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## The lived experience of nurses caring for the dying

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# **THE LIVED EXPERIENCE OF NURSES CARING FOR THE DYING**

**BY**

**DAVID M BYRNE**

A thesis submitted as partial fulfilment for the degree of

**MASTER OF NURSING**

At the School of Nursing, Edith Cowan University,  
Perth, Western Australia

Date of Submission:

## Abstract

The study reported in this thesis describes and analyses the lived experience of caring for the dying amongst nine (9) nurses in a hospice setting. The research was established within the context of published literature on the subject of caring for the dying from nursing.

A qualitative, phenomenological approach was chosen as the most appropriate for this study, in order to describe and interpret the understanding and shared meanings nurses have in the care of the dying. The major mode of data collection in this study was by in-depth interview of nine (9) nurses, which was supplemented by the researcher's field notes. Data collection, data analysis and validation took place concurrently.

Five key themes were identified from the information by the nurse participants which explain the structure of the lived experience of nurses caring for the dying. These themes are; being transformed by the experience, the influence of context on caring, the embodiment of caring, caring for the family, and coping.

The findings of this study support, in part, related findings in published literature. However, this study extends prior research by capturing the essence of the experience of nurses caring for the dying, in the context of hospice care.

The major implications for nursing practice are that nurses who care for the dying need an awareness of the processes involved in caring for the dying to better understand their own, and their patients' experiences. Several recommendations were made for further research which would substantiate and extend this work.

### Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for any degree or diploma in any institution of higher education, and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature: 

Date: 21st Nov 1995

## Acknowledgements

In absentia, to my parents, who gave me the most precious gift of all, the gift of life.

To the nurses who freely participated in this study, I am indebted. Their warmth, honesty, openness, and compassion for others stands as a calumet, for others to follow.

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## CHAPTER 1

### The Problem

#### Introduction

This thesis describes a study of the lived experience of nurses caring for the dying. Nurses as individuals and members of a caring profession, play a major role in the care of the dying. It is important to explore death and dying in depth, from the perspective of those caring for the dying so that their experiences can be used as a basis for greater understanding of the process. This chapter provides a background for examining the meaning of dying and death. The concept of anticipatory grief and traditional attitudes towards caring for the dying are discussed. The experience and development of hospice care is then outlined as it influences and informs the processes of caring for the dying. The significance of the study and a statement of the problem are outlined, followed by explication of the purpose and objectives of the study. Definition of terms, the study rationale, and assumptions underlying the study are provided ending with a thesis overview.

#### Background to the Study

The meaning of dying and death has been of central concern amongst human beings since ages past. Becker (1973, p.15) stated that:

The fear of death is natural and present in everyone, that it is the basic fear that influences all others, a fear from which no-one is immune, no matter how disguised it may be.

To face death, and dying, is to begin to master life. In so doing, priorities are re-ordered thereby emphasising the position of importance death and dying should hold. The fact that we cannot truly understand or accept our own mortality however, may be evidenced, in part, by the paucity of research on anticipatory grief. Lack of acceptance with regard to mortality appears to be exaggerated by the lessening permanence of society, the omnipresent threat of global annihilation and the "death" of the extended family (Fiefel, 1977).

Uncertainty, anxiety and the inevitable inability to cope with dying and death are reflected in Lifton and Olsen's (1974, p.26) assertion that:

When a society's values and institutions are seriously questioned, life transitions become anxious and traumatic .... what does it mean to grow old when old people are isolated .... what does it mean to die when science has challenged sacred religious beliefs and in the place of spiritual comfort has left only the 'scientific' method?

Thus, we are left with "science" to supplant the original support and guidance on issues of dying and death, which were once left to ritual and belief systems. Medical science especially, has reduced mortality rates and prolonged the life expectancy of the general population. Not only has the age at which a person can expect to die changed, but also the time and place of death.

Dying occurs more often in institutional settings. As Aries (1974, p.111) noted:

The initiative has passed from the family .... to the doctor and the hospital team. They are the masters of death .... and .... they try to obtain from their patient 'an acceptance of style of living while dying'. The accent has been placed on 'acceptable' .... it is an antithesis. 'The embarrassingly graceless dying' which embarrasses the survivors because it causes too strong an emotion to burst forth .... death has been interdicted because it violates the rule that life must be at all times happy.

The individual is often left alone without the social network that preceding generations could rely upon. Dying and death do not occupy the central position they once had in western society and the manner of dying has become hidden, cutting people off from what family and friends they may have. Thus, as Wolfe (cited in Troup & Green, 1974, p.4) stated, “we have the curious situation that *medical progress* [italics added] has made death more stressful for relatives, more expensive for the family, and more troublesome for society.” This also appears to negate what Lindemann (1944) originally termed “anticipatory grief,” which is a technique of preventive intervention which focusses on helping individuals to cope with impending loss through open discussion and problem solving before the actual death (Caplan, 1964). However, this is still important in some cultures, where family members take a leading role in, and primary responsibility for the care of the dying and the deceased. As Moore (1970, p.141) notes for example, “uniformly, one meets the flat assertion that the funeral is the single most significant family ceremony among Mexican Americans.” Whether viewing the entire culture or subculture, dying and death appear of primary concern. In their caring, they also appear to have had the opportunity to work through their grief in the anticipation of impending death, moving toward personal re-organisation and the everyday business of living. In western society however, death has been expelled from common experience and is a mystery to most of us. As Fiefel (1977, p.5) notes:

It is paradoxical that while direct exposure of children and young adults to dying and death is decreasing .... (they) are being given considerable but unrealistic attention in .... horror films and in derivative TV renditions .... usually removed from the realm of feeling.

It seems understandable then, that dying and death are seen as an abomination which invite repudiation and even interdiction. The ambivalence toward dying and death is in all of us, and Fiefel's observation twenty years ago is ever more relevant today, as increasingly sophisticated technology impinges on our lives, distancing people from one another and the feeling states people would normally experience. Fortunately however, numerous professionals remain committed to the human, caring aspect of facing dying and death, exemplified in the resurgence of the hospice movement.

Hospice and palliative care organisations are said to benefit from, "the promotion of open and fluid communication styles, appropriate role assignments, flexibility within the system, and healthy, flexible boundaries" (Rando, 1984, p.438). These settings also offer the unique opportunity to study the effects of dying and death on patients, families and nurses in their constant day-to-day interactions, some of which appears to be addressed.

### The Nursing Perspective of Caring for the Dying

As members of families, society in general, and as professionals, it is particularly important for nurses to increase their awareness and understanding of the way they experience caring for the dying. Fundamental to this process is the phenomenon of anticipatory grief. Increased understanding of anticipatory grief and other elements of interacting with dying patients may enhance the quality of the nurse-patient relationship by improving nurses' ability to foster the therapeutic use of "self".

More germane perhaps, is that the feelings, attitudes and behaviours which nurses, as "survivors," may be experiencing, are in actual fact, hidden. This may lead to questioning personal effectiveness, which jeopardises the observation by Shusterman and Sechrest (1973, p.411) that:

Nursing staff are particularly important in shaping the experiences of the dying, since they spend more time with the patient .... and are most directly responsible for fulfilling .... immediate needs.

If nurses as professionals cannot fulfil their own needs or continue to find meaning in caring for the dying, then they do both themselves and their patients an injustice. For themselves, they are likely to experience what has been termed, "burnout," associated with:

Colds, headaches and fatigue. Colleagues who appear to be healthy may actually be depressed. However, they often become so totally consumed with their patients that they withdraw from everything but work (Bolivar, 1991, p.51).

Nurses have long regarded themselves as indispensable and have been reluctant to express their feelings openly. When caring for the dying this may be compounded if nurses see life as endless suffering without any prospect of cure. The danger is that the effect may be cumulative, which may lead to a subtle form of guilt, in turn leading to, "over-giving as a kind of penance for being well (apparently), or as a magical ritual to remain that way" (Lorenz, 1991, p.49).

Patients will also suffer if nurses are laden with tension-related conflicts. Objectivity will be impaired and a patient's needs ill-defined if a nurse is too pre-occupied with "self". The rapport between a nurse and a patient may be hampered such that a positive nurse-patient relationship is fractured and all that ~~issues~~ from this basic step will flounder. It may well be that because of the

complex nature of relationships in caring for the dying, the determination of meaning in anticipatory grief for nurses may not easily be resolved.

Anticipatory grief affects not only the dying person and close relatives but also those providing care, such as nurses, who often form close personal relationships with the dying. Anticipation of death may place nurses in an individious position, primarily because of ambivalence in taking or not taking certain actions concerning patient care. This may lead to such feelings as guilt or denial and may be manifest in certain behaviours, which may range from withdrawal, to over-involvement or poor nurse-patient relationships. However, Rando (1986, p.24) suggests that:

The truly therapeutic experience of anticipatory grief mandates a delicate balance among the mutually conflicting demands of simultaneously holding onto, letting go of, and drawing close to the dying patient.

The inference is that feelings of guilt and denial, as well as behaviours such as withdrawal, over-involvement and apparent poor nurse-patient relationships are invalid and may actually serve to improve the relationship between nurse and patient if seen and understood within the overall context of the phenomenon. Similarly, profound identification with the patient and the inevitable frustration associated with caring for the dying by nurses (and other professionals) may have a salutary effect. As Kastenbaum and Aisenburg (1972, p.92) noted, "death tends to level the distinction between professionals and everyone else." The omnipotence of professionals is therefore shattered and their place in the world is under challenge. Thus, as Marris (1974, p.33) states, "a sense of purpose must be redefined. When the dead person has

been, as it were, the keystone of life, the whole structure of meaning in that life collapses when the keystone fails."

For nurses, the degree of disorganisation depends on the significance of the relationship the professional has had, regardless of self-concept, support systems, beliefs and values which normally hold the individual in good stead.

A further point usually missing from discussions on caring for the dying is the social component of the phenomenon, which necessarily involves a restructuring from a narrow emotional focus to a sociopsychological one. Rando (1986) makes reference to the family and social processes in that, "the dying of the patient takes place in a social context, which itself is affected by the loss" (p.73). This may include society's loss or the loss felt by family members of the extended family, particularly where a family member is cared for at home.

