

Chapter 1

INTRODUCTION

1.1 BACKGROUND

In a society characterized by an emphasis on science and technology, where answers to many questions can be pursued through science, understanding the experience of death, as opposed to dying, is methodologically and logically beyond us (Lawler, 1993). In contemporary society, death is no longer so visible. Death is often depersonalized in our culture, perceived as something abstract, which only happens to others and everything about it can be consciously avoided. The language used today is evidence of a death denying society. Language is euphemistic; phrases such as “passing on” and “no longer with us” reflect an attempt to protect ourselves from the reality of death. Institutionalized and given over to professional caregivers, death is kept apart from the rest of society (Ellis and Nowlis, 1994); we hide it behind the sterile walls of hospitals and find refuge in technological interventions and narrow medicalization.

Death is one of the last great taboos in our society. Surrounded by images of death in the media, modern western society can make it all too easy to insulate our-selves from the reality of death in our own lives and to be unprepared to deal with it. Deaths now occur more frequently in busy hospitals than in homes (Myers, 2000). The fact that a significant number of people die in hospital indicates the importance of the role nurses play in relating to the dying and those who are significant in their lives, as it is most often the nurse who takes the team plan to the bedside of the dying person. However, research indicates that the care received by those dying in this setting is far from ideal (Doyle, Geoffrey, Hanks and Macdonald, 1998).

The displacement of death from homes to institutions also confronts nurses with several personal and professional conflicts. The defence that death is remote is no longer available to those who work with the dying, not only do they spend much time with the

dying, they are also dealing with the questions and powerful emotions (McKay, 1990), which may trigger situations of personal crisis. Working in a professional role does not protect the nurse from the fears and anxieties in the field of terminal care (Ellis and Nowlis, 1994).

The dying patient calls into play a series of human events where the needs of the patient cease to be translatable into routines and rituals. It is in this fundamental sense that the dying patient threatens the hospital and its personnel. The routine orders, the predictable activities, when applied to the dying patient, cease to be meaningful, cease to be effective, and above all, cease to be satisfying either to the people doing them or to the patients who receive them (Ellis and Nowlis 1994, Backer, Hannon and Russell 1982).

One criticism of health caregivers is their difficulty in responding to the emotional circumstances of patients who are terminally ill. Even the most thoughtful carers struggle with issues that arise during the care of the dying. Overall evidence suggests that the majority of health care workers are prepared inadequately for terminal care issues in general hospital settings and that caregivers in hospices are better equipped in the psychosocial care of the dying (Mills and Davies, 1994).

To understand the difficulty caregivers have in providing care rather than cure, and in not informing patients of their dying, we must again go back to society's socio-cultural expectations of the helping professions and of hospitals. We expect treatment of disease; we expect caregivers to do something; we look for miracles instead of death. We must also again understand that, as caregivers, we are part of our death-denying society, and unless a conscious effort is made to examine our attitudes toward death and dying, we may be unaware of how these attitudes influence our care of dying patients (Spall and Callis 1997, Backer, Hannon and Russell 1982).

Caring for the dying patient presents unique challenges. If nurses themselves have not come to terms with death, caring for the dying patient can present many problems. Defending against one's own death anxieties may take the energy and focus away from

the dying patient's needs. Defences commonly used by nurses to avoid interacting with dying patients are behaviors such as evading conversation, avoiding patients, briskness and efficiency in providing physical care, speaking only when spoken to by the patient, and talking only about topics that are comfortable for the nurse (Cook and Oltjenbrun 1998, Poss 1981).

A discussion of death can evoke fear, sadness, and anger about one's own mortality and powerlessness. These are personally uncomfortable feelings as well as being disturbing ones in a society and a profession where keeping one's emotions in control is emphasized. The problem with clinical detachment is that it can be associated with a denial of the importance of acknowledging feelings. In nursing it is often far easier and sometimes encouraged either to ignore or to rationalize feelings as they occur in day-to-day practice and even to pretend that they simply do not exist (Cook and Oltjenbrun, 1998). This is evident in the image of the nurse as an implacable, objective carer who has somehow learned to detach herself from emotion. Human suffering always calls for involvement, and involvement in the human condition always includes feelings. To ignore the domain of feelings in nurses is to ignore an important part of what it means to be a human being (Spall and Callis, 1997).

