Griffiths, 1999, p56).

2.7. THE MEDICAL PERSPECTIVE

Mc Cormack (1998) argues about the doctrine of acts and omissions, stating that it is not legal for a doctor to kill his or her patient, but it is sometimes permissible to allow patients to die. In medical ethics, killing is clearly rejected, but in some instances withholding of treatment in the full knowledge that the omission would probably result in an earlier death than would be the case if treatment were given, is accepted. The American Medical Association (1985) statement as written by Rachels (1986) gives the following guidelines on terminal illness: "The social commitment of the physician is to

prolong life and relieve suffering. For humane reasons with informed consent a physician may do what is medically indicated to alleviate severe pain, or cease or omit treatment to let a terminally ill patient die, but he or she should not intentionally cause death”

(Rachels, 1985 pg. 102).

The South African Medical Association (1999, 2001) has stated that “it is with regret that issue of active and voluntary euthanasia remain unresolved, however the commission is aware”. “ Proposed legislation for euthanasia should be put on hold” (South African Medical Association, 1999, 2001, pg 1).

Beuchamp, (2000) wrote that the opponents of voluntary active euthanasia emphasizes that health care providers have a professional obligation that prohibits killing. These opponents maintain that active euthanasia is inconsistent with the roles of nursing, care giving, and healing. Opponents also argue that permitting physicians to engage in active euthanasia creates an intolerable risk of abuse and misuse of power over life and death. They also argue that sanctioning the practice of killing would on balance, cause more harm than benefit.

2.8. THE RELIGIOUS PERSPECTIVE

Rachels (1986) wrote that euthanasia is not permissible simply because God forbids it. The sixth commandment ‘thou shall not kill’ is taken as a directive or condemnation of the practice of killing or euthanasia. The second theological argument starts from the principle that ‘the life of a man is solely under the dominion of God’ it is for God alone

to decide when a person shall live and when he or she shall die; we have no right to play God and take such decisions unto ourselves. So euthanasia is forbidden, (Rachels, 1986). The last religious argument is based on the idea that suffering is part of God's plan for us. God has ordained that people should suffer; He never intended that life should be continually pleasurable (Rachels, 1986).

Oosthuizen, Shapiro and Strauss (1978) wrote that the Roman Catholic Church is in favor of passive euthanasia. In Roman Catholic teachings they affirm that it is wrong to seek to prolong life, when all the medical evidence points to the fact that the death process is well established. Kjellstrand and Dosseter (1992) cite the Vatican statement from the New Testament where Jesus voluntarily chose a path to early death entailing much suffering, but who overcame death to be with his father. The Protestant view is similar to the Catholic view. The Islamic view of euthanasia is also cited by Kjellstrand and Dosseter (1992) as follows " The holy book, the Quran and the law, or Shari 'a, form the basis for all behavior. Man is a divine vicegerent or deputy here and now, and the preservation, conduct and enhancement of life on earth are paramount. Hence abortion is restricted and suicide and euthanasia are completely forbidden. The time of death is dependent on the will of Allah and man has no right to terminate life except for judicial reasons" (Kjellstrand and Dosseter, 1992, pg 44). Therefore, even with the most remote possibility of recovery continuation of life support remains justified in Islamic thought. Hindus clearly disapprove of euthanasia. It is clearly stated that the soul has to undergo all pleasures and pains allotted to the body in which it resides (Oosthuizen, Shapiro and Strauss, 1978).

2.9. THE CULTURAL PERSPECTIVE

Ekblad, et al (2000) stated that, “death and disease are inevitably understood within a complex web of cultural meaning” (Ekblad, et al, 2000, pg624).

Kjellstrand and Dosseter (1992) wrote that there are great differences between different regions in the incidence of stopping treatment. In Michigan it was discovered that stopping treatment was twice as common among whites as among blacks. About 5% of Japanese patients below the age of thirty end their lives by terminating therapy. These were the result of a study conducted on chronic renal patients on dialysis (Kjellstrand and Dosseter, 1992).

Okuno Tagaya, Tamura and Davis (1999) conducted a study in Japan, to determine the strength of cultural values in end of life issues. The result demonstrated that there is a strong tendency to adhere to cultural values. The oldest cultural value stressed was group cohesion, which emphasizes an obligation to one another, more especially in times of illness. The distinction of what is culturally defined, influences concepts of family privacy and places boundaries on the norms of socially acceptable care giving.

There is another cultural value, which makes writing of a living will unnecessary, because it stresses leaving every decision to your family (Okuno, et al, 1999).

In another study conducted in Stockholm by Ekblad, Marttila and Emilson (2000), the qualitative focus group was used to gather reflections about cultural issues among

hospice staff nursing patients from a multitude of cultural backgrounds. It was concluded that cultural sensitivity is important in end of life care. Leininger (1977) has been cited by Ekblad et al (2000) as stating that common patterns of behavior and communication exist within a given culture, but variances exist, based on the degree of integration with the mainstream culture. In end of life care, the category of difference is cultural variation. Generalization about any ethnic group or cultural group cannot be expected to be true for all group members.

TABLE 2.1.

<u>BASES FOR DECISIONS</u>	<u>SUPPORT FOR DECISIONS</u>	<u>CONSEQUENCES</u>
<u>Right based ethics</u> <ul style="list-style-type: none"> • Autonomy • Self determination 	Level of knowledge Current medical status Mental status	Informed decision making Freedom of decision making
<u>The value based ethics</u> <ul style="list-style-type: none"> • Self assertiveness • Right to know the truth • The right to respect 	Professional advice Religious beliefs Financial status Culture family support ordinary and extra ordinary care	Support for rational choices Respect for patient's rights

2.10. A CONCEPTUAL MODEL

The conceptual model was created by the researcher using different theoretical perspectives. The aim was to clarify the relationship between ethics, which forms the base for decisions, and factors influencing an individual's decision-making. Consequences of decision-making lie in the background of ethics and the factors influencing an individual's choices. The researcher intends to use this conceptual model to analyze the data gathered from the participants of this study.

This conceptual model will act as a theoretical starting point for this study. Ethical models are used to create a base for decision making for participants of this study. Right-based ethics look at patient's autonomy in decision-making as an act of self-determination (Bandman and Bandman, 1985). Kjellstrand and Dosseter (1992) state that individuals require only themselves in order to refuse treatment with moral authority. Individuals require agreement, commitment, or common moral understanding shared with others in order to choose treatment with moral right. The right to refuse treatment is in contrast a forbearance right, justified in the core of the secular morality that binds every persons (Kjellstrand and Dosseter, 1992).

The value -based ethics were used in this model to argue against the point that a patient could loose his autonomy in decision-making because of illness. Jacob (1994) wrote that in the value based ethics they reject the idea that "biological, psychological or social forces limit a person's freedom to decide, on the grounds that a person can perceive or comprehend alternative courses of action" (Jacob, 1994, pg299). Therefore the

responsibility for decision-making should be given to patients with support of adequate information.

The deontological perspective of the value-based ethics developed by Kant (1724-1804) was cited by Holloway and Wheeler (1996). They investigated whether humans have free will. Kant then developed a moral law, which states that no person should be treated merely as a means but as an end. This means that a person's freedom of choice should be recognized. Ethical decisions are based on a belief in this moral law (Holloway and Wheeler, 1996). The relevancy of these ethical models to this study arise from the fact that they all address individual's right to decision-making and self-determination.