Nurse-patient relationships also occur within a social context that has been determined by the social organisation of work in large institutions. The socio-economic and value systems underlying health care organizations appears to be changing, however, such that there is a shift in emphasis from institutional to community-based care. Nurses play a major role in this change in many different specialities, including care of the chronically ill and the dying. The social, psychological and cultural benefits for patients and families of truly individualised care are enormous, especially with regard to patients and their families making decisions regarding their own care. The logical consequence of this change mandates a nurse who possesses the requisite knowledge and skills on, "The anticipatory grief process; the experience of the dying patient; family systems theory; ... reactions to death; and the problems accompanying



illness in general and the patient's illness in particular" (Rando, 1984, p.356).

The major flaw in this repertoire however, is lack of knowledge of the processes and consequences dealing with death and dying. Until these are better understood, nurse-patient relationships within this wider social context may fail to adequately meet the needs of the chronically ill and the dying.

In the absence of such knowledge and experience, nursing educational programmes may also be less than adequate (Bertman, Greene & Wyatt, 1982; Davidson, 1978; Degner, et al, 1982; Field, 1984; Fleming & Brown, 1982; Gow & Williams, 1977; McCorkle, 1982; Rainey, 1983; Roach, 1978, & Wylie, 1978). Preparing nurses for care of the dying seems to concentrate too much on variables such as, "stress" (Alexander, 1990); "death anxiety" (Degner & Gow, 1988); "critical behaviours" (Degner, Gow & Thompson, 1991); and "occupational problems" (Quint, 1967).

It is not surprising that there is great similarity between the recommendations of Degner and Gow (1988) and Quint (1967) with regard to death education for nurses, suggesting that almost nothing has changed in over twenty years. This may be due in part, to the complex nature of dying and death, which is not easily explained or discussed. Alternatively, it may be due to the fact that little or no attention is given to the effect that anticipation of death may or may not have on the behaviours and attitudes of nurses toward dying patients. Ultimately, as Saunders and Valente (1994, p.318) bluntly state, "most nurses receive little practical educational preparation for .... coping with dying patients or death."

Further, nurses may view institutionalised deaths as reminders of their own mortality and contact with dying patients as vicarious rehearsals for their own deaths (Vanden Berge, 1966; Weismann, 1972). While this may be so, contact with any significant person in any setting would surely result in the same observation, but would probably involve more meaning for the survivors as they struggle with the acceptance of being alive. However, “being alive” must be tempered with the judgement that, “time along with space can now be annihilated. Even celebration of the tragic will be beyond our power. Death is becoming a wall” (Fiefel, 1977, p.4).

### Hospice Care

Hospice is a programme to ensure care for the dying such that people may die easily and peacefully. Hospice programmes, also support survivors and encourage the dissemination of knowledge and the potential of hospice into hospitals and patient’s own homes (Saunders, 1977).

The emergence of the hospice movement appears to have been a manifestation of a shift in emphasis from a cure orientation to a view of the human needs of people in the final phase of life, and a concern for those people who survive them. However, Walker (cited in Thomas, 1983, p.22) asserts:

Hailed as a new approach .... hospice is as old as nursing itself. It is, for nursing, a symbolic return to its roots. Humane and compassionate care, one cherished ideal which has motivated nurse for centuries.

The ideal of compassionate care may also have been the motivation for the, “Knights Hospitaller of the Order of St John of Jerusalem .... Father

Damien's work among the lepers of Molokai, or the ministrations of the Quaker, Elizabeth Fry .... in England" (Fulton, cited in Rando, 1986, p.ix). The Irish Sisters of Charity began to use the term hospice for homes of dying patients which opened in the nineteenth and twentieth centuries. Contemporary hospice care was founded by Saunders in 1948, but it was not until 1964 that St Christopher's Hospice opened in London. The philosophy of hospice was seen as:

The active relief of various types of distress and a personal approach to a patient and his or her family, at home as well as in the wards. A hospice is not only a place that 'cares for the dying' but a community giving less technology and more personal care than the usual busy hospital ward (Saunders, cited in Feifel, 1977, p.161).

Currently, the hospice programme is said to be burgeoning and there is an increasing body of evidence which suggests that it has attracted wide admiration and endorsement. However, Weisman (1988, p.65) questions, "whether hospice care is actually able to provide unequivocal benefit (that) has not been established beyond doubt." Nevertheless, benefits for patients and nurses appear to be greater than for those in traditional institutions. Thomas (1983, p.11) suggests that, "the nurses role is pivotal and extremely satisfying," which is undoubtedly true of the role of the nurse in many settings. Thomas (1983) also identifies many inherent stressors in hospice care, purportedly documented in the literature (but with no specific reference) that include:

Feelings of helplessness about the inevitability of death, anger over patient/family conflicts that increase the patient's difficulties; lack of co-operation by physicians in alleviating the patient's symptoms; guilt over failure to provide adequate care, whether or not the guilt is realistic and sadness at the loss of patients who have become good friends (p.26).

Grief is mentioned, in passing, but anticipatory grief is glaringly absent, and a thorough review of published literature shows for example, continued emphasis on: death anxiety (Amenta, 1984), burnout (Bram & Katz, 1989); performance and persistence in volunteers (Lafer, 1989); measuring fear of death (Littlefield & Fleming, 1984); bereavement (Parkes & Weiss, 1983); occupational stress (Vachon, 1987) and the coping capacity (Weismann, 1984).

It therefore appears, that while the hospice movement may yield benefits for both patients and nurses, without an attempt to describe and interpret the lived experience of nurses, many potential benefits for both patients and nurses may not occur.

### The Significance of the Study

This study is important because of the pressing need to understand nurses' experiences, feelings, intuitions and the meaning associated with caring for the dying. The feelings of nurses impinges directly on nurse-patient relationships in the care of the dying and lack of such understanding may compromise the quality of such relationships. Further, nurses experience death and dying in private and professional circumstances which may be compounded, leading to a lack of caring for "self" and an inability to fulfil patients' needs. An understanding of the experiences of those involved in the care of the dying, may have a salutary effect, leading to openness in expression of feelings and greater awareness of need in order to enhance quality of life for the dying, and for the nurse.

### **Statement of the Problem**

Little is known about nurses' personal experiences, feelings and behaviour in caring for the dying. Hence, it is necessary to procure knowledge of the care of the dying, how nurses understand it and how it may affect them. This information needs to be obtained by self-report, such that nurses can describe their own experiences. If more is known about how nurses experience meaning for themselves an increasingly legitimate base could be formed for nursing research, improved patient care and greater service to the community. This study will therefore begin to collect this information in context, by obtaining experiential descriptions from nurses who care for the dying.

### **Purpose of the Study**

The purpose of the study was to provide information on nurses' perceptions and understanding of the care of the dying and how it affects them. This was accomplished by describing nurses' experiences and interpreting meanings caring for the dying has for them.

### **Objectives of the Study**

To describe nurses' experiences of caring for the dying.

To interpret the shared meanings nurses have in caring for the dying.

To use this information as a contribution to knowledge which may be utilised for improving nursing practice.

### **Definition of Terms**

**For the purpose of this study:**

**Anticipatory Grief is defined as, "knowledge beforehand that death is probable, or inevitable in the near future .... this anticipatory grief .... may affect both the dying person and those close to him" (Raphael, 1984, p.50).**

**Nurse is defined as any registered nurse licensed with the Nurses Board of Western Australia and practising in a clinical setting.**

**Meaning is defined as, "that which exists in the mind .... is conveyed, denoted, signified or understood by acts or language" (Webster's Dictionary, 1979, p.1115).**

**Experience is defined as, "an actual living through an event or events; personally undergoing or observing something" (Webster's Dictionary, 1979, p.645).**

**Perception is defined as, "insight or intuition, as of an abstract quality" (Webster's Dictionary, 1979, p.1330).**

**Hospice is defined as, "not only a place that 'cares for the dying' but a community giving less technology and more personal care than the usual ... hospital ward" (Saunders, cited in Feifel, 1977, p.161).**

**Hospice Care, refers to, "the active relief of various types of distress and a personal approach to a patient and his or her family, at home as well as in the wards" (Saunders, cited in Feifel, 1977, p.161).**

Hospice Nurse is defined as a registered nurse licensed with the Nurses Board of Western Australia and who follows, "a program to provide comfort and support to the dying and their survivors, and respect for their autonomy" (Thomas, 1983, p.22).

### **Assumptions Underlying the Study**

Assumptions in phenomenology are dealt with by "bracketing" examining and identifying presuppositions and preconceived ideas which relate to the phenomenon under examination. There needs to be the recognition that as Van Manen (1984, p. 9) states:

Common-sense preunderstandings, suppositions, assumptions and the existing bodies of scientific knowledge predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological questions.

Thus, setting aside certain questions and experiences about what the researcher thought was understood of the care of the dying and to discover what was really being experienced by the research participants' allowed the researcher to arrive at a new depth of the phenomenon (Kvale, 1984).

The researcher was further aware however that one's own experience may be an important source of phenomenological data. As Bergum (cited in Morse, 1991, pp. 61-62) states, "there was a consciousness of the interaction .... I was not merely a privileged observer, I was involved."

Therefore the assumptions and beliefs of the researcher include:

Dying and death in western society is generally a 'taboo' subject and research participants may be hesitant to talk about them;

Research participants share meanings that constitute the substance of caring for the dying;

This group of participants share social psychological problems which are not necessarily articulated;

The researcher's previous personal experience with caring for the dying;

The researcher's involvement in the study did not mean the suspension of objectivity.

### Thesis Overview

This study seeks to describe the lived experience of nurses caring for the dying. Chapter one provides the background for examining the meaning of dying and death and the concept of anticipatory grief. The significance, purpose, rationale and assumptions underlying the study are discussed. Chapter two presents a literature review, highlighting gaps in the literature and relevant findings from both qualitative and quantitative studies, where they exist.

Chapter three outlines the methodological approach of the study including an overview of phenomenology as a philosophy and as a method, followed by a discussion of qualitative and quantitative methods of research used in nursing. The steps of the research design are described, followed by examination of the issues of validity, reliability and ethics. Finally, data collection and data analysis are outlined followed by explication of coding and storage of data. Chapter four reports the findings of the study and chapter five discusses the



findings in relation to the research questions and previous knowledge of particular themes which emerged from the study.

Chapter six concludes with a brief summary of the methodology and research findings. Limitations of the study are presented and the implications for nursing practice and recommendations for further research are provided, followed by conclusions.