Caring for dying patients may be viewed as being in conflict with the nursing goals of promoting health and maintaining wellness. Death would seem to have no part in these professional goals. However, at the point when death becomes a certainty for a patient, the treatment goals change from recovery to comfort. The nursing staff assumes the major responsibility for providing this comfort, and this is indeed a significant part of nursing interaction with a dying patient (Ellis and Nowlis 1994).

Caring for patients who are dying and who are dependent on others is a difficult part of nursing. The day to day total physical care and psychological support required unceasingly by such people taps nurses' energy levels. Nurses do not have the mobility on hospital units to come and go throughout a shift as doctors and social workers do; nurses remain on the unit with the patients. Although this can be problematic at times, in

terms of nurses' own needs to get away from the situation for a short time, it also provides them with a unique experience – being there when patients need someone (Backer et al. 1982).

Research findings in terminal care suggests that nurses in acute care settings need to confront their limitations as professional caregivers and become aware of their own vulnerabilities, needs and expectations. Insight into their own needs, vulnerabilities and expectations can allow professionals and volunteer caregivers to separate their own issues from those of their patients (Cook and Oltjenbrun, 1998) and as humans, professionals have significant emotional needs that they must cope with to ensure successful intervention with dying and grieving individuals. Unless these needs are acknowledged, the helping relationship may be jeopardized. Emotions, particularly anxiety, can affect professional perceptions, diagnosis and even treatment of patients. Caregivers should be respectful of their own needs; otherwise they may be sowing the seeds of burnout. Apart from the latter being detrimental, it would also mean that they wouldn't really be able to help those in situations of loss. Often support may be viewed as secondary, something only to be concerned with if there is time. This attitude unfortunately devalues their own needs and themselves and indirectly undervalues patients because it makes them less effective helpers (Spall and Callis, 1997).

Knowledge about terminal care does not automatically lessen the caregiver's apprehension about her work since subjectivity, denial and projection abound in this field (Poss, 1981). Although formal training on how to help dying individuals and grieving families has increased, little training is designed to help professionals deal with their own feelings of loss, grief and self- doubt (Neirmeyer, Behnke, and Reiss, 1983). Hence the most successful death education efforts seem to be those that integrate intellectual content with the opportunity to explore feelings and attitudes (Doyle, Geoffrey, Hanks, Macdonald 1998, Poss 1981).

People who work with the dying need to gain personal insight into their responses to dying and death rather than follow rigid stereotyped positions about patients and patient

care if they want to foster their own personal growth, attitudes and behavior change. Dying and death issues do not have to be totally worked through, but if those who work with the dying do not try to understand them, their anxieties and defences will hamper their work (McKay, 1991).

1.2 PROBLEM STATEMENT

Increase in South African mortality rates due to chronic diseases related to lifestyle changes and HIV/AIDS has emphasized an urgent need to develop palliative care facilities. Despite the fact that the number of deaths within the public sector is not comparable to the number of deaths in private health facilities, these institutes have also seen an increase in the mortality rates of the population they cater for. Hence the private health sector has recognized a need for palliative care, education and training. However, many healthcare professionals have acknowledged difficulties in working in terminal care situations and while physical care is good, the more complex spiritual, existential, emotional and family relationship issues that most concern terminally ill patients are rarely addressed. This may be attributed to nurses' unaddressed anxieties and death concerns, by various authors cited previously. Although numerous death anxiety research studies have been conducted (Mills and Davies 1994; McEvoy 1990; Lerea and LiMaura 1982; Davitz and Davitz 1975), little is known about the death anxiety experienced by nurses working in private acute care hospitals and their death attitudes towards terminally ill patients. If these are explored, nurses may be encouraged to explore their concerns in the terminal care setting in relation to themselves, thus enabling them to provide quality end of life care without allowing their own anxieties to interfere in their work with the dying patient. The lack of knowledge regarding death anxieties and attitudes within this context has motivated the researcher to undertake this study.