Ethical bases will be strengthened by support, which looks into factors that influence the patient's decision-making in end of life issues. These factors can be divided into professional support, family support and personal values like religion and culture. Professional support deals with the obligation by the health personal to give adequate information about the patient's condition and quality of life and options of treatment. Patients need to know the difference between ordinary and extraordinary treatment. This advice should include information about the existing legal, ethical and medical perspectives on the end of life issue, so that patients are aware of their rights. Family support and the issue of religion and cultural factors might play a role in a patient's decision-making. Financial status might influence the health team and the family's decision-making. Personal issues are considered, like the level of education of the patient in understanding the information received and using it to decide on his life. The mental

status of the patient is important in determining whether the capacity for decision-making is legally sufficient. The patient should be helped to overcome any personal conflict that might be experienced. Thereafter the patient is expected to reach a decision, which should be voluntary, well informed, and supported. It should be the rational choice of the patient so that there are no guilt feelings thereafter (Holloway and Wheeler, 1996).

2.11. CONCLUSION

In this chapter the researcher has described the studies that address the issue of euthanasia and physician assisted suicide, factors surrounding them like moral conflict, substitute decision making and problems associated with end of life decisions. Important aspect of decision-making like, the legality, cultural, religious, and ethical issues have been inspected for their influence in end of life care. The relevancy of this chapter emerges when the researcher analyses the data obtained in this study. The conceptual model will be useful when the researcher is analyzing data. The researcher will make a comparison of the results obtained with those of the studies that have already been conducted. The researcher has included a lot of philosophical ideology in discussing this chapter. In the next chapter the researcher discusses the methodology used in the study.

Chapter 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

This chapter gives an overview of the methodology that was used in this study. It covers the approach, the study design, population studied, sampling procedures, data collecting technique and analysis. The ethical aspect is discussed towards the end, then lastly the discussion of the credibility and confirmability of this study are discussed.

3.2 THE APPROACH

The qualitative approach was used in this study. Thomas (1990) described this approach as “consisting of information derived from communication or observation of behavior. It focuses on human perception, beliefs, attitude, and experience of participants” (Thomas, 1990, p 18). Munhall (1998) has cited Benoliel, (1984) describing the qualitative approach as “modes of systematic inquiry concerned with understanding human beings and the nature of their transaction with themselves and with their surroundings” (Munhall, 1998, p27). Wilson (1985) described this approach as “a science of distinct modes of inquiry oriented towards understanding the unique nature of human thoughts, behaviors, negotiations and institutions under different sets of historical and environmental circumstances”(Wilson, 1985, p59).

In this study the aim is to gather individual’s attitudes, that can only be revealed when an in-depth analysis of a person’s feelings are obtained from a detailed interview.

The researcher has chosen the qualitative approach because it is appropriate for the in-depth mode of inquiry.

3.3. THE STUDY DESIGN

A qualitative descriptive design was chosen for the study. In this design the researcher adopted a person centered and holistic perspective. Mouton (1998) wrote that a descriptive design includes data, facts, empirical generalizations, narratives and stories, and provides truthful descriptions of phenomena in the world. In this design, the researcher developed an understanding of human experiences, which is important for focusing on caring, communication and interaction. This facilitated gaining of rich information and insight into human beings. This method focuses on human beings within their social and cultural context (Holloway and Wheeler, 1996).

This approach was chosen because it facilitated an exploration of the knowledge, attitudes and awareness of participants regarding the research topic. The knowledge of participants was gathered and analyzed according to this design's specificity.

3.4. POPULATION STUDIED

Population can be described as the entire individuals or elements that meet a study's sampling criteria (Burns and Grove, 1997). In this study, the population was the patients who were in the step down unit from the intensive care unit, with life threatening conditions. Five patients were studied. From a total of seven patients discharged from the intensive care unit, these patients were chosen because they had experienced great pain

and suffering. They had been through the intensive care unit and undergone extraordinary treatment, like artificial ventilation, invasive monitoring and or dialysis. They might even be faced with readmission to the intensive care unit. The above category of patients was compared to five patients who were outpatients suffering from minor ailments, who had never been admitted to the intensive care unit. These participants were chosen from a total of approximately eighty-five patients seen per day in casualty. They were chosen on the bases of consenting to participate in the study after receiving an explanation about the study from the researcher.

3.5. SAMPLING PROCEDURES

To select patients as participants, purposeful sampling was employed. In this sampling method, the selection of units is based on a previously specified purpose (Holloway and Wheeler, 1996). Burns and Groves (1997, p366) wrote that “it involves the conscious selection by the researcher of certain subjects or elements to include in the study”. In this study the selection of participants was conducted as follows:

The post intensive care unit criteria to be included in the study were admission for more than two weeks in the intensive care unit, with a life threatening condition, an experience of great pain and suffering, and medical treatment with extraordinary means as defined in the study.

The pre intensive care unit criteria were an experience of illness, no previous admission to the intensive care unit and being an outpatient. The age range of the sample is 26 to 52 years.

The qualitative approach necessitates in-depth interviewing. For this reason the researcher has chosen a sample of ten participants, as shown in table 3.1 in page twenty nine. This small sample would prevent gathering of too extensive data, which will be difficult to analyze. The researcher has included an equal amount of inpatients and outpatients in this sample. The aim was to identify whether an experience of serious illness and admission to the intensive care unit as opposed to no admission and minor ailment, has any influence in individual's attitudes concerning end of life care.

3.6. RESEARCH SETTING

This research was carried out in King Edward Hospital, which is situated in the Durban metropolitan area. This hospital caters for the above-mentioned category of patients (in sampling procedures); furthermore it is an academic hospital, attached to a medical school. The intensive care unit of this hospital has fifteen beds. Patients are often treated with extraordinary means, like ventilators. The out patient department of this hospital treats a total of approximately eighty-five patients per day. In this section clients with minor ailments and injuries, surgical problems, and emergencies are seen.

3.7. DATA COLLECTION PROCEDURES

An interview using the semi-structured method was used. Miller and Crabtree (1997) describe the semi-structured interview as a guided, concentrated, focused, and open-ended communication of events that are co-created by the researcher and the interviewees and occur outside the stream of everyday life. The questions, probes and prompts are

written in the form of a flexible interview guide. An interview guide that focused on issues to be covered also directed this study. Sequencing of questions was not the same for all the participants, as each interview was allowed to follow its individual process (Holloway and Wheeler, 1996). Pseudonyms were used to identify each taped interview from individual participants.

Interviews were collected from the third day after transfer out from intensive care unit, when the patient's state of mind was clear from sedation. Interviews lasted from thirty to forty five minutes. The interval of the interviews was alternate days, before patients were discharged. Data was collected from at least two or three interviews. The first interview was conducted to explain the purpose of the study and to obtain permission to participate in the study. The researcher targeted only patients who met the criteria to be included in this study as described in the sampling procedures. The consecutive interviews were suited to the participants state of health such that for post intensive care participants, the need not to exhaust the patient required interviews to be broken into three sessions.

For outpatients, interviews were conducted on a weekly basis, until data saturation was reached. For each participant two to three interviews were adequate for data saturation. The set time was the same as for the above category of patients. Tape recording was used to collect data, so that it was captured verbatim, Some of the data pertaining to the health status of the patient, was collected from medical records, by writing of notes.

TABLE 3.1. SAMPLE REALIZATION

Cases	Age	Occupation	Education	Admission	Criteria	Religion
1	43	Taxi driver	Std8	Never	Outpatient	Christian
2	27	Casual	Matric	Never	Outpatient	Christian
3	28	Marketing	Diploma	Never	Outpatient	Christian
4	52	Unemployed	Std7	Never	Outpatient	Christian
5	27	Hawker	Matric	Never	Outpatient	N/a
6	46	Pensioner	Illiterate	Yes	Inpatient	N/a
7	29	Administrator	Diploma	Yes	Inpatient	Christian
8	36	Worker	Std8	Yes	Inpatient	Christian
9	27	Unemployed	Std9	Yes	Inpatient	Christian
10	26	Student	Matric	Yes	Inpatient	Christian

3.8. DATA ANALYSIS

Holloway and Wheeler describe analysis as “ the processing of data by coding, transforming it from raw data by recognizing patterns and themes and making linkages between ideas” (Holloway and Wheeler, 1996, p152).