## CHAPTER 2

### Literature Review

#### Introduction and Overview

In phenomenological studies it is not typical to undertake a substantial literature review. As Van Manen (1990, p.76) suggests, "it is sound practice to attempt to address the phenomenological meaning of a phenomenon on one's own first". Therefore, a substantial literature review was not conducted, primarily to avoid possible distortion of the data and the researcher's interpretive understanding of the phenomenon. However, this chapter provides a critique of selected literature concerning care of the dying, in order to identify the current state of knowledge related to the phenomenon. The associated concepts of grief, dying and death are examined and perceptions on death are offered prior to a discussion of the concept of grief itself. Related research is discussed from the perspective of hospice and palliative care as this was felt to be central to nurses' experiences' of caring for the dying.

#### Perceptions of Dying and Death

Dying and death have always been viewed with mystery, superstition and even a fascination by people in society. Today however, each person may be reminded of dying and death frequently enough, yet the personal reality of dying and death is often too remote and usually of only momentary concern.

Dying and death is not purely a personal matter however, as society still prescribes standards, culturally hued, for dealing with grief (anticipated or not) as well as bereavement and mourning. Appropriate ways to respond in one culture may be punished in another, all of which suggests that, "any work with people in the area of loss and death must take into account their social, cultural, religious/philosophical, and ethnic backgrounds" (Rando, 1984, p.5).

The dominant attitude in western society is one of denying dying and death, resulting in an apparent refusal to confront death. Thoughts and experiences of death are antithetical to the prevailing cultural philosophy which proclaims that death is not a "natural" part of human existence. People shy away from dying and death, despite the benefits for the terminally ill associated with the caring philosophy of the hospice movement. Central to this persistent trend is that most people today tend to die in hospitals or nursing homes (Pattison, 1977; Rando, 1984) away from family and friends. Dying and death remain largely "taboo" subjects. Further, advances in medical science have prolonged life such that people are progressively depersonalised and alienated from mainstream society, whether healthy or sick. For the sick, the interim between diagnosis and death is lengthening, and has been termed the "living-dying interval" (Pattison, 1977; 1978). This brings a myriad of problems to the sick and the healthy, not the least of which is the care of dying, but also the fundamental and relatively unrecognised phenomenon of anticipatory grief.

Freud (1961) undertook to establish the normal process of grief within the context of his classic paper "mourning and melancholia." He wrote that mourning is:

The reaction to the loss of a loved person, or to the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal, and so on .... it is also well worth notice that, although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. We rely on its being overcome after a certain lapse of time and we look upon any interference with it as useless or even harmful (Freud, 1961, pp. 243-244).

The implicit assertion is that grief is prompted by loss and that loss does not only involve death. Further, grief is seen as a normal and expected process, implying a self-healing aspect which, under normal conditions, occurs without intervention (Rando, 1984).

Thus, grief is seen as the price paid for love (Freud, 1918), in psychoanalytic terms. Grief has also been variously described as, a psychological wound or even a disease (Engel, 1961); a normal reaction to a distressing situation (Lindemann, 1944); the response to loss of meaning (Marris, 1974); or a physical injury or blow (Parkes, 1986). One of the few points of agreement apparent in the literature is that grief is a process which takes time from which to recover (Engel, 1961; Lindemann, 1944; Marris, 1974; Parkes, 1986). Time of recovery is variable, according to the intensity of the grief, the nature of the relationship with the deceased but especially the success (or otherwise) of, "grief work" (Lindemann, 1944, p.143).

Grief may give rise to somatic symptoms, pre-occupation with the dead, guilt, hostility and an inability to conduct oneself according to social norms (Lindemann, 1944). However when symptoms of grief are seemingly absent, it may indicate that feelings are being suppressed, or the death of a person did not evoke the expected emotional reactions. Fulton and Fulton (1971) suggest there may be many factors that might generate such a response, but one of the most important to understand within the context of caring for the dying is the phenomenon of anticipatory grief.

Phases, or stage theories of grief are quite evident in the literature. Bowlby (1961) presented three main phases: The urge to recover the lost object; disorganisation and despair; and re-organisation. Engel (1964)) identified five characteristic features of grief including:

Interruption of automatic, taken-for-granted aspects of living .... attempts to refute, deny, and dispute the reality of the death .... various ... cries for help .... attempts to construct a mental representation of the deceased to replace the physical presence. Personal, social, and institutionalised experiences of grief that serve to detach the mourner from the dead and restore him to his place as a member of the social community (p.94).

Engel saw grief as a healing process which could be interfered with by unsound intervention, suboptimal conditions for healing, or a lack of individual coping resources.

Kübler-Ross (1969) outlined five stages which an individual undergoes when coping with imminent death. These stages include denial and isolation, anger, bargaining, depression and acceptance. However, Kübler-Ross's model has been inappropriately applied to bereavement and it is also suggested that, "stage models have been criticised as inaccurate and misleading because they

ignore individual differences and lack empirical support" (Saunders & Valente, 1994, p.320). The controversy surrounding stage or phase theories has persisted for some time, and Rando (1984) suggests that caregivers in particular have believed stages to be invariant such that, "they have tried to fit the individual to the theory instead of using the theory to gain a better understanding of the individual" (pp. 38-39). She goes on to suggest that theories provide a general pattern, not a static or absolute course.

A final point, generally missing from the literature, but consonant with the research methodology and philosophy of this study, is Mullen's phenomenological insight (cited in Hill, Murray, & Thorley, 1979, p.27) which states:

When I observe another person grieving, his grief does not have the same significance for me as my grief, for whereas he lives through his grief for me it is an external object of observation. To do justice to a description of his grief an attempt to place myself in the position of experiencing that grief must be made while remembering that it is always an 'as if' construction however carefully I observe and listen to the account he gives of his experience.

One assumes the existence of other conscious minds as one tries to grasp the essence of an object (in this case the mind of another person) and, in a phenomenological sense, by reflection, bracketing and intuition, one tries to reveal the necessary features of the object under study, in order to describe and extract meaning from it. In this study nurses' experiences of caring for the dying are the "object" of study. Few identifiable studies have sought to elicit nurses' experiences utilising a qualitative, phenomenological methodology. It is hoped therefore, that this study will, in part, provide new knowledge, which will act as basis for recommendations in improving the care of the dying.

### **Nurses, Grief and Anticipatory Grief**

There is a dearth of information on nurses' understanding of anticipatory grief (or grief itself) in relation to the care of the dying. Lerea and Limauro (1982, p.604) also noted that, "research on grief among health care personnel has been sparse and anecdotal." Lerea and Limauro's (1982) quantitative study compared the grief responses of 47 nurses and 58 aides who worked in three associated geriatric facilities and 42 nurses and 25 aides who worked in a general hospital. Of these groups, nurses in general hospitals recalled more grief symptoms. The suggestion is that death in hospital tends to be more sudden than in a nursing home and generally, society accepts the death of an older person as natural and expected. Saunders and Valente's (1994) descriptive study of nurses' grief, actually looked at factors that influenced nurses' bereavement based on the analysis of over 300 questionnaires completed by oncology and hospice nurses who had attended the authors' bereavement workshops, as well as the authors' clinical experience and a review of the literature. They suggest that when patient death is frequent, the experience of bereavement is common and makes the tasks of making sense of death, managing emotions and realigning relationships more difficult. In order to facilitate their own grief, nurses need to understand theories and factors which influence bereavement and reduce bereavement overload. It should also be understood that nurses (and other professionals) need to be clear as to what they mean by grief, bereavement (and mourning) as these terms are often used interchangeably.

In a recent attempt at providing new evidence for anticipatory grief, Huber and Gibson (1990) conducted an exploratory study on the needs of 134 bereaved survivors of hospice patients, 20 months after the deaths of their loved ones. They developed a transitions framework to conceptualise both hospice care and anticipatory grief through the use of a new clinical tool "the 10-mile bridge." This last is a hypothetical, visual analogue scale (Aiken, 1969) which purports to reflect the personal beliefs and feelings of bereaved individuals. Despite the admitted limitations of the tool itself, (no reported validity or reliability, difficulties in self-disclosure, and lack of a control group), Huber and Gibson (1990) unashamedly conclude that their study, "is seen as new evidence that early grief work was facilitated through hospice care" (p.69). These authors seem to be confusing the concept of anticipatory grief with grief work per se, further limiting the credibility of this new evidence.

In a descriptive article, Jones (1991) suggested that nurses can maintain the emotional well-being of patients, provided they have an understanding of the processes of anticipatory grief. However, he cited other authors' conclusions on how nurses cope with dying patients without explication of the processes of anticipatory grief. The suggestion that grief work is paramount seems laudable, but this also confuses two separate although related concepts.

Sweeting and Gilhooly (1990) presented a review of the evidence for anticipatory grief, much of which has been repeatedly analysed. What is of note however, is the suggestion that, "it is not only family members who require information on the nature of the anticipatory grief reaction .... caregiving staff are involved as well" (p.1079). The premise is that if not prepared in caring for



the dying, caregivers may be unable to fulfil their role. Additionally, they may fall victim to stress, burnout, withdrawal from patients and experience feelings of guilt.

Welch (1982) utilised a quantitative methodology in studying the psychosocial impact of anticipatory grief amongst 41 family members of adult cancer patients in an acute care setting. She concluded that the role of health maintenance professionals involves helping families maintain grief responses within normal boundaries. The implication is that nurses do understand anticipatory grief as a phenomenon, can describe it, and utilise strategies to minimise post-death grief, which is not apparent in the literature.

In a descriptive article, Benoliel (1974) suggested that physicians and nurses responses to anticipatory grief within the context of terminal care created high vulnerability to professional loss. These losses purportedly relate to an inability to prevent the death of a patient, occasionally resulting in negligent performance and behaviour which may be viewed by peers as unprofessional, such as lack of control and composure, lack of competence and “distancing” behaviour.

Enlow (1986) offered a personal description of anticipatory grief as she prepared for the death of her mother three times. She suggested that preparation for death involves various phases of adjustment and depending on individual circumstances, these phases occur in different sequence and degree in intensity. Further, if the resolution of grief becomes fixed, it may become morbid and destructive.