1.3 RESEARCH QUESTIONS

This study seeks to answer the following questions:

- What are the death anxieties and attitudes of nurses towards dying patients in a private acute care hospital?
- Is there an association between nurses' levels of death anxiety and their attitudes towards dying patients?

1.4 PURPOSE OF THE RESEARCH

The purpose of this study is to identify, explore and describe nurses' personal fear of death (death anxiety) and explore whether an association exists between death anxiety and their attitudes towards dying patients in a private acute care hospital in Johannesburg. This study will attempt to determine whether correlations exist between levels of nurses' death anxieties and their attitudes towards dying patients. In identifying these death anxieties and attitudes, this study will also indicate whether a need exists for ongoing institutional support and education regarding end of life care.

1.5 OBJECTIVES

The objectives of this study are:

- To identify nurses' attitudes towards death.
- To measure the level of nurses' death anxiety through their responses to death and dying.
- To explore whether an association exists between nurses' death anxiety and their attitudes toward the dying patient.
- To describe the association between nurses' different levels of death anxiety and their attitudes towards dying patients.
- To identify the need for ongoing institutional support and education regarding end of life care.

- To suggest recommendations for appropriate institutional support and education regarding end of life care for nurses caring for dying patients.

1.6 RESEARCH HYPOTHESIS

Rests on the premise that death is an eventuality everyone faces but the emotional impact it has on the caregiver is significant with regard to the quality of care terminally ill patients receive within a hospital setting. It is also based on the premise that management of the dying patient elicits anxiety and the results of several studies that have found a correlation between individual differences in elevated levels of physician death anxiety and discomfort working with the terminally ill patient.

As a result of the above, the following hypothesis is proposed:

Nurses evidencing high death anxiety will express more negative death attitudes than nurses with low death anxiety.

1.7 METHODS AND PROCEDURES

1.7.1 Research Design

This study adopts a quantitative, descriptive, correlational design.

The purpose of this study is to examine the relationship between death anxiety and nurses' attitudes toward terminally ill patients. Various extraneous variables have been identified and defined. No attempt will be made to control or manipulate the situation as it is currently occurring.

1.7.2 Population and Sample

The target population comprised of all categories of nursing personnel (registered nurses, enrolled nurses, nursing auxiliaries and student nurses) in a private acute care hospital that met the sampling criteria and consented to participate in the study.

All nurses involved in patient care and those who have nursed a dying patient in the last six months will be included. The sample criteria are non-exclusive to gender, ethnic background, educational, religious or professional status. The inclusion of all nursing staff from the various units may be justified on the basis that, although exposure to death and dying may vary, staff working in units with lower mortality rates, for example maternity units, are frequently seconded by management to assist in other units for various reasons, which may have a higher mortality rate. Therefore nursing staff is exposed to terminal care and terminal care issues. The total population of 394 nurses within one private hospital's employ was used, however only half of this population was expected to form the study population as those nurses who are involved in administrative, managerial and non-nursing tasks were excluded from the study. A population of 197 was expected.

1.7.3 Instrument

A self-report research questionnaire will be administered to all categories of nurses working in a private acute care hospital who volunteer to participate. The research questionnaire consists of three parts. The first part addresses the following demographic data: the respondent's age group, number of years in the nursing profession and gender. In addition respondents will be asked if they feel that they have adequate training in dealing with death and dying concerns; whether they feel they have the support of their unit/hospital and to explain their response. They will also be asked if they have nursed a terminally ill patient in the last six months.