Wilson, (1985, p235) states, “analysis is the separation of data into parts for the purpose of answering a researcher question and communicating that answer to others. In qualitative analysis the numerical organization and interpretation of data is carried out, in order to discover patterns, themes, forms and qualities found in field notes, interview

transcripts, open-ended questionnaires, journals, diaries, documents, case studies, and the likes. This process allows for the discovery of shared themes across participants but also a search for natural variations in the data” (Wilson, 1985 pg. 28).

The NVIVO software, which uses computerized categorization of the data, was used. The researcher consulted a statistician to aid with the coding of the data using the NVIVO software program. Using the conceptual model the researcher formulated categories of the data. The researcher attempted to become immersed with the data by listening to tapes and transcribing the tapes from Zulu to English, under the guidance of the researcher’s supervisor. Interpretations involve making sense of the data “the lesson learned” as it is described by Lincoln and Guba (1985) cited by Creswell (1997).

3.9. ETHICAL CONSIDERATIONS

Permission was sought in writing from the deputy director of nursing services in KwaZulu – Natal, the hospital authorities, and heads of departments where the study was carried out.

The researcher obtained informed verbal consent voluntarily, observing the principle of respect for patient’s autonomy (Holloway and Wheeler, 1996). Participants were made aware of research benefits. No major risks were involved. They were informed of their right to withdraw from the study should they wish to do so. Anonymity was maintained in the study by not revealing participant’s identities in addition, any information that might reveal their identities or was deemed by them to be threatening was not revealed.

Confidentiality was maintained during interviews by providing privacy and showing sensitivity. The participants were assured that information collected would be kept confidential, and would be used for research purposes, for the study only and no names would be attached to it. Pseudonyms were used for identifying the tapes.

3.10. THE ASPECT OF CREDIBILITY AND CONFIRMABILITY

To establish credibility, interviews with respondents were repeated at an average of two to three interviews per participant, to check for consistency of the responses. Data triangulation was used in this study, when the researcher developed a conceptual model using different theories. The combining of different ethical theories, to describe the same theoretical point of view, adds to the credibility of the study. Campbell and associates (1956) were cited by Burns and Groves (1997) describing triangulation as “ a term used in surveying and navigation to describe a technique whereby two known or visible points are used to plot the location of a third point. It was first used as a metaphor to characterize the use of multiple methods to measure a single construct, a practice also referred to as multiple operationism, it is used for mutual confirmation” (Burns and Groves, 1997, p297). Fielding and Fielding (1986) were cited by Morse (1989) as advocating “the combining of multiple theories and methods in a single study, in order to add to the investigators’ depth and breadth of understanding. The important feature of triangulation is not the simple combination of different kinds of data, but the attempt to relate them so as to counteract the threats to validity, identified in each” (Morse, 1989, 213). To add to the study’s confirmability, the researcher used two groups as data sources, the inpatients and outpatients.

The researcher eliminated bias by describing her point of view in the appendix, under bracketing. Exposing the researcher's opinion was purposely done to constantly check that it does not affect data collection and analysis; this was also verified with the researcher's supervisor. Burns and Groves (1997, p98) describe bracketing as "suspending or laying aside what is known about the experience being studied".

To strengthen the truth value of the study the researcher employed the assistance of an independent researcher, to assess and monitor data coding using NVIVO software. Throughout the study the researcher member checking was employed by the researcher, using fellow researcher to check data gathered and to monitor and assist with translation from Zulu to English. This research was also monitored and checked by the researchers' supervisors. All this was done to ensure neutrality and objectivity of the study

3.11. CONCLUSION

This chapter gives an overall plan of the investigative method that was used to tackle the research problem. The main focus was extensive explanation of the research methodology used in the study. In the next chapter the researcher will present the data analysis.

CHAPTER 4

PRESENTATION OF THE FINDINGS

4.1. INTRODUCTION

In this chapter, the researcher starts by coding the data using the NVIVO program for open coding, transforming it from raw data by creating nodes and identifying themes and finally linking all emerging ideas. The conceptual model is used to develop categories and discover meaningful themes within the categories of data.

4.2 AWARENESS OF PATIENT'S RIGHTS

Awareness is a fundamental concept when decisions about treatment choices have to be made. Patients need to know their rights in order to be able to utilize them. Under this heading, the researcher explored whether patients were aware of their rights and used them accordingly. The researcher will proceed to analyze the right-based ethics and value based ethics.

4.2.1. The right based ethics/ patient's rights

The rights considered under this heading were autonomy, and informed consent which was discussed in support of autonomy. Assertiveness, as the right to self-determination, has also been discussed. Under assertiveness, the category of the level of awareness about health matters was explored.

- **Autonomy in decision making**

In this study the researcher seeks to identify whether autonomy, which is a basic patient right, is being utilized, and whether patients are aware of this right. Data was collected from the participants to explore autonomy in relation to decision-making in end of life issues. The researcher determined whether patients received adequate information prior to life support. . All respondents identified the importance of adequate information and being involved in the decision making, but inpatients respondents stated that they received very little to no information at all prior to life support. They were excluded from the plan of care by the health team. The response of one participant, who was an inpatient and never fully understood what was going on, can be quoted as an example:

The only procedure that was explained to me was the washing of my kidneys. No one discussed anything about complications and even now, I do not know how I ended on a breathing machine, because no one told me anything about that even after that treatment.

All respondents identified the need for adequate information in order to be able to make end of life decisions. Participants indicated that information dissemination in hospital was very inadequate.

Another aspect of autonomy is obtaining an informed consent prior to treatment, and that was also looked into.

- **Informed consent**

The researcher explored the category of obtaining consent prior to treatment with life support. On this aspect the researcher wanted to identify whether the health care team

was expected by the participant to receive a verbal consent from the patient or proxy (spouse or family member) before initiating treatment. Most respondents indicated that doctors should use their own discretion when they have to initiate life support. The reasons given for that response were that they felt that they were ignorant about health matters, and that they trusted that doctors would always act for the good of the patient. This is illustrated by following response:

Doctors are intelligent people and they know more about health issues than us ordinary people, therefore we should put our trust in their judgment and let them do things according to their discretion.

Some respondents indicated that they were restricted in their communication with the doctors because of the language barrier problem as well as fear of not being given other options of treatment and hence being refused treatment. Two respondents felt that before the health team initiated treatment it was important that they got the patient's consent, as no one, especially in the family, should be given that right. This respondent is quoted as follows:

I think that doctors and nurses should first ask a person whether he or she agrees to being put into those machines, more especially if a person might end up having problems afterwards.

Whilst these respondents wanted sole involvement in decision-making in end of life care, the other respondents felt that the family could give the verbal consent when patient was unconscious, as this quote illustrates:

The patient is the most reliable person to give life support decisions, but if unable to do so the family can make that decision.

The reason that was given for involving the family was that a patient belongs to the family so it is expected that family members would naturally be involved. Another reason given was that, if the capacity to decide is lost, the anxiety experienced by the family will be reduced if they are part of the treatment planning.

- **Assertiveness with regards to rights**

Assertiveness is part of the right to self-determination, where the courage of the patient to question and utilize his rights is observed. Under this heading, two categories were explored, is the level of awareness about health matters and the capacity for decision-making.

- **Level of awareness about health matters**

The researcher used the categories of awareness about the living will and life support, to determine the level of awareness of the participants that would give them assertiveness for deciding on treatment choices.