Similar to Glaser and Strauss's (1968) view of a hyper-mature death, when someone takes too long to die, is O'Donnell's (1991) descriptive observation of secondary anticipatory grief reactions associated primarily with human immunodeficiency virus (HIV). Earlier diagnosis and improved clinical intervention is resulting in people with HIV living longer. Consciously or unconsciously, people who have anticipated and prepared for death, find that they are alive and well (apparently), and are now not likely to die for some unspecified time. The ramifications of these secondary anticipatory grief reactions are far from being understood, but may also apply equally to people with primary degenerative disorders and the simple fact that people are living longer.

The published research reviewed here has focussed on bereavement, responses to and coping with dying patients, as well as studies which purport to provide new evidence for anticipatory grief within the context of care of the dying. It is clear however, that these studies reflect the continued ambiguity and poor understanding of anticipatory grief amongst researchers. It is evident that there needs to be a clearer understanding of anticipatory grief in order to guide research and practice in the care of the dying. In order to fulfil a patently obvious need, this study will describe nurses experiences of caring for the dying and provide the basis for future research and practice.

### **Qualitative Studies**

Field's (1984) utilisation of grounded theory in describing 19 nurses' accounts of dying patients in a general medical ward reported that nurses had

high levels of emotional involvement with dying patients and they preferred to be honest in discussing patients conditions. However, nurses still preferred to nurse people who knew they were dying rather than those who were unaware. In some ways Field's account seems to reflect a shift in nurses' involvement with the dying while maintaining a preference to communicate openly with those who knew they were dying. This shift seems to be a gradual move to what Glaser and Strauss (1965) termed an open awareness context, but the shift is painfully slow.

Carter (1989) utilised three theoretical perspectives from Freud, Kübler-Ross and existential phenomenology in analysing themes associated with grief. Subjects included thirty adults who had experienced the death of a loved one. Nine themes were identified in thirty narrative accounts of bereavement. Several features of bereavement, not previously addressed included; the changing character of grief, preserving the reality and meaning of the lost person's existence and the significance of personal history in affecting the meaning of bereavement. Unfortunately, Carter is dealing with post-death grief and appears to be using grief and bereavement interchangeably, which is confusing.

Smith (1990) utilised Parse's (1981) methodology to uncover the lived experience of struggling through a difficult time (for ten unemployed persons). Also, Cody (1991) used Parse's (1981) methodology to uncover the lived experience of grieving a personal loss from four participants. Both studies uncovered the concept of "valuing" as an integral part of the phenomenon of grieving. At the same time, these studies may also be seen as validating and

even extending Parse's (1981) theory of nursing, in that both studies effectively "uncovered" the essence and structure of the lived experience, as a process of "becoming" as defined in Parse's theory.

It is obvious that the number of published qualitative studies on grief, bereavement and mourning are few. Qualitative studies on the phenomenon of anticipatory grief amongst nurses caring for the dying are, for practical purposes, almost negligible, therefore this study is a beginning attempt to redress the imbalance, extant in the literature.

### Related Issues in Hospice and Palliative Care

The published literature suggests several issues that have been the focus of prior research. These include grieving (Kubler-Ross, 1967; Lerea & Limauro, 1982); burnout (Amenta, 1984; Bram & Katz, 1989; and Yasko, 1983); stress (Cross & Fallon, 1985; and Vachon, 1978); fatigue and cancer (Jensen & Given, 1991; and Winningham et al., 1994); quality of life (McMillan & Mahon, 1994); and euthanasia (Kuhse & Singer, 1993; and Wilkes, White, & Tolley, 1993).

The need for nurses to attend to emotional responses has long been recognised, and health care professionals, as a group, are said to experience a sense of loss when patients die, and they also grieve (Parker, 1979; Pett, 1979; Rando, 1984; Stowers, 1983; and Vachon, 1978). Rando (1984) suggests that many caregivers are "rescuers" who wish to save people from distress and even the inevitability of death. Vachon (1978) describes how stress increases as professionals discover the reality of death. Disillusionment is common with

the recognition that dying patients are not, “all young, beautiful, and articulate people who are longing to spend their dying months talking about their philosophy of life and death” (p.117).

Professional loss (and grief) is said to parallel that of family members but is not seen as being as intense (McCain, 1983). Grieving is also said to help professionals cope with the stress of caring from the terminally ill and failure to grieve may parallel Cundey’s (1981) assertion that, “an inability to cope with dying, death and bereavement is a major contributor to stress” (p.23). The cumulative experience of caring for the dying and the losses involved has received some attention in the literature (Parker, 1979). Both authors emphasise that constant encounters with the threat of death, often results in the threat of failure and loss. Evans, Esbenson, and Jaffe (1981) further suggest that:

One patient’s death produces a sense of grief, that increases .... emotional involvement with other patients, making us even more vulnerable when these new patients die. Thus the cycle feeds itself, bringing heightened distress, fatigue, and depression (p.56).

An extension of this observation, pertaining to the longer-term sequelae of trauma in nursing has been explored by Davidson, 1981; Davison & Jackson, 1985; and Quint, 1967. However, the suggestion that nurses have emotional needs in response to the demands of terminal care has not been popular, usually by nurses themselves (Davidson, 1981). This phenomenon was also described by Quint (1967) who suggested that the long-term effects of trauma and difficult situations has not been fully appreciated. Davidson and Jackson (1985) in their integrated review conclude that, “the concept of cumulative

trauma is useful to explain why some susceptible nurses as 'survivors' respond maladaptively and present long-term symptoms, while others bring more adequate and healthier coping mechanisms to bear" (p.10).

Working with terminally ill patients is also said to result in professionals considering their own mortality (Epstein, 1975; Kavanaugh, 1972; Newlin & Wellisch, 1978). As summarised by Cundey (1981, p.24), "nurses need to examine their feelings, fears and beliefs about their own deaths. This is not morbid. Nurses who cannot face death in their own lives will project this fear on to patients." In other words, nurses who cannot accept that their lives are finite, will be unable to afford themselves the dignity, self-respect and self-worth they deserve, nor will they be able to do the same for their patients.

In order to cope with the stress of caring for the terminally ill, Harper presented a five stage model for health professionals to become comfortable in their daily interactions. The stages represent a "normative" model of emotional and psychological progress, growth being attained as the professional gains:

Understanding, knowledge, strength, and works through conflicts, internal and external, thus adding a new human caring dimension to his existent capacity to be helpful. In other words, this is the maturing of the health professional (Harper, 1977, p.21).

Whether this model has been utilised by professionals in caring for the dying is unclear. Published literature on continued sources of stress indicates that this is not the case. It may be that individuals prefer to pursue their own maturing process. Alternatively, personal and organisational factors may be such that the maturing of anyone in caring for the dying is problematic.

Further, professionals are often poorly prepared in caring for the dying, and the

failure of educational programmes in addressing this problem is quite apparent.

As Rando (1984, p.437) asserts:

To expect traditionally trained caregivers, who have been taught to focus on the medical and technological aspects of intervention, to be able to automatically respond to the psychosocial needs of patients and families without training and practice is quite unfair. It predisposes them to feelings of failure, frustration, anger, and ultimately, burnout.

Other sources of stress for professionals include lack of organisational support, unclear delineation of expectations, inappropriate supervision, inappropriate feedback, lack of early intervention when stress is apparent, a "we-they" mentality and a lack of encouragement to address the emotional needs of professionals.

Ultimately:

The role of caregiver to the dying and bereaved is filled with experiences that bring grief and stress. We must attend to our own needs for relief from these demands; if we don't, we will hurt ourselves and diminish our capability to help others (Rando, 1984, p.443).

These needs may be resolved by a greater understanding of the shared meanings nurses have in caring for the dying.

### Summary

People are too far removed from experience with dying and death today, such that useful insights on anticipatory grief within the context of caring for the dying are difficult to extract from the meagre amount of published studies on the concept. Grief and its attendant consequences, as well as bereavement and mourning have been studied extensively, but usually from the bereaved's perspective, not that of the nurse.

Perceptions of nurses toward dying and death have been studied mainly from a quantitative perspective and have concentrated on nurses anxieties and fears in caring for the terminally ill. Few studies have attempted to elicit the meaning of the experience in caring for the dying and no study has sought to establish the effect of anticipatory grief amongst nurses caring for the dying, as a means of primary prevention.

Studies from hospice and palliative care reflect continued concern about the inherent stressors in caring for the dying. Few studies indicate any emphasis on professional loss yet the need for a study which describes the perceptions of nurses, by nurses in the context of caring for the dying, is quite apparent. However, studies reviewed here have been conducted in situations other than Australia. Therefore, there is a pressing need to build a body of research relevant to an Australian context. This study seeks to address the problem by utilising a qualitative, phenomenological approach in order to identify and describe nurses' feelings, intuitions and meanings as they impinge directly on nurse-patient relationships in the care of the dying. Hopefully, this study may make a contribution to knowledge as a basis for further research, improved nursing care and greater community service.



## CHAPTER 3

### Methodology

#### Introduction

This chapter situates the study in an interpretist rather than positivist paradigm for inquiry, as the major purpose was to elucidate meaning, in context, from the participants' point of view. The qualitative, phenomenological methodology is then presented, within a discussion of qualitative research approaches in general. This is followed by a description of the steps inherent in the research procedure. Issues of reliability and validity are examined followed by procedures for the coding and storage of data. Finally, data collection and analysis are discussed followed by a consideration of ethical issues.

#### The Paradigm For Inquiry

This study seeks to describe and interpret the understanding and shared meanings nurses have in the context of caring for the dying. As such, it is concerned with the tacit world of nurses as it is experienced. The researcher does not attempt to control variables, or manipulate the data to arrive at presupposed truths, as in positivistic research. Rather, research concerned with eliciting meaning from the participants' point of view is particularly suited to interpretist methods of inquiry. As Patton (1990, p.55) suggests:

The interpretist researcher's commitment is to understand the world as it is, to be true to complexities and multiple perspectives as they emerge, and to be balanced in reporting both confirming and disconfirming evidence.

The qualitative researcher enters the field of study as a learner, with no pre-conceived ideas or presuppositions whereas:

Positivists begin an inquiry *knowing* (in principle) what they don't know, constructivists typically face the prospect of not knowing what it is they don't know (Guba & Lincoln, 1989, p. 175).

In order to understand the world of the participants:

The interpretive researcher creates a dialogue between practical concerns and lived experience through engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds (Benner, 1994, p.99).