The second part of the questionnaire assesses attitudes towards death. This survey includes eight items from a possible twelve-item questionnaire developed by Neville Strumpf. Two more items were added to the existing scale addressing the feelings of anger. Items are scored on a 5-point Likert scale ranging from "strongly agree" to "strongly disagree". Permission for use of this scale was obtained from the project manager for the study.

In the third part, death anxiety is measured using the Collett-Lester Fear of Death Scale that consists of four sub-scales which measure the subject's fear of his or her own death; one's fear of someone else's dying; fear of someone else's death and lastly fear of one's own dying.

A respondent can respond to each question using a Likert scale of 1-5 with one and two being low death anxiety, three and four being somewhat anxious and five being very anxious. (Lester, 1990)

The Collett-Lester Scale's cut off score for low death anxiety is two or less for each question. Permission for use of this scale has been obtained from David Lester who made this scale available for the use of all researchers on the website www.dunamai.com

1.8 ETHICAL CONSIDERATIONS

Permission to conduct this study was obtained from the hospital management, the University of Witwatersrand Human Research Ethics Committee (Medical), and the Faculty of Health Sciences Postgraduate Committee. In addition, verbal approval was obtained from the ward managers and subjects were provided with essential information for informed consent and signed a consent form. Any participant who exhibited any emotional distress either verbally or non-verbally was to be referred to the hospital social worker for counselling as required. This had been verbally negotiated with the hospital's social worker.

1.9 SIGNIFICANCE OF THE STUDY

With the displacement of death from homes to institutions, nurses' and other caregivers in oncology and other medical specialties are involved in a constant process of attachment and loss occurring in the context of their own personal histories and the setting in which they work. Staff reactions to caring for patients at the end of life are highly individual. These reactions are influenced by specific patient and family situations, as well as by the staff members' own skills, history of loss, experiences and resources. From the perspective of the individual, the ability to continue to care for others

presupposes a responsibility and commitment to care for self (Miaskowski and Buchsel, 1999).

Diverse issues may be triggered in those providing care for individuals and families who are nearing the end of life. For example, feelings of ambivalence, guilt, and failure regarding the ability to affect a cure and worry about being overwhelmed by multiple losses may present difficulties for staff (McEvoy, 1990) and result in distant carers. As a result of this, the provision of quality end of life care is jeopardized.

Given the perception that expression of emotion is incongruous with being a “professional”, the emotional aspects of loss may go unacknowledged and unsupported in institutional settings. Just as bereavement is a most important issue for families, the impact of loss on staff can also be significant in a setting where close and valued relationships have developed with patients and family members through interactions over a long period of time (Miaskowski and Buchsel, 1999).

This study allows nurses to gain personal insight into their emotional needs and professional limitations through identification of their attitudes and anxieties related to death and dying, thus maintaining standards of excellence in caring for dying patients in acute care hospitals. In doing so, the nature and effectiveness of the nurse-patient relationship in terminal care is enhanced.

1.10 DEFINITION OF VARIABLES

For the purposes of this study the following definitions will be used.

1.10.1 DEFINITIONS OF DEPENDENT VARIABLE

1.10.1.1 Death Attitudes

Conceptual Definition

In this study, the nurses' attitudes toward death and dying is defined as their dispositions, the patterns of feeling that enter into and often become habitual in their ways of thinking about the world. Societal attitudes toward death have changed with time and have typified certain societies and periods in history (Doyle, Geoffrey, Hanks and Macdonald, 1998).

Operational Definition

Philippe Aries analysis of attitudes toward death in Western societies from Middle Ages to present, cited by Doyle et al. (1998), led him to identify five basic patterns in such attitudes:

- Tame death (all people die)
- Death of self (death held the potential for everlasting suffering or redemption for everlasting life based on religion)
- Death of the other (relationships were broken by death)
- Forbidden death (mourning is restrained and perfunctory-dying is displaced from the home to institutions. (Doyle et al. 1998)

These five patterns will be measured using the Neville Strumpf Death Attitude Scale (retrieved from www.mywhatever.com. 4/7/2003). Eight questions out of a possible twelve will be used and each response will be allotted a numerical value.