- Living will

On the aspect of the living will, the majority of the patient had no awareness of the existence of the living will. A few respondents differed. Of those who differed, some knew about it from previous experience as expressed in this response:

“I have heard about it, I do not think it is a fair thing to make, considering your family in all the decisions you make is important. I know of a case that a person made a living will with his partner as a witness, that caused a dispute in the family, therefore living wills are not a good idea”.

The remaining respondent felt strongly that something like it should exist, as can be illustrated in this response

“, As I speak I have already informed my family that when I reach the terminal stage of being of illness they should not take me to hospital, that will just be wasting money, and I think it is important that a person should die amongst people who love him or her”.

Care covered in the living will is extra ordinary care. The researcher saw that it was necessary to cover that aspect as well.

-Ordinary and extraordinary care

For the participants to be able to make the choice of treatment, the researcher needed to know whether they knew the difference between ordinary and extraordinary care.

The majority of the respondents did not know the difference. Reason given for not knowing was poor understanding of health matters. The remainder of the respondents knew about this difference, because of personal experience.

-Life support

On the aspect of life support, the inpatients had awareness because of personal experience.

Some of the inpatients stated that they had a very vague recollection of being on life support because they were kept on sedation into the intensive care unit. On the outpatients, one respondent knew because her mother was admitted in ICU in the past and she died there. The other remaining outpatients had some awareness from general conversations. One said she knew of it from reading articles, others had visited people who were admitted into the ICU.

The level of awareness of the respondents about health matters ranged from very vague to personal experience.

- **The capacity for decision making**

The researcher explored this category of capacity for decision-making by looking into two aspects, the level of consciousness or mental status, and substitute decision-making by family.

-Mental status

The mental status was chosen by the researcher in order to identify whether participants thought it would limit the capacity for decision-making. Participants were asked whether they associated the mental state, or unconsciousness, or being sedated with not being able to make end of life decisions. All respondents agreed that not being fully mentally alert did affect the capacity for decision-making, as illustrated by this quotation:

It is obvious that once you are unconscious you cannot talk, therefore decision-making becomes impossible.

The researcher explored other available options, once the mental status was affected.

-Substitute decision- making

In this category the researcher explored familiarity of respondents with the involvement of the family members as substitutes for decision-making. The researcher assessed whether participants would express that, in the case of unconsciousness during admission, family members could take the responsibility for decision-making. Different responses were obtained.

Some respondents felt that families must not be involved in this aspect of decision-making. The reasons given were that it would cause too much guilt when the patient died. Others thought that it would cause family dispute. For example, the family could be divided with some wanting treatment to be continued and others wanting it to be stopped. Another reason was that family members would make decisions for personal reasons like finance either greed for inheritance or a perception of futile waste. These participants were worried that substitute decision- making would not consider the benefit of the patient. The majority of respondents were in favor of involving the family. They said that the family was the next best option to decide, once the patient had lost the capacity for decision -making. Therefore the majority was in favor of involving the family.

- Dependence vs. level of knowledge

To examine this relationship the researcher examined the result of the decision-making capacity, which was explored in the categories of consent to initiation of life support. In

this category it was noted that the majority of respondents felt incapable of deciding, and preferred that doctors should decide for them. With consent to initiation of life support most respondents could not decide. For each respondent who showed dependence on the doctors, the educational status was taken into consideration and a comparison was made. It was noted that of these respondents, some had tertiary education, one had standard ten and the remaining, only a few were below standard ten. It was thus established that dependence on doctors for decision making was not related to the educational status of the respondents.

The researcher then went on to check if any relationship existed between family involvement and the experience of being very sick

-Family support vs. experience of the severity of illness

This relationship was checked because inpatients and outpatients had a different experience of being sick, so the researcher felt that it was important to check if their views on involving the family would be any different. In this aspect the researcher compared the responses of inpatients and outpatient on the category of substitute decision making. Most of the respondents favored family involvement, both the in-patient and out patient. In other words the severity of illness was not seen to influence the need to involve the family in decision-making, in this study.

4.2.2. Value based ethics

Under this heading the issues of religion and culture, which are thought to influence decision making, were looked into.

- **Religion**

It appeared that religion had some influence in making end of life decisions, as can be illustrated by the following quotation:

People should trust God in every situation they encounter, because He alone never fails even if man does at times, giving up is never a good idea so no matter how sick you are you must never stop praying and believing that your prayers will be answered.

Most respondents used religion for different purposes. It was clear to the researcher that religion was used to support decision-making. One respondent supported withdrawal of treatment with religion, as illustrated in this statement :

God never intended for people to be kept alive by machines.

Yet in opposition to withdrawal of treatment one respondent used religion. To support treatment continuation, some respondents used religion. On withholding of treatment, religion was used by another respondent. The other respondents used religion to oppose physician- assisted suicide.

The remaining respondents thought that religion was not relevant to decision making in end of life issues.

- **Culture**

The researcher chose this category because it was thought to be a strong base for a patients value system. Only one respondent used culture to support his views on physician-assisted suicide as is illustrated in this quotation:

In the olden days when a person was known to be terminally ill he or she would request that a cow be slaughtered and its liver be fed to him or her, or smell it if unable to eat, and death will immediately occur thereafter. I suppose requesting to be put to death by injections is the modern version of that tradition.

The other respondents did not refer to culture in the discussions.

4.3. ATTITUDES TOWARDS END OF LIFE DECISIONS

In this study the aim was to establish attitude of participants towards decision making in end of life issues. The researcher thought that values were the basis for the formation of attitudes.

4.3.1 Attitude towards withholding of life support

The researcher explored this category in order to determine how participants viewed this aspect of decision-making. The researcher assessed whether patients thought it was necessary to initiate treatment on a person who was known to be dying or who would have poor quality of life post life support. The majority of them were against withholding of treatment, as they saw that as denying patients a basic right to treatment. This is illustrated by this statement:

Everyone must receive treatment no matter what illness he or she is suffering from. Terminally ill patients with AIDS or cancer must be given every kind of treatment available because no one knows for sure when they will die, except GOD, therefore they too have a right to treatment.

Other respondents were in favor of withholding treatment as they saw no need to over-treat patients unnecessarily. This attitude is illustrated by this statement:

Initiating life support on patients who are known to be dying like AIDS cases is not a very good idea, that only serve to prolong the persons suffering unnecessarily, if I could be in that situation I would request doctors to give me an injection that will quickly end my life and suffering.

4.3.2 Attitude towards withdrawing treatment

The researcher determined attitudes towards withdrawal of life support, by assessing the responses. Half of the respondents, felt that it was better to leave that decision to the doctors because they know better, as illustrated by this statement :*“In such cases the health team should make a decision according to their knowledge whether it is better to disconnect life support and let a person rest in peace.*

A few respondents were in favor of treatment withdrawal. The reasons given for their responses were that it was pointless to continue with life support when it is obviously futile. This response illustrates this point of view:

A person cannot survive on machines forever, God never intended for a person to be kept alive by machines, but for a family to agree to termination of life support may cause intense guilt feelings, when the patient is dead.

One respondent said that medical bills would escalate unnecessarily, when no positive outcome was expected. A few others were totally against withdrawal of treatment, they felt that nature should be left to take its course.

4.3.3. Religion vs. attitude towards treatment termination

The researcher assessed if any relationship existed between religion and the attitude towards termination of treatment. For termination of treatment, the categories of withdrawal of treatment were explored for each respondent. This category was chosen because most respondents justified answers to it with religion.