Alternatively, the positivist paradigm suggests that the world and people are, "structured by lawlike generalities which can be identified, predicted, manipulated and controlled" (Munhall, 1994, p.12). Universal statements are yielded by observation and measurement, the researcher remains aloof, pursuing the testing of hypotheses from a specific theoretical framework, all the while, employing specific designs to reduce bias and error from intrinsic or extrinsic variables (Munhall, 1994).

In areas where the understanding and meaning of a particular phenomena are of central concern, a positivist approach may not be sensitive enough. Not all phenomena can be measured, controlled for, or manipulated to serve the ends of a particular research approach. Thus, interpretive studies are particularly useful when:

Little is known about a domain, when the investigator suspects that the present knowledge or theories may be biased, or when the research question pertains to understanding or describing a particular phenomenon or event about which little is known (Field & Morse, 1985, p.11).

Nursing purports to have, as one goal, an understanding of the people being cared for. In order to care for people however, nurses must understand (and care for) themselves, within the context of an interactive situation. Nurses then become the participants of an interpretist study. The meaning embedded in nurses' thoughts, feelings and behaviours becomes the focus of the researcher's interest and the researcher, in an interpretist study, becomes part of the research process. Thus, "The goal is to understand human beings not only to know how they 'are', but to understand them, in order to know how to act" (Lynch-Sauer, 1985, p.105).

The intent therefore is to understand more meaningfully, some aspect of human experience and to communicate that understanding to others. The process moves from the concrete to the abstract, as the researcher begins with particular human experiences and generates concepts to express those meanings (Ammon-Gaberson & Piantanida, 1988). The concept of "naturalistic generalisations" (Stake, 1978, p.6) is helpful in understanding how the results of qualitative studies move from the idiosyncratic to the realm of shared knowledge:

Naturalistic generalisations develop within a person as a result of experience. They derive from tacit knowledge of how things are, why they are, how people feel about them, and how these things are likely to be later or in other places with which this person is familiar. They seldom take the form of predictions but lead regularly to expectation. They guide action, in fact they are inseparable from action ... these generalisations may become verbalised, passing of course from tacit knowledge to propositional, but they have not yet passed the empirical and logical tests that characterise formal ... generalisations.

Whether it is necessary or sufficient to then pass empirico-logical tests is arguable. It may be sufficient to accede to Guba and Lincoln's (1989) proposition to, "define science as existing on a continuum with discovery at one end and verification at the other" (p.113).

Proponents of positivism or interpretivism have offered argument and counter-argument against the "opposing" paradigm. Positivists assert that interpretivism is too subjective, unreliable or insufficiently generalizable. Morgan (1983) however, asserts that the same assumptions also undergird the positivist paradigm. Guba and Lincoln (1989) suggest that, "differences at the ontological and epistemological levels ... do not matter in the day to day conduct of inquiry *because methods and paradigms are independent*" (p.157).

The practical application of any paradigm appears to depend on the problem and/or situation as Miles and Huberman (1984) note:

More and more 'quantitative' methodologists, operating from a logical positivist stance, are using naturalistic and phenomenological approaches to complement tests .... on the other side, an increasing number of ethnographers and qualitative researchers are using predesigned conceptual frameworks (p.20).

Cook and Reichardt (1977, p.19) suggest that, "evaluators should feel free to change their paradigmatic stance as the need arises." Similarly, Patton (1982, p.190) contends that an evaluator can make, "mind shifts back and forth between paradigms," even within a particular investigation.

This study however, attempts to remain true to the intent and purpose of interpretivist research by being concerned with understanding nurses' experiences and the meanings they have in caring for the dying.

### **Methodological Approach**

Phenomenology was chosen as the most appropriate methodological approach for this qualitative study as it best reflected the purpose of describing nurses' experiences, meanings and understanding of the care of the dying.

### **Qualitative Research in Nursing: Changing Paradigms**

Published literature seems to suggest a consensus on the genesis of qualitative research in nursing. Silva and Rothbart (1984) have identified 1976 as the year in which the commitment to a logical positivistic approach began to be questioned. Interest in qualitative research spans more than a century (Bogdan & Biklen, 1982), but has waxed and waned. The renewed interest in qualitative methods is said to parallel the social unrest of the 1960's, including the feminist movement (Oiler Boyd, 1993). Grounded theory as a qualitative methodology was developed by Glaser and Strauss (1967) and in nursing, Quint (1967) used this method to study nurses' and patients' experiences with death and dying, while Paterson and Zderad (1976) introduced phenomenology in what they describe as a return to the human face of nursing. Prior to this time, quantitative research methods, characterised by objectivity, deductive reasoning, statistical analysis and methods of control was the dominant force. Only ten years have passed since the first three books on qualitative research were published (Field & Morse, 1985; Leininger, 1985; and Parse, Coyne & Smith, 1985), but the literature appears to be expanding rapidly.

Morse (1991, p.14) also notes that, “qualitative methods came into nursing through nurses who .... obtained their doctorates in other fields, such as anthropology.” While Chinn (1983) suggested that nurse researchers who had the advantage of a better education in the established disciplines developed a commitment to that discipline’s research method.” It is argued therefore that nurse researchers, at least initially, adopted a strictly scientific method as the only process for scientific discovery. Further, nurse researchers may have adopted the prevailing quantitative approach in order to gain acceptance and respect, not only by colleagues, but also for research publications and for the purpose of funding for research projects (Leininger, 1985).

The shift to qualitative research methods was not simply a matter of challenging the truth of quantitative research. Munhall and Oiler Boyd (1993, pp.11) suggest that, “the acknowledgment of a major scientific revolution in other disciplines and the desire to attain a level of professionalism where we base practice on a distinct body of nursing knowledge, led to a perceptual shift.” This shift led to a change in the language of nursing, the way nursing viewed people (and people viewed nursing) including the notion that nursing identified itself as a humanistic profession. The change was said to be representative of a transition from the, “medical, atomistic, causal model to a distinct nursing, holistic, interactive model” (Munhall & Oiler Boyd, 1993, p.12).

Five types of qualitative research, extant in the literature, are phenomenology, grounded theory, ethnography, case study and historical research. It seems appropriate at this point to clarify what researchers mean

by qualitative research, remembering that language is said to be a link to the philosophical underpinnings of the method (Munhall, 1994). For example,

Leininger (1985, p.5) states that:

The qualitative type of research refers to the methods and techniques of observing, documenting, interpreting attributes, patterns, characteristics, and meanings of specific, contextual, or gestaltic features of phenomena under study.

Benoliel (1984, p.7) stated that:

Qualitative approaches in science are distinct modes of inquiry oriented toward understanding the unique nature of human thoughts, behaviours, negotiations and institutions under different sets of historical and environmental circumstances.

Leininger appears more concrete in her definition and concentrates more on method. Benoliel's definition, seems to emphasise the uniqueness of human beings and stresses qualitative approaches such as phenomenology, as being quite distinct modes of inquiry.

Philosophical foundations are also seen to vary amongst researchers, as are the methods they choose. However Munhall (1994, pp. 10-11), suggests that qualitative researchers perceive reality and assign meaning from some of the following assumptions:

Individuals are viewed within an open perspective as active agents, interpreting their own experience and creating themselves by their inner existential choices.

Individuals and specific groups of individuals have varying histories, varying 'here and nows,' and varying perceptions of the 'future'.

**The world and its people are constantly changing and evolving: this assumes a dynamic reality.**

**'Truth' is an interpretation of some phenomenon: the more shared that phenomenon is, the more factual it seems to be, yet it remains temporal and cultural. Exploration may be 'partially' true depending on certain variable conditions and then only 'true' for specific individuals.**

**Interacting with subjects does not mean the suspension of 'objects'.**

**Objectivity, itself, can be viewed as a subjective discovery, a perception of its own.**

**The subjective experience of the individual or group is valued and described. Meaning comes from the source and is not presumed, assumed or assigned.**

**Linguistic, social and cultural considerations help imbue experience with meaning.**

**Qualitative research also has an ethical dimension which is determined by a reverence for the subjective, self-determined and self-described realities of individuals and groups (Punch, 1986; Munhall, 1988).**

**Essentially, qualitative research seeks to document and interpret as fully as possible the "gestalt" of whatever is being studied from the participants' point of view. Qualitative research is essential to grasp the "essence" of the person or domains of nursing which are revealed as being important.**

**This is most evident in phenomenological inquiry which, according to Van Manen (1990, pp.9-13) is:**



**The study of lived experiences .... the explication of phenomena as they present themselves to consciousness .... the study of essences .... the description of the experiential meaning as we live it .... the human scientific study of phenomena ... the attentive practice of thoughtfulness .... a search for what it means to be human .... a poetising activity.**

**Thus, qualitative research seeks to discover essences, attributes, meanings and characteristics of humans as persons rather than as “objects.”**

**In pursuing her own argument, Leininger (1985) also suggested that people are not reducible to measurable objects and do not exist independently of their historical, cultural and social context. By the same token, however, Dzurec (1989, p.74) comments on the tenacity of logical positivism in nursing, suggesting that:**

**The period beginning in the 1960's and stretching to today is perhaps the first in which the power relations in nursing and in human sciences in general, have allowed the recognition of logical positivism as a single philosophy of science rather than as science itself.**

**The dominant theme here is the recognition of logical positivism as a philosophy. It may be that “science” has stepped back and looked upon itself, resulting in a new perspective, which may supplant the dominance of the “scientific method.”**

**The impossibility of “completeness” with either method, or a mix of both, at present seems out of reach. Paths to knowledge and ways of knowing are changing exponentially, and it may be all that we can do is to accomplish a common goal and, as Morgan (1983, p.18) states:**

**Steer clear of the delusion that it is possible to know in an absolute sense of ‘being right’ and devote our energies to the more constructive process of dealing with the implication of our different ways of knowing.**

### **Phenomenology As Philosophy**

Phenomenology (Husserl, 1859-1938) may be seen as a philosophy and a research approach that focusses on the meaning of the “lived experience,” as the intention is to examine and describe phenomena as they appear in the lived experience of the individual. “Thus, human experience is inductively derived and described with the purpose of discovering the essence of meaning” (Field & Morse, 1985, p.138).