1.10.2 DEFINITIONS OF INDEPENDENT VARIABLE

1.10.2.1 Death anxiety

Conceptual definition

Death anxiety has been defined as “ the fear of extinction, annihilation, obliteration, or the ceasing to be” (Kastenbaum and Aisenberg, 1972).

It is also defined as a feeling of dread, apprehension, or solicitude when one thinks of what happens after death, the process of dying, or ceasing to be. Death is defined as a state of non-being, the termination of biological and social life.

Pollak (1980) concludes that his findings from reviews of empirical studies suggest that death anxiety is a complex construct that interrelates in a variety of ways that are not completely understood with a host of demographic and personality variables.

Then for this study the operational definition is as follows.

Operational definition

In the context of this study death anxiety will be defined as a complex, multi-dimensional concept.

Schultz, cited by Faull, Carter and Woof (1998), articulated eight components to death anxiety

- Fear of physical suffering
- Fear of isolation and loneliness
- Fear of non- being
- Fear of cowardice and humiliation
- Fear of failing to achieve important goals
- Fear of impact on survivors
- Fear of punishment or of the unknown
- Fear of death of others

- Fear of the act of dying, e.g. pain; loss of control; rejection because of illness.

These are given as items on the death anxiety scale that will be used in this research study. Each of the components is equally significant and is addressed in the four subscales of the Revised Collett-Lester Fear of Death Scale (Refer to chapter three).

1.10.3 DEFINITION OF TERMS

1.10.3.1 Private acute care hospitals

In this study, the private acute care hospital is an institution for the care of the sick or injured that offers advanced medical treatment and various specialties of care, with the primary focus on the curative care and prolongation of life. Despite the focus being directed toward curative care, the mortality rate from complications of trauma and chronic illnesses, for example: malignancies; endocrine diseases; HIV/AIDS; cardiac and respiratory illnesses, while not comparable to government institutions is significant. In view of this, these hospitals have also recognized the need for palliative care. It is governed by the country's laws and healthcare policies, but is privately funded with the aim of profit generation. It caters for a select group of people who can afford the services provided either by private funding or by virtue of medical insurance.

1.10.3.2 Terminally ill patient

Is a patient suffering from an incurable condition that he or she will eventually die from. The word terminal is used when the patient is close to the end of life, which is measured according to all clinical and statistical parameters known about the prognosis of the particular disease or condition and when mutual consensus is reached by the multi-disciplinary team in whose care the patient is, that active medical intervention is no longer an option and palliative care is the alternative treatment offered to the patient.

1.10.3.3 Positive death attitude

Is a disposition or pattern of feeling that suggests emotional or psychological ease or comfort in caring for the dying patient, which is demonstrated by the caregiver's competent and compassionate care given to the dying patient and their family.

1.10.3.4 Negative death attitude

Is a disposition or pattern of feeling that suggests emotional or psychological discomfort in caring for the dying patient, which is demonstrated by the caregiver's reluctant and clinical detachment toward the dying patient and their family.

1.10.3.5 Nurse

Refers to an individual rendering patient care, who has successfully completed a course in nursing and is currently registered with or engaged in pursuing a course of study leading to registration with the South African Nursing Council under the Nursing Act as a registered nurse, enrolled nurse, auxillary nurse or nursing student.

1.11 SUMMARY

The fact that a significant number of people die in hospital and that terminal care issues were poorly addressed within the framework of an acute care hospital, provided the motivation for this study. The purpose of the study was to identify and describe the levels of nurses' death anxiety, their attitudes and the association between nurses' levels of death anxiety and their attitudes towards dying patients in a private acute care setting.

This study will also attempt to highlight the need for ongoing institutional education and support. The terms relevant to this study have been defined.

In the next chapter the relevant literature and existing research on death anxiety and death attitudes will be reviewed.