It was noted that religion was used on more than one occasion to justify reasons for treatment choices. On the category of withdrawal of treatment the majority of the respondents used religion to justify their treatment choices. It was established that religion might influence the attitude towards termination of treatment

4.3.4. Attitude towards financial status

The researcher assessed whether respondents thought it was necessary to consider an individual's financial status before initiating and withdrawing treatment. Only a few respondents thought that money was a very good reason for not initiating treatment and also for withdrawing treatment. One respondent thought that it was wise to save whatever money was left for the family especially the children, rather than wasting it on treatment when death was inevitable. The other participant's reasoning was based on previous experience. She saw that her mother was maintained on life support for a long time, when it was known that there was no chance of recovery. At the end of the day the family had to pay a huge bill, which was made even more painful by the fact that her mother died in the end. She strongly felt that it is very important to consider the financial status of the family, to avoid exposing the family to more suffering when they would be unable to settle the debt of hospital bills. This response illustrates this view:

Patients should be given a chance to decide with the family whether to be given life support or not because in the end tax payer's money is wasted unnecessarily.

Most respondents felt that it would be very unfair to consider money as an important deciding factor on continuation of treatment. They cited reasons such as life had more value than money. One even said that if money was all that important, then only the rich would benefit on life support, the poor would be left to die. Generally the idea of equating money to a patient's life bothered participants as is illustrated in these response:

That is definitely a very poor excuse for not treating a patient, our nation will be destroyed unlawfully if people should be taken out of life support when funds are exhausted.

4.3.5. Attitude towards physician- assisted suicide

The researcher assessed the participants' responses towards physician- assisted suicide, to determine their attitude. Of all the respondents, very few were totally in favor of physician- assisted suicide and they justified it by the need not to prolong suffering. The remaining majority respondents were not in favor of physician-assisted suicide as it was regarded as killing the patient. Some participants were concerned that this practice might corrupt doctors and lead to abuse of their powers over vulnerable patients. These respondents expressed being more comfortable with doctors as healers, who always promote the well being of patients. The following statement illustrates a participant's response:

That is still unacceptable. If you have a terminal illness, you should accept and treat it like any other illness and persevere because it is still part of life to suffer.

4.3.6. Attitude towards the living will

The researcher explored the category of respondent's attitude towards the living will in order to decide on treatment choices. Of all the respondents, the majority thought that the living will was a good idea. Reasons cited were the fact that it would be carrying out the patient's wishes, prevent conflict amongst the family about who should decide, and prevent unnecessary over-treatment. Some mentioned that it would also protect doctors from being prosecuted for taking decisions alone. Very few respondents were totally against the living will. Reasons given were that it would cause conflict in the family. One respondent actually admitted to lacking the courage to accept death so easily.

4.3.7 The influence of age on attitudes

This relationship was examined by comparing the attribute of the age of each respondent with the category of attitude towards end of life decisions, in relation to physician-assisted suicide and the living will. Age was chosen in order to ascertain whether it has any influence on the readiness to die or the making of end of life decisions. The older respondents, above forty, showed more readiness to accept death, but the younger ones, below thirty, had mixed responses.

4.3.8. Health status vs. readiness for end of life decisions

To examine this relationship, the researcher compared the responses of inpatients and outpatients on the category of attitude towards the living will. Inpatients were known to be exposed to life threatening conditions, as compared to outpatients who were suffering

from minor ailments. For readiness for end of life decisions the examiner looked at the responses of participants on the living will. All outpatients favored the living will and most inpatients had a negative attitude towards the living will. It was noted that this result was also influenced by the amount of insight towards illness, as those individuals who knew the prognosis of their illness considered the living will as a valuable option. The fact that outpatients do not readily experience serious ill health was seen to influence their favorable attitude towards the living will, as death was not viewed as an immediate reality for them. The reality of death impacted differently on inpatients who had experienced the threat of death, hence the mixed feelings.

4.4. CONCLUSION

This chapter began by describing the coding of data, then the researcher concentrated on the main issues of the study, which are patients rights and the values central to decision making. The researcher discussed patient's rights under categories like autonomy in decision-making and assertiveness for making decisions. Personal factors that influence an individual's capacity for decision- making were described. Other issues like finance and the role of the family were investigated for their influence in end of life decisions. The influence of an individual's attitudes in matters concerning end of life issues like withholding and withdrawing of life support has been discussed. Lastly the researcher attempted to establish the existence of relationships between different categories within the study.

In the following chapter the result of the study would be discussed under conclusions that the researcher has drawn from material discussed in this chapter.

CHAPTER 5

DISCUSSION, CONCLUSION, SUMMARY, RECOMMENDATIONS, AND LIMITATIONS

5.1. INTRODUCTION

In this chapter the researcher discusses the results of the study, from the analysis that was done in chapter four. The conclusions that the researcher drew from the data will be compared to the theoretical framework, particularly the studies previously done, that were discussed in chapter two. Recommendations, which are thought to be appropriate for future directions, are made, and lastly the researcher discusses the limitations that were encountered during the study.

5.2. DISCUSSION

The purpose of this study was to seek to explore the level of awareness and knowledge about end of life issues, to determine individual's attitude towards decision making in end of life issues.

To determine the above stated purpose, specific research questions which (appeared in chapter one) were asked here for the reader's convenience:

- What do patients know about end of life issues?
- What are patients' attitudes concerning end of life decisions?
- What are factors that influence patients' decision-making concerning end of life issues?

This chapter is organized into three parts: conclusions recommendations and limitations.

5.3. CONCLUSIONS

The researcher will discuss deductions that were made from the analysis that was done in the previous chapter. Conclusions were drawn from the the data as presented by the study's participants and they were done in consideration of the theoretical aspect of the study. The researcher used the sequence followed in the previous chapter, therefore the same headings are repeated. Starting with right- based ethics, the results gathered under autonomy will be discussed.

5.3.1 Autonomy

From the data, it emerged that participants were not able to exercise their right to decision making. According to the findings, the participants were excluded from the plan of care by the health team. Most respondents reported that no information was given prior to treatment. Lack of information dissemination was the main reason identified. The researcher concluded that the health team members had been using a paternalistic approach, by taking decision-making unto themselves, and not involving the patient.

Mak and Clinton (1999) in their outcomes research concluded that health professionals are required to acknowledge patient's autonomy and to accommodate their wishes by allowing them more control over their dying trajectory, by establishing a partnership in decision-making.

5.3.2. Informed consent

From the data gathered from participants, it was noted that participants were not familiar with patient or family involvement in decision-making about health issues. According to the findings the majority of respondents expected the doctors to use their own discretion and proceed with treatment without obtaining their consent. Another problem that was identified is that language was seen to be a communication barrier, as most doctors are English speaking whereas clients are Zulu speaking. The researcher concluded that health team members did not usually practice the concept of getting an informed consent prior to treatment.

5.3.3 Awareness about the living will

It was observed that the level of awareness about the living will ranged from not knowing about the concept at all or having a vague idea to knowledge from personal experience. The researcher noted that the majority of the respondents, did not know. It was concluded that there is inadequate awareness about the living will. This lack of awareness was taken to limit the ability to make treatment choices. The researcher expected that decision-making should be based on full awareness and professional advice. In a study conducted in Japan by Okuno et al (1999), only four percent of the respondents had awareness of the living will. In another study by Hayden (1999) in Alabama, only 15% of the sample was aware of the living will.

5.3.4 Awareness of ordinary vs. extraordinary care

Responses gathered from the participant led the researcher to notice that the majority (six respondents) could not tell the difference between ordinary and extraordinary care. It was concluded that lack of knowledge in this aspect was hindering the decision-making process.

5.3.5 Awareness about life support

In this category all respondents had awareness about life support from personal and previous experience and general knowledge. The researcher concluded that although respondents knew about life support, knowledge of one aspect was not enough for informed decision-making.