Husserl believed that phenomenology was not only a philosophical but a scientific method, which appears quite divergent from the existentialism of Sartre (1905-1980), and Merleau-Ponty (1908-1961), or the Hermeneutic phenomenology of Heidegger (1889-1976). However Husserl’s concern with scientific knowledge gave way, later in his life to the idea of the “Lebenswelt” or life-world, the world of everyday experience, from which the world of science ultimately is derived.

It is perhaps understandable that phenomenology has branched off into many directions. Husserl saw himself as a “beginner”, not wanting his teachings to be finished results, but rather the preparation for a responsible setting of the problem (Warnock, 1970). This is reflected in the continuing explication of what phenomenology actually is and to the use of phenomenology as a method of enquiry.

Merleau-Ponty (1962, p.vii) notes, “it may seem strange that this question has still to be asked half a century after the first works of Husserl. The fact

remains that it has by no means been answered." Omery (1983) also notes that as a method of research, phenomenology has grown, "out of a philosophical movement that is still in the process of being clarified. As a result, one can find multiple interpretations and modifications of phenomenological philosophy" (p.50).

A consistent and critical assumption of the phenomenological perspective is its emphasis on language. Language involves and informs experience. It does not exist apart from thought or perception, for it generates and constrains the human life world. From a qualitative perspective, language and the ability to express oneself to others is the only way we can bring experience into a form that creates in discourse a conversational relation (Van Manen, 1990).

Further, experience and perception are of concern in phenomenology. Perception takes place through the body and is therefore an individual's access to experience in the world. Perception of experience is what matters, not what may be perceived as contrary or truthful. Interpretation from the individual's perception is the critical point, not what is happening, but what is perceived to be happening (Merleau-Ponty, 1964).

In phenomenology therefore, an individual's perceptions are a mirror to meaning which is the starting point of perceptual experience intrinsic to the interface between subject and the world. It is the life-world, upon which existential-phenomenological thought is built.

### **Phenomenology As Method**

Ray (1985, p. 84) states that, "Phenomenology .... can offer a means by which the lived experiences of the 'life-world' of nurses can be studied and understood." Phenomenology searches for meaning, to describe experiences and to interpret that experience (Bergum, 1989). Upon this foundation, nurses' perceptions of caring for the dying may be better understood. However the researcher is aware of Spiegelberg's (1976, p. 645) cautionary note in that one must:

Proceed with the greatest care. For the phenomenological method is not foolproof, and plenty of fools have rushed in where neither angels nor conscientious phenomenologists have set foot .... There is no substitute for constant checking and re-checking.

The phenomenological method is also a research approach encompassing five basic elements, like other qualitative (and quantitative) methods which, according to Parse, Coyne and Smith (1985, p. 16) includes:

- a. Identifying the phenomenon;
- b. Structuring the study;
- c. Gathering the data;
- d. Analysing the data; and
- e. Describing the findings.

The phenomenological method therefore, is seen to be particularly appropriate for enquiry into the richness and diversity of the human experience and inter-relatedness within the world, and where little research has been conducted such that further inquiry and research can be initiated. The point of

phenomenology is to create a more thoughtful understanding of relating to and experiencing the world. As individuals, we need meaning and phenomenology offers a way to arrive at that meaning. Provided we remain open to seeking meaning, “we are always being and becoming” (Munhall, 1994, p.215).

Relevant questions are answered by an holistic approach to people interacting in their worlds, rather than a rigorous empirical approach. The strength of a qualitative, phenomenological approach lies in the fact that it, “provides methods to challenge myths of the ultimate truth, objectivity, the perfect method, scientific supremacy, empirical evidence, higher authority and significance” (Taylor, 1993, p.173).

The notion of method however, according to Van Manen (1990, p.28), “is charged with methodological considerations and implications of a particular philosophical or epistemological perspective.” For example, “one should not confuse phenomenological .... analysis of texts as a mere variation of .... content analysis, or as identical to analytic coding, taxonomic and data-organising practices common to ethnography or grounded theory method” (Van Manen, 1990, p.29).

The method of phenomenology is such that it posits an approach toward research which is presuppositionless. The task of the method is to investigate and describe all phenomena, including human experience, in the way these phenomena appear in their fullest depth and breadth (Spiegelberg, 1965).

However, in a real sense, there is no “method” in phenomenology which one can master easily. Indeed, it has been said that in the method of

phenomenology (and hermeneutics), there is no method!" (Gadamer, 1975; Rorty, 1979). Van Manen (1990) suggests however:

That there is tradition, a body of knowledge and insights, a history of lives of thinkers and authors, which, taken as an example, constitutes both a source and a methodological ground for present human science research practices (p.30).

Thus, this may be taken as a set of guides and recommendations for a principled form of enquiry that neither simply rejects or ignores tradition, nor slavishly follows it (Van Manen, 1990). Other interpretations of phenomenological method are given by Giorgi (1970); and Van Kaam (1969), all of which engage the researcher in a greater awareness of consciousness.

The phenomenal world is a world of conscious, perceptual, living people in constant contextual interaction. This interdependency implies that, "there is no world without a consciousness to perceive it and, similarly, no consciousness without a world to be conscious of" (Valle & King, 1978, p.12). Therefore, in order to understand human experience from the participant's (actor's) point of view, the phenomenologist utilises three general strategies which include phenomenological reduction, imaginative variation and interpretation (Keen, 1975). The first step is to bracket one's preconceptions and presuppositions by making them explicit preferably in writing, in effect, "one must 'lay out' ... assumptions so that they appear in as clear a form as possible to oneself" (Valle & King, 1978, p.12). Beliefs in the reality of the natural world are suspended in order to study the essential structures of the world.

Imaginative variation allows one to imagine the appearance of a phenomenon against the background of various meanings of experience in an attempt to determine what the phenomenon means (Keen, 1975). Finally, interpretation is the articulation of meanings as they emerge in the phenomenon (Keen, 1975). Any description remains faithful to the meaning of the phenomenon for the participant, as the person is describing his/her perceptions.

The process of bracketing “reduces” the natural world to one of pure phenomena however, as Merleau-Ponty (1962) remarks, “the most important lesson that the reduction teaches us is the impossibility of a complete reduction” (p.xiv).

### Reliability and Validity

Over the last decade, consistency in issues of reliability and validity in qualitative research have been discussed in depth by several authors (Lincoln & Guba, 1985; Leininger, 1985; Miles & Huberman, 1984; Minichiello et al, 1990; Morse, 1991; Munhall, 1994; Sandelowski, 1993; Van Maanen, Dabbs & Faulkner, 1983; Whyte, 1984; Yin, 1984).

In qualitative research Leininger (1985, p. 68) states that validity:

Refers to gaining knowledge and understanding of the true nature .... of a particular phenomenon .... and .... that reliability focusses on, identifying and documenting recurrent, accurate and consistent (homogenous) or inconsistent (heterogenous) features, as ... phenomena confirmed in similar or different contexts.

Rigour, in a “naturalistic” sense, according to Guba and Lincoln (1981) is not defined in terms of reliability and validity but rather in terms of credibility,

fittingness, auditability, and confirmability. Credibility is the criterion against which the truth value of qualitative research is evaluated and is achieved when, "data and interpretations will be at least ... credible to the audiences that are in the best position to judge them" (Guba & Lincoln, 1981, p.113).

Previously, Psathas (1973, p.12) alluded that the credibility of investigations:

Lies in the extent to which the findings are faithful to and consistent with the experiences of those who live in that world .... (and) .... whether the descriptions or accounts of the activities would allow others ... to recognise the activities if confronted with them in the life-world *after* having only read ... the accounts presented.

Credibility is ensured by returning findings to the participants for verification. The second criterion, fittingness, is met when the findings of a study:

Fit more or less well into a context other than the one in which they were derived .... (and) .... seem to be well borne out within the local context that spawned them (Guba & Lincoln, 1981, p.118).

Fittingness is accomplished by appropriate sample selection. Auditability, the third criterion is achieved, according to Guba and Lincoln (1981, p.122) when investigators can:

Review each decision and the consequent actions, verifying that substantially and methodologically sound options were chosen .... (ensuring) .... that documentation of the decision trail (that is, the audit trail) be adequately maintained.

Therefore, auditability is represented by ensuring clear, meticulous recording of the analysis

The final criterion, confirmability, equates to neutrality in qualitative research. Guba and Lincoln (1981, p.126) suggest that confirmability, "simply



**asks that the inquirer report his data in such a way that it can be confirmed from other sources if necessary." Confirmability is achieved when auditability, credibility, and fittingness are established.**

**Burns and Grove (1981, p. 80) note, "rigor is associated with discipline, scrupulous adherence and strict accuracy" which goes on throughout the research process. Sandelowski (1993, p.2) suggests however, "that rigor is less about adherence to the letter of rules and procedures than it is to the spirit of qualitative work." The best test of rigour in qualitative work is the, "creation of true-to-life, and meaningful portraits .... of human experience" (Sandelowski, 1993, p.2). Rigour may be augmented by the researcher's personality, being able to empathise with the participants' experiences in order to interpret them, while remaining open to the perception of the participant rather than attaching the researcher's own meaning to the experience.**

**Reliability (auditability) may be established by the use of equivalence tests, "when the researcher is interviewing an informant for a single time only" (Brink, cited in Morse, 1991, p. 177). Therefore identical or alternate forms of questions are asked during the interview itself. Also transcription of interviews from tape recordings is seen as another form of equivalence (Brink, 1991) which the researcher, in the present study, employed in an attempt to ensure reliability (auditability).**

**Triangulation of data occurred throughout the study. Miles and Huberman (1984, p.234) describe triangulation, "as supporting a finding by showing that independent measures of it agree with or at least don't contradict it". Their final**

point suggests that triangulation is a state of mind, in that using multiple modes of evidence, verification of data will largely be built into the process. In essence, triangulation of data allows the researcher to “discover” similar and dissimilar phenomena as well as those which change over time and those that differ according to group membership (Mitchell, 1986). In this study the researcher used in-depth interviewing, tape recordings, transcripts and a personal diary in order to remain ontologically and epistemologically consistent over time. The data in this study were, therefore, analysed with the intention of achieving confirmability (Guba & Lincoln, 1981).