5.3.6 Family involvement vs. experience of severity of illness

When comparing the responses of participants on family involvement and experience of severity of illness, the researcher noted that the number of outpatients and inpatients who wanted family involvement was equal. Therefore being an inpatient or outpatient may mean experiencing the severity of illness differently but it does not affect the need to want family involvement in decision-making.

5.4 VALUE BASED ETHICS

Under this heading the researcher discussed the result obtained from the categories of religion and culture.

5.4.1. Religion

It was noted that religion is a very strong base for respondents' values, and it was used by the majority (eight respondents), to support their responses about end of life matters. These results are supported by those, which were obtained by Mak and Clinton (1999) that Christians and Hindus considered religious beliefs as very important for a good death.

5.4.2. Culture

In the data that was gathered from the responses of the participants, it was noted that only one, referred to culture to support views on decision-making. The researcher concluded that culture had not influenced the decision-making of the respondents on end of life issues. These results are not supported by those of Okuno et al (1999), where cultural values were considered by Japanese people to be the sole most important determinant of decision making in end of life care. In another study by Ekblad et al (2000) it was concluded that cultural sensitivity in end of life care is very important and is promoted by open communication.

5.5. ATTITUDES

The results obtained from the data will be presented according to the sequence followed in the previous chapter, when attitudes were analyzed.

5.5.1. Financial status

In the data analysis it emerged that the majority of respondents were against making the individual's financial status an important consideration when making end of life decisions. It was concluded that respondents valued life more than money.

5.5.2. Withholding of life support

From the responses of participants the researcher gathered that the majority (six respondents) was against withholding of life support . It was noted that even with poor prognosis, they still wanted treatment continuation. The researcher noted that this was a sensitive and controversial issue, as is supported by the result of another study. In a survey conducted by Emmanuel (1999) where the decision not to initiate treatment was regretted by 25% of physician.

5.5.3Withdrawal of treatment

The result from the data showed that five respondents, felt that it should be left to the doctors to decide for them. The researcher concluded that respondents felt incompetent to decide on such a serious health issue, this was attributed to the fact that they were not familiar with being responsible for decision-making. Their reluctance was also seen to be a direct result of lack of knowledge. These result are supported by those obtained by Wlody (1997). In this study 47% nurse respondents had received requests from patients to hasten death by treatment withdrawal.

5.5.4. Physician assisted suicide

The data showed that eight respondents were against physician- assisted suicide.

These results are in contrast with those obtained by Emmanuel, (1999) where fifty tree percent of patient respondents with significant pain, considered physician assisted suicide as a choice of treatment. On the other hand, another study by Young et al (2000), showed that nurse respondents were wary of the potential for abuse.

5.5.5. The living will

The majority of respondents favored the living will, (six out of ten), and stated that if they had a chance they would make the living will. In Hayden's (1999) study fifteen percent participants had made the living wills.

5.5.6. The influence of age on attitudes

The result of the relationship that was examined in the previous chapter, between age and attitude towards end of life decisions, showed that those individuals above the age of forty showed an attitude of readiness to make end of life decisions. The respondents below the age of thirty had mixed responses depending on their insight about their health status. The researcher concluded that age does influence attitudes towards end of life decisions.

5.5.7. Health status vs. readiness for end of life decisions

The result of a comparison between inpatient and outpatients on readiness for end of life as measured by attitude towards the living will, showed that outpatients readily

wanted to make the living will. The researcher concluded that outpatients had not experienced serious ill health and therefore could easily want to make a living will, as death was not viewed as an immediate threat or reality to them. The reality of death impacted differently on inpatients who, had already experienced the threat of death, and did not favor the living will (three out of five).

5.5.8. Summary of the findings

- **Poor communication**

From this study poor communication between the health team and the patients, was identified as the main reason that rendered patients unable to make informed decisions. It was noted that because of lack of adequate knowledge about health matters, personal or patients' wrights, patients were unaware of their autonomy in decision-making. Furthermore the opportunity to make such decisions is not presented to patients.

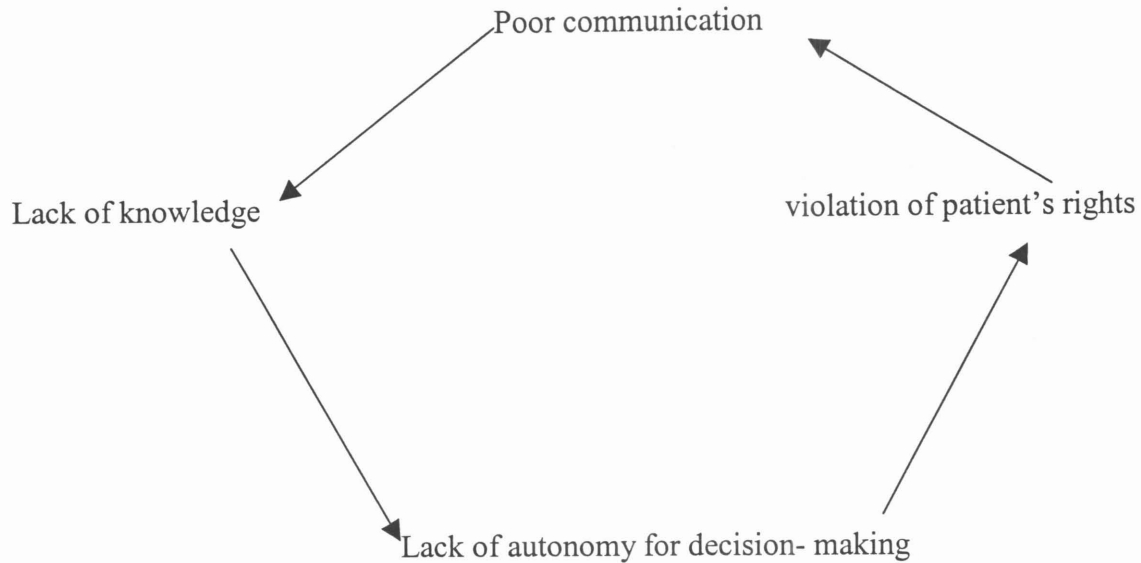
Because of poor communication, the health team does not enquire from the patient about the availability of the living will or discuss proxy decision-making. According to the right-based ethics, promoting patient well-being emphasizes the principle of promoting good and avoiding harm. The patient's choice must include the medically accepted and available option of no further medical intervention, even when that would not be viewed as preferable by the health care providers (Bandman and Bandman, 1985).

- **Lack of knowledge**

The researcher noted that patients are not well informed about health matters, and are therefore unable to realize that there are other treatment options available. For instance it was noted that the majority of patients (six respondents) could not tell the difference between ordinary and extra ordinary care and had no knowledge of the living will. This ignorance leads to lack of autonomy for decision-making, according to Bandman and Bandman (1985), the principle of autonomy has become even more important in this era of technological revolution. The question has moved from acceptance or rejection of a single intervention for a specific condition to the more complex question of which intervention to choose. This complexity has redefined the role of health care givers, as patients expect to maintain control for decision-making about their lives and health status in the light of their values and goals and health (Bandman and Bandman, (1985). For instance, the option of substitute decision-making is never discussed with patients. According to the results of this study, most participants would prefer that, when they are unconscious, their family members be involved in the decision-making process about the end of their life.

- The following causal links become clear from the result:

TABLE 5.1



- **Dependence on the health team**

The health team reinforces this dependence, which is shown by patients. It emerges from the data that when participants were asked to make decisions about withdrawal or withholding of treatment, most felt that the decision should lie with the health team, as they were authorities on the subject of health. It is concluded that this attitude results from lack of knowledge. The health team reinforces this attitude of helplessness by neither informing the decision –making process nor involving the patients in this matter. A paternalistic attitude, which views patients as ignorant is demonstrated by the health team, by taking away the responsibility for decision-making from patients. This is in contrast with the value based (existentialist) ethics view that a person is not limited by any forces to perceive or comprehend alternative courses of action, (Jacob, 1994). In

other words with adequate information patients can be empowered to make rational choices. In the conceptual model in chapter one it was discussed that professional advice is a necessary part of informed decision making.

The quality of life (being unconscious) is another aspect that limits the capacity for decision-making. Participants felt that when a person was conscious it was acceptable for the health team to proceed with treatment without any consultation. This belief was also based on the idea that the health team would use their discretion for the benefit of the patient and not to harm the patient. This contention is supported by the right-based ethic of promoting patient wellbeing. This acceptance highlights the magnitude of trust that patients have in the health team that they trust with their lives.

- **Influence of personal values**

The decision-making is largely influenced by personal values of religion, and culture. The value based ethic states that responsibility is a major issue in decision-making (Jacob, 1994). A responsible individual bases his or her choices on a religious or ethical background. In this study the results showed that the decision-making process is largely influenced by religious belief.

5.6 RECOMMENDATIONS

Implications for future trends:

5.6.1. Legislation and policy formulation

The result of this study indicates that there is a dire need for formulation of legislation that will direct decision-making in the future. This will not only serve to protect patient's interest but will help to give clear directions to doctors' actions in the future. Legislation would provide universal guidelines that would help to reduce conflict and misunderstanding. It was mentioned in chapter one that the process of formulating such legislation is still under way. It is being delayed and complicated by the need to satisfy the public and to protect doctors' moral values. As AIDS related deaths and suffering are on the increase there is a need to speed up this process because there is an increase of circumstances whereby end of life decisions complicate the care of patients. The way forward is for the government to allocate funds for research that will determine the opinions both of the health sector and public opinion. For extensive coverage the media can also be used to gather opinion.

In this study it became apparent that people have differing views with regard to physician-assisted suicide, withholding of treatment and withdrawal of treatment. A nation-wide study could be the starting point for planning of future research. With the result of those mass studies it would be possible to formulate policy and legislation.

5.6.2. Awareness campaigns.

Autonomy remains the fundamental right of patients. The health team should devise means to reinforce the practice of giving all relevant information to the patients. This could be done by distribution of pamphlets to make patients aware of their rights and of current hospital practices. Once legislation is formulated, it should be distributed to patients, and emphasis must be laid on their right to information.

Education of the public masses about patients' rights can be done through the mass media. Information outlets must be publicized. For instance, an internet address where patients can obtain information pertaining to health matters should be advertised in the media and prominently displayed in hospitals. Public relations officers can hold open days where the public can come to hospital to discuss important issues of their concern. Hospital inspections should include assessing the adequacy of this aspect of promoting awareness to patients about health matters.

5.6.3. Patient involvement and substitute decision-making

When a diagnosis of a fatal condition is made, or when a person is exposed to life threatening conditions, there is a need for open discussions about the treatment plan. Patients must be prepared in time for the end of life. Such preparation could be done by promoting open communication with the family and the patient about the subject of death. The health team could take the initiative to open the discussion and provide necessary support and information. The living will should be discussed with patients as an available option, once a diagnosis of fatal and chronic illness is made. The option of

proxy decision making by family members or close friends must be made known to patients. The legal aspect of who can make end of life decisions should also be discussed, as it is important that such matters are concluded whilst the capacity for decision-making (in legal terms) is still viable.

5.7. IMPLICATIONS FOR FUTURE RESEARCH

The result of this study showed that, there are mixed feelings about euthanasia. The researcher would therefore propose a survey, which should involve all the provinces of the country, to determine the extent of acceptance or rejection of these components: Physician assisted suicide, withholding and withdrawal of treatment. This study should include both the public and health personnel, and then a comparison of both results can be made. Another study to determine readiness for end of life decisions in terminal illness would also be relevant, and could facilitate policy formulation. Another study to explore the impact that the living will can have in terminal decision-making could be done.

5.8 LIMITATIONS

- Patients were reluctant to acknowledge the reality of death or even to talk about it. The researcher had to reassure participants that the motive of the discussion was purely for academic research and that they would benefit from the information gathered in this study.
- Two interviews could not reach the stage of verification because one respondent died before the end, and in another one the condition changed and the patient had to go back to life support again.

- Some participants verbalized that it was very difficult for them to answer the questions put forward because of lack of knowledge and a lower educational level (below std 10), although the researcher had tried to simplify the information as much as possible.
- The interviews had to be conducted in Zulu, which was the mother tongue of the participants, then later translated to English for the sake of the study, the researcher could not therefore give direct spoken words of the participants.
- The major limitation of this study is that it cannot be generalized to the whole population, since the selection of the sample was purposive and the sample size is small.
- An ethical dilemma was encountered in that patients did not have full awareness of the seriousness of their conditions, some were in denial and were reluctant to talk about their health status, and they did not want their health status to be included in the study.
- The researcher noted that there is not much information about end of life issues, research and studies conducted in Africa, therefore the references used mostly are of overseas studies.

5.9. CONCLUSION

In this chapter it was highlighted that four main issues are the main themes emerging from the data analysis. Those are poor communication, lack of knowledge, dependence on the health team and personal values. These issues are seen to have a major compromising effect on decision-making in end of life issues.

The result of the study can be supported by factors discussed in the conceptual model, that for an individual to be able to make an informed, rational choice, of his or her own free will, exercising his or her own right as a patient, the background of professional support, family support and self support also plays a role .

A summary of the result of the data analysis was also presented. The researcher discussed the recommendations which could possibly improve conditions in the future. Issues, which remain open for discussion, were highlighted for future research. Finally the researcher discussed the limitations that were encountered during the process of conducting this study.

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ANNEXES

Annexure A- Application for permission to conduct research

Annexure B- Approval by the ethics committee

Annexure C- A letter of approval from King Edward hospital

Annexure D- Bracketing

Annexure E- Interview guide

Annexure F- Interview specimen

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DEAR SIR

APPLICATION FOR PERMISSION TO CONDUCT RESEARCH IN KEH

I am a master's student in the above mentioned university, doing a nursing specialist course, critical care and trauma, as a part timer. I work within the same hospital. I request to conduct research, interviewing patients, post intensive care admission, and with minor ailments, in the trauma section. My area of study is patient's awareness and attitude towards end of life decisions.

Accompanying this letter is my proposal and permission from the ethics committee. I appreciate it if my request meet with your approval.

Yours sincerely
Khanyile Bathini Purity



Annexure A

Faculty of Community & Development
Disciplines

RESEARCH ETHICS COMMITTEE

Student: BATHINI PURITY KHANYILE

Research Title: AN ANALYSIS OF PATIENTS' ATTITUDE AND
AWARENESS CONCERNING END OF LIFE DECISIONS.

A. The proposal meets the professional code of ethics of the Researcher: YES NO

B. The proposal also meets the following ethical requirements:

	YES	NO
1. Provision has been made to obtain informed consent of the participants.	✓	
2. Potential psychological and physical risks have been considered and minimised.	✓	
3. Provision has been made to avoid undue intrusion with regard to participants and community.	✓	
4. Rights of participants will be safe-guarded in relation to:		
4.1 Measures for the protection of anonymity and the maintenance of confidentiality.	✓	
4.2 Access to research information and findings.	✓	
4.3 Termination of involvement without compromise.	✓	
4.4 Misleading promises regarding benefits of the research.	✓	

Signature of Student: [Signature] Date: 3/11/00

Signature of Supervisor: [Signature] Date: 3/11/00

Signature of Head of School: [Signature] Date: 6/11/2000

Signature of Chairperson of the Committee: [Signature]

Date: 17/11/2000

KING EDWARD VIII HOSPITAL



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Ref: KE2/7/4**

21 February 2001

Miss B.P. Khanyile
Faculty of Community and Development
Disciplines School of Nursing
Nelson R Mandela School of Medicine
UNIVERSITY OF NATAL


Dear Ms. Khanyile

REQUEST TO CONDUCT CLINICAL RESEARCH

I acknowledge receipt of your undated letter requesting to conduct Clinical Research at King Edward VIII Hospital

Your request has been approved, and you will be requested to fill in the indemnity form. Kindly note that at the completion of your study, you are expected to furnish this office with a full comprehensive report of your findings.