### Research Procedures

#### Strategy for Sampling

When obtaining a purposeful (Patton, 1990) sample, the researcher selects participants according to the needs of the study (Glaser & Strauss, 1967; Diers, 1979; Bogdan & Biklen, 1982). In the present study this selection resulted in thirteen (13) participants giving initial consent, four (4) of whom withdrew, resulting in nine (9) participants willing to proceed with the study. This particular group of people was selected for their specific characteristic behaviours and experience, considered important for the research and who were thought to be appropriate and adequate (Morse, 1986; Walker, 1985). The primary assumption therefore, was that participants held similar views and that their experiences rendered them relatively homogenous.

While the sample size is small, "an unbiased sample ... chosen randomly violates the qualitative principle of obtaining information from experts" (Morse, 1991, p.125). In addition, the time involved in transcribing and analysing large amounts of data from each participant as well as the researcher's own field notes, precludes larger numbers. However, it was felt that, "each verbal description was a complete description of the ... interaction and as such described the essential structure of that interaction" (Reimen, cited in Munhall & Oiler, 1986, p. 94).

The power of purposeful sampling lies in selecting information-rich cases for in-depth study. Such cases are those from which one can learn a great deal about issues of central importance to the purpose of the research (Patton, 1990). Thus the sample was selected according to the participants' assumed knowledge of the research phenomenon.

The study population was obtained from registered nurses employed in a hospice setting as the researcher felt that this group may be better placed to experience caring for the dying than would their counterparts in an acute care setting.

The following selection criteria applied in this research, namely that the participants be:

- a. Registered with the Nurses Board of Western Australia.
- b. Practising nursing in a hospice setting.
- c. Have previous experience in a hospice or palliative care setting.

**d. Speak English as a first language.**

The researcher was also aware that information gained from this study may not be evenly distributed amongst the total population of registered nurses nor those working in a similar setting. However, because this is not the aim of the research it should not be a concern to the investigator (Diers, 1979)

**Access to the Sample**

The governing body of the Hospice including the Director of Nursing was requested to participate in the study by providing a list of potential participants.

Following a review and acceptance of the researcher's proposal a meeting was arranged between the Director of Nursing, the Clinical Nurse Specialist, the Nurse Manager and the researcher, to decide on the best way of enlisting the help of potential participants. The researcher felt that it would be better if some time was spent becoming familiar with the environs of the Hospice and, in that way, meeting potential participants in an informal manner. This was achieved by visiting the Hospice on several occasions and at different times, such that as many of the incumbent staff could be met as was possible, without interfering with any responsibilities nor impinging on the confidentiality or anonymity of the residents.

The Clinical Nurse Specialist facilitated the process of identifying potential participants and being introduced to the researcher. Initial contact with potential participants enabled the researcher to establish a rapport and briefly explain the purpose of the study.

A letter of introduction (see Appendix C) was given to potential participants and one letter was also posted in the staff room, giving the name of the researcher, the purpose and potential benefits of the study. Thirteen (13) participants gave initial consent to be interviewed. Four (4) participants withdrew from their original decision to participate until the final sample consisted of nine (9) registered nurses all of whom had had experience in hospice care.

The researcher was aware of the limitations and criticisms of purposeful samples in that the sample was biased by virtue of the selection process. While the method includes a participant with certain knowledge, this is acknowledged in the purpose and intent of using this method and as Morse (1991, p.138) suggests, “bias is used positively as a tool to facilitate the research.”

The purpose of non-probability sampling is to facilitate understanding, to describe experiences, and elicit meaning from experts, while remaining faithful to the emergent data without regard for “scientific” adherence, as in quantitative research.

### In-Depth Interviews

In-depth interviews were used to obtain information from registered nurses who were licensed with the Nurses Board of Western Australia and were employed in a hospice setting.

These were, “face-to-face encounters between the researcher and the informants directed toward understanding informants’ perspectives on their lives, experiences or situations as expressed in their words” (Taylor & Bogdan, 1984, p. 77).

At this juncture, it is important to differentiate between therapeutic and research interviews, in order to avoid the pitfall of the interviewer becoming the interviewee. As Patton (1990, p.354) states:

The purpose of the research interview is first and foremost to gather data, not to change people .... neither is a research interviewer a therapist. Staying focussed on the purpose of the interview is critical to gathering high-quality data .... on the other hand, the interviewer, in establishing rapport, is not a cold slab of granite.

Thus, in this study in-depth interviewing (Minichiello, Aroni, Timewell & Alexander, 1990), utilising open-ended questions as well as therapeutic listening (Kemper, 1992) was used to allow participants to communicate their feelings, in order to empathise with and confirm what the participant was conveying. This generated information on nurses’ experiences and shared meanings in caring for the dying.

The participant’s and researcher’s accounts are egalitarian and that, rather than using an interrogative process, a more conversational style is used to understand the participant’s world, in language natural to them (Minichiello et al, 1990). Thus, in-depth interviews were conducted to elicit informants’ perceptions of caring for the dying.

## **The Interview Guide**

An interview guide is developed around a list of topics without fixed wording or fixed ordering of questions. "The content of the interview is focussed on the issues that are central to the research question, but the type of questioning and discussion allows for greater flexibility" (Minichiello et al, 1990, p. 92). This was felt to be useful because this technique is used when, "information is required about a topic, when the structure of the topic is known but the answers cannot be anticipated" (Field & Morse, 1985, p. 67). At the same time, participants were permitted freedom to respond and describe feeling states.

Following initial preamble with the participants' all interviews were guided by the question, "What are your experiences related to the care of the dying?" Recursive probes were used in order to focus participants' attention and for the participants' and researcher to become involved in the social interaction of the interview.

As topics emerged, these were expanded upon as the participants wished. Additionally, the use of open-ended probes occasionally facilitated the emergence of new topics, for example, further contact with families and the meaning of death.

Therapeutic listening augmented the interview process, and is defined by Kemper (1992, p. 22) as:

An interpersonal confirmation process involving all the senses in which the (researcher) attends with empathy to the (participant's) verbal and nonverbal messages to facilitate the understanding, syntheses and interpretation of the (participant's) situation.

Implicit in this definition is the maintenance of eye contact, an attentive posture, appropriate touch, gestures, encouragement, an open facial expression and verbal responses consonant with what the participant is saying. This allowed for empathic understanding and the enhancement of rapport, as well as increased flexibility in moving through content areas, following emotional or behavioural cues and ultimately, ensuring all questions were covered with each participant.

### The Interview Procedure

Potential participants who met the criteria for the study and who had agreed to participate were contacted personally by the researcher. A mutually agreeable time and venue for the interview was arranged, one which did not interfere with the duties and responsibilities of the participants. Participants were aware that the interview would take approximately sixty (60) minutes, according to need.

Participants were aware of the research topic, but not specific questions, therefore the researcher felt that this did not delimit the research questions because of prior knowledge, nor bias the data being gathered (Field & Morse, 1985).

Face-to-face interviews were conducted in the Hospice setting. This was a familiar environment for the participants in which they felt comfortable. The choice of a familiar and quiet environment assists in the development of rapport



and trust with the researcher (Field & Morse, 1985). A quiet room away from the main area of the hospice was used and with most participants, at a quiet time in the activities of the hospice, usually mid-afternoon. One participant was interviewed in her office and one was interviewed in an empty bedroom.

No one refused to continue with the interview once it had commenced and the researcher ensured that each person felt comfortable after the interview and was not distressed in any way. All participants were asked if they had any questions for the researcher, none were forthcoming.

Immediately following the interviews, the researcher recorded field notes, by writing down pertinent observations of non-verbal behaviour and subjective feelings, in a personal diary (see excerpt in Appendix F), which was available for inspection by the participants at any time. Interviews ranged over a period of seven (7) months in order to fit with the participants personal and professional time.

### Data Collection and Analysis

The major mode of data collection in this study was in-depth interviewing, supplemented by the use of open-ended questions and the researcher's diary. Data collection, data analysis and validation of the data took place concurrently. In particular, validation took place by returning to the participants on two occasions, firstly after the tape recordings had been transcribed and asking participants to read the transcripts and correct any omissions or commissions. Secondly at the end of the data collection period, participants

were asked to verify if the formulated exhaustive descriptions were an accurate description of their experience (Beck, 1992).

Data analysis serves two purposes, as suggested by Field and Morse (1985, p. 97):

The first purpose is to code the data so that categories may be recognised, analysed and behaviours noted. The second is to develop a data filing system that will provide a flexible storage system with procedures for retrieving the data.

While the method of data analysis varies amongst phenomenological researchers, the goal of all data analysis is the interpretation of data while remaining faithful to the phenomenon (Knaack, 1984). Methods of analysis have derived from the work of existential phenomenological psychologists such as Colaizzi (1973, 1978); Giorgi (1970) and Van Kaam (1969). The methods of existential psychologists have been adapted by many nurse researchers such as Benner (1983, 1985); Davis (1973); Oiler (1982, 1986); Parse (1987); Ray (1985); and Riemen (1986).

The transcriptions of this study were subjected to thematic analysis based originally on the work of Benedict (1948) and Murray (1938).

The data were analysed as they were collected in order to generate new questions (if needed) and obtain a greater understanding of the care of the dying (Omery, 1983). The sequence of steps during analysis of the data using Colaizzi's (1978) method of analysis:

- a. Written descriptions were read in order to obtain a feel for them.

- b. From each transcript significant statements and phrases that directly pertain to the care of the dying were extracted, using latent and manifest content.
- c. Meanings were formulated from these significant statements and phrases.
- d. The formulated meanings were organised into clusters of themes, which were referred back to the original descriptions in order to validate them, and discrepancies or contradictory clusters were noted.
- e. "Saturation" of the themes was ensured such that no new data could be found.
- f. The results of data analysis were integrated into an exhaustive description of the care of the dying.
- g. The exhaustive description is as unequivocal statement of the essential structure of the care of the dying as possible.
- h. A final validation by returning to the participants with the exhaustive description. Any new relevant data that was obtained from the participants was incorporated into the fundamental structure of the experience.

The steps for analysing the data included tape recording the interviews, obtaining a full and accurate record, leaving the material available for analysis and the researcher free to concentrate fully. Schwartz and Jacobs (1979) also point out that with tape recording there is greater analytical depth available and an accurate picture remains, enhancing validity by preservation of authentic

data. Use of a tape recorder is not without problems however, the most significant, and obvious, being that one cannot record non-verbal data (Minichiello et al., 1990). Therefore, a diary was kept to record non-verbal data as well as personal feelings and reflections on the interview process. The researcher felt this was helpful in offsetting potential bias and in supporting the triangulation of data.