Yours sincerely


**DR. S.A MHLAMBI
CHIEF MEDICAL SUPERINTENDENT**

ANNEXURE C

◆ BRACKETING

Prior to undertaking this study the researcher set down her own assumptions and preconceptions, to avoid concealing them. This exercise is expected to improve the rigor of the research (Holloway and Wheeler, 1996).

- ❖ Personally I have read extensively about euthanasia, physician-assisted suicide, and the living will. Having worked in an intensive care unit for seven years, I have encountered people who have regretted being resuscitated and put on life support, because of their poor outcome. Some have verbalized that it gave their families false hope for their full recovery. Others have complained that money has been wasted when the futility was obvious. Lastly, some people felt that once they are put into life support they will be unable to speak and hence, would not have an opportunity to leave their last words to their loved ones.
- ❖ This has made me wonder if people are aware of their choices in these matters.
- ❖ Personally I believe that such people would benefit from the living will and passive euthanasia/ withholding of life sustaining treatment
- ❖ Being born a Christian, I could not tolerate the idea of active euthanasia and physician-assisted suicide, because of the psychological impact on the doctors and nurses caring for such a patient and having to be part of that decision. The moral conflict would be unbearable.
- ❖ For the future, I would strongly support the legalizing of passive euthanasia. As for active euthanasia and physician-assisted suicide I would leave that for the public to decide.

Annexure D

❖ INTERVIEW GUIDE

1. What do you know about life support?
2. What are your views about withholding of life support?
3. What is your opinion about withdrawing of treatment?
4. How do you view physician-assisted suicide?
5. Do you have any knowledge about the living will, what is your opinion on that?
6. What could have an influence in the decision about the end of life?

AN EXAMPLE OF AN INTERVIEW TRANSCRIPT

Outpatient

AGE 28YRS

SEX: MALE

EDUCATION LEVEL: MATRIC + DIPLOMA

IQ = Interviewer's question

RQ = Respondent 's question

RA = Respondent 's answer

IA = Interviewer 's answer

IQ – What do you know about life support and admission in the intensive-care unit?

RA- In that unit they use advanced machine to save the lives of the very ill people. That kind of treatment is very helpful.

IQ- What do you mean by very ill?

RA-Those are people who are critically ill.

IQ-Do I understand you correctly, if I interpret that as meaning that, all critically ill patients should be treated in the intensive care unit?

RA- People who are in a coma and critically ill can receive life support, but people who will not benefit like severely paralyzed people, and brain damaged people should receive ordinary treatment. A person, who is known

that his chances of survival are slim, might as well not be put into the intensive care unit because he will die anyway.

IQ- Could you clarify about the terminally ill?

RQ- That is a hard question, for terminally ill patients are there any other options of treatment that are available other than life support?

IA- Treatment can be divided into ordinary and extra-ordinary. Ordinary includes things like basic nursing care, pain relief, procedures to ensure comfort and safety. Whilst extra ordinary includes things like life support, operations, dialysis. Those are all the options available for treatment.

RA- Well in that case, the terminally ill should be admitted in the intensive care unit, because it will be for humane reasons to give them all the care they need, before their departure.

IQ- if that is the case, should a person's consent be obtained before initiating life support?

RA- That should depend on the condition of the person, if a person can communicate, it is his or her right to decide on what treatment they want. But if a person is unconscious, the health members should consult relatives. And in the mean time a risk must be taken and treatment continued without the consultation with the patient, for his or her own good.

IQ- do you mean that the relative's opinion is important in determining life support?

RA- Not necessarily, relatives need to be informed of a person's condition; otherwise it is not wise to include them in such decision making. An adult

person must take his or her own decisions, failing which health team members must use, their own discretion according to what is important and beneficial to the patient. Decisions must always be weighed whether they are not harmful to the patient and what is best for the patient must always be

IQ- What is your opinion on withdrawal of life support when the prognosis is poor?

RA- That is the time that the hospital staff should contact relatives to explain that their loved one has got no hope of surviving, then the relatives can decide what must be done.

IQ- If you were a relative, what decision would you take in that circumstance?

RA- Doctors must make another plan or consult another doctor for opinion, but they must never switch off the machine, that is very wrong, its murder. Nature should always be allowed to take its course. Eventually that person will die anyway.

IQ- Have you heard of cases where the terminally ill persons request doctors to end their lives, what do you think of that ?

RA- that is totally unacceptable life is God's gift. If you have a terminal illness you should just accept it like any other illness and persevere because suffering is part of life.

IQ- in other words you are saying doctors are not allowed to end patient's lives?

RA – no one has a right to end to end a person’s life, more especially the doctors, because they will kill more people wrongfully and that will finish our nation

IQ- Do you think finance has an impact on end of life decision -making?

RA- Money must not be an important issue, if people have financial problems, the government must take responsibility and assist such people; it must also reduce financial charges for them. So that everyone receive treatment as necessary.

IQ- Do you know anything about the living will?

RA- No please explain that to me.

IA – It is when an adult gives written directives, that should he or she be in a life threatening or terminally ill condition, and unconscious; unable to communicate his or her choices of treatment, he or she wishes not to be put in life support. Instead he or she must be given only ordinary treatment, she or he signs and has a witness sign as well. That is reviewed every six months.

IQ- What is your view on that?

RA- I think a person who has considered certain circumstances can benefit from that, but that cannot help everyone.

IQ- What do you mean by that?

RA-People are not the same, some people still believe in traditional things,

And some do not. Those who do not consider traditional issues may easily take the living will option, but traditional people may see the living will in a bad light, basically it depends on how you have been socialized.

IQ- What exactly do you mean by that?

RA- In this life you share everything with family, friends and relatives, who loves and needs you. If you sign a living will, it means you are depriving them of your existence when they still love and need you. So it is not a very good idea, instead it shows selfishness.

IQ- What are your views on withholding and withdrawing life support, should they be legalized or not?

RA- The government must formulate a policy, which gives guidelines to doctors about how to handle these situations, that would prevent uncertainty.

RQ- Do you know , if there is anything which the government is doing about that?

IA- The policy is still being drafted, but it is complicated by the fact that there are conflicting views about end of life decisions, some are for withdrawal of life support, others are against it.

RQ- who is in the majority?

IA- That has not been determined since both sides have a very strong argument.

IQ- do you have any opinion on that?

RA- In view of the apartheid regime, which is still very much evident here in S.A., legalizing withdrawal of life- support will lead to victimization. People will be killed for the wrong reasons more especially if they are in a vulnerable position.

IQ- Don't you think there will be stipulations to guide against that?

RA- No people have a tendency to over look regulations that restrict their actions. Personally I think it will be a very bad idea for people to agree to any form of being killed by doctors because it will definitely lead to abuse. I think the best solution is to continue with previous practices where by a person dies when the time comes, no assistance or speeding of death should be done even if the person request it.

IQ-What is your last word on this discussion?

RA- I still maintain that every person is God's creature therefore should be allowed the dignity of dying without interference, and the family should maintain the same stance in the matter. I don't think there is a person in the family that can agree to their loved ones killed, never!

The end