Each tape recorded interview was transcribed by a typist who was well versed in the vagaries of transcription. Each tape was transcribed verbatim, pauses were noted with a dash and gaps were noted by a series of dots. All exclamations including laughter, crying and expletives were dutifully recorded. Interviews were typed single-spaced and there was a definitive blank line between the researcher and the participants comments. A 3.5 cm margin was left on both sides of the transcript, permitting the left margin for a summary note of the participants response and the right margin for comments on the content. On the top left of the transcript was written the participants number, interview number and time and date of the interview.

In order to become "extraordinarily familiar with the data" (Field & Morse, 1985, p. 97) each tape was replayed with the researcher listening carefully to the questions and the emotional tone of the responses as well as the content. Some participants were quietly spoken which necessitated further replaying of these tapes such that gaps in the transcripts could be filled. All tapes were replayed twice, again checking for accuracy, changes in voice, tone or inflections which may have indicated an emotional topic (Field & Morse, 1985).

All transcripts were read and re-read in order to obtain “a feel” for the participant’s responses and to uncover the meaning of the lived experience for the participant. This was used with the technique of imaginative variation in order to apprehend essential relationships between essences (Spiegelberg, 1976, p. 682):

Keeping one essence constant we try to combine it with various other essences, leaving off some of its associates, substituting others for them, or adding essences not hitherto encountered together with them .... the question at issue is whether or not several essences stand in relationships not contained in either of them alone, but entailed by them jointly.

Thus, through imaginative variation the researcher used, “experience and intuitive procedures in conjunction, to synthesise knowledge about a phenomenon” (Oiler, cited in Munhall & Oiler, 1986, pp. 78-79).

Following this step, the researcher formulated significant statements and phrases from each participant using latent and manifest content analysis, Field and Morse (1985), who suggest that:

Latent content analysis is the most commonly used in qualitative analysis. Passages or paragraphs are reviewed within the context of the entire interview in order to identify and code the major thrust or intent of the section and the significant meanings within the passage. This permits the overt intent of the information to be coded, in addition to the analysis of the underlying meanings in the communication (p.103).

While this method may be valid, Field & Morse (1985) suggest that reliability may be lessened due to the possible subjective nature of the coding system. Thus in order to ensure reliability, especially in single interviews, the researcher attempted to be disciplined, accurate and adhered to the phenomenon of concern.

The researcher initially wrote down significant statements and phrases from each participant, which had been identified in the text, in the left hand margin of each transcript. An example from the transcript of participant S08 in response to a recursive question "Is life endless suffering?" was:

Oh no it's not. I see life as, well thinking of this environment, I see life as a place where opportunities are offered and there is life to live. I don't see people as dying until they actually die. I see them living until they die.

The marginal note on the transcript was therefore "I see life as full of opportunities and I don't see people living until they actually die."

After extraction and denotation of significant statements and phrases from all nine (9) transcripts, duplicate or essentially similar statements were eliminated. Significant statements were refined (See sample in Appendix B).

Meanings were formulated from the significant statements. "These meanings were arrived at by reading, re-reading and reflecting upon the significant statements in the original transcriptions to get the meaning of the .... statement in the original context" (Riemen, cited in Munhall & Oiler, 1986, p. 99). Clusters of themes were organised from the aggregate formulated meanings and represent themes that emerged from and were common to all of the participants descriptions (see Appendix A). Clusters (of themes) were referred back to the original descriptions in order to validate them. Each description was examined to see if there was anything in the original that was not accounted for in the cluster of themes, and whether the cluster proposed something that was not in the original (Riemen, cited in Munhall & Oiler, 1986, pp. 99-101).

The researcher was aware that some themes may contradict others or appear to be unrelated to others. If either was true the researcher referred to the original descriptions. From the integration of the analysis an exhaustive description of the phenomenon resulted, which was as unequivocal a statement of the essential structure of the phenomenon as possible (Riemen, cited in Munhall & Oiler, 1986, p.95).

A final validation of the descriptions and shared meanings nurses have in caring for the dying, was undertaken by returning to the participants and asking them to verify whether the formulated descriptions were a true reflection of their original experiences. While this form of participant checking has been hailed as a way of enhancing the rigour of qualitative research, Sandelowski (1993, p.4) cautions that, "Its potential .... belies the deeply theoretical and ethical difficulties involved in this technique that may serve paradoxically to undermine the trustworthiness of a project." Whilst perceptions may change over time, participants were still in the best position to check accuracy, as it was their perceptions which were of primary importance.

### Coding and Storage of Data

As data were collected and analysed, coding began concurrently. Miles and Huberman (1984) suggest that late coding weakens the analysis and that:

Coding is not just something one does to 'get the data ready' for analysis, but something that drives ongoing data collection. It is .....a form of continuing analysis. Qualitative field work should be iterative; one pass at site leads to a re-shaping of one's perspective (p. 63).

In this study the researcher looked for themes in each transcript. “Themes may be expressed in single words, phrases, sentences, paragraphs or even entire documents” (Minichiello *et al*, 1990, p. 289-290).

Significant statements related to the research question were extracted from the transcripts after they had been underlined and highlighted. Significant statements from all participant’s transcripts were colour coded to allow for ease of identification and comparison both across and within transcripts.

Coloured items from the transcripts were cut and pasted onto 150 x 200mm system cards in order to identify subcategories. Verbatim extracts from each participant were pasted on the appropriate card for each subcategory. Each extract denoted the participant number and page number of the transcript.

The original transcripts and tapes were kept in a “mini” filing cabinet with separate compartments which was locked. Three photocopies of each transcript were made for the purpose of cutting and pasting onto the system cards, and duplicate copies of each tape were made for the purpose of replaying, the originals being available should any tape break in the process. All copies were kept in a separate, locked filing cabinet.

Each participant was designated a file which contained the original transcript, original tape recording, consent form and the form for demographic data. Each participant’s file was randomly assigned an alpha-numeric notation, for example G09 and S08, in an attempt to preserve anonymity by obfuscating any particular ordering of interviews. The assigned alpha-numeric notations were used on copies of transcripts and tapes for anonymity, retrieval of



information and identification in the findings and discussion chapters. Diary notes were kept in the filing cabinet along with the copies of transcripts and tapes. The identification of participants followed the same format as for the transcripts and tapes.

### Ethical Considerations

The research proposal for this study was approved by Edith Cowan University's Ethics Committee and the governing body of the Hospice. Throughout the study, the researcher held to what Munhall (1994) sees as the most critical obligation, which is, "to describe the experiences of others as faithfully as possible" (p.153).

Potential participants were made known to the researcher and informed of the purpose of the research activity, the means by which they were selected and the interview procedure. Participants were asked to sign a consent form (see Appendix D) and to complete basic demographic information (see Appendix E). It was explained to the participants that they had the right to refuse participation at any time during the study, to omit particular aspects of the study and to withdraw from the study at any time without fault.

Participants were informed that if they felt distressed at any time they could terminate the interview altogether or continue at a later time. Participants were also informed that if they wished to see a counsellor, they may do so of their own choosing.

**The status and conditions of employment for any participant were not affected by being involved in the study. Participants were informed that no names would be used on any forms or tape recordings and each participant was assigned a number and corresponding code. Participants were informed that all tape recordings would be coded separately and on completion of the study all tapes would be erased.**

**Written consent was obtained at the commencement of the initial interview and participants were again informed of the previous considerations, ensuring confidentiality and anonymity.**

## CHAPTER 4

### Findings: Caring For the Dying

#### Introduction

The purpose of this study was to describe nurses' perceptions and understanding of their experiences of caring for the dying in order to interpret their shared meanings of caring for the dying.

A profile of the study participants is given, followed by a presentation of the data related to the research objectives that guided the study in the nursing care of the dying.

#### Phenomenological Analysis

Following the tape-recording and transcription of interviews with nine (9) nurses, significant statements were extracted which pertained directly to the phenomenon of interest (Colaizzi, 1978). Meanings were formulated from approximately 178 significant statements and organised into five clusters of some 18 themes. These clusters were referred back to the original transcripts in order to validate them (Colaizzi, 1978). This involved ascertaining whether there was anything in the original transcripts that wasn't accounted for in the clusters of themes and whether the clusters of themes suggested anything that was not implicit in the original transcripts. Themes were also noted for ambiguity; that is, those themes which flatly contradicted, or appeared totally

unrelated to others. No such themes were found. Resultant analysis identified five key themes: being transformed by the experience of grieving, the influence of context on caring, the embodiment of caring, caring for the family, and coping. Each key theme subsumed other emergent themes and the total experience of these nurses is described in terms of how caring for the dying affected them.

### **Profile Of Participants**

All participants were female and all spoke English as a first language. One was widowed, three were divorced and the remaining five were married. Seven people were born in Australia, one in New Zealand and one in the United Kingdom.

Three participants worked full-time, the remainder working an average of thirty two point six (32.6) hours per week. Eight nurses had spent up to ten years in hospice nursing and one nurse had up to twenty years experience in palliative care and hospice nursing. The number of years spent in present employment ranged from under one year, to six and one half years.

Seven participants completed initial nurse training in a hospital-based programme, and one in a college-based programme leading to registered nurse qualification. One commenced as a nursing assistant prior to becoming a registered nurse. Three of these nurses hold Bachelor of Nursing Degrees, one with an Honours Degree. One was currently pursuing a Bachelor of Nursing Degree, another was studying for a Post Graduate Diploma in nursing and one was undertaking a Graduate Certificate in Teaching. Two were also

registered midwives, one of whom also held a Certificate in Palliative Care Nursing, while another nurse had completed a post-basic course in paediatrics.

### The Experience of Caring for the Dying

The following is an overview of the experience of working with the dying. Following this, each of the themes will be discussed with their corresponding evidence. Hospice nurses have a deep sense of concern, compassion and empathy for others, reflected in their commitment to caring for the dying. Nurses did not regard themselves as being “special” in order to fulfil their obligations to their patients. On the contrary, most nurses saw themselves as “ordinary” and felt it was a privilege to care for the dying. Their conversations embodied the fundamental principles of sound nursing practice combined with the essential knowledge and experience of caring for the dying. In effect, the nurses cared for the family as a unit, not only the identified patient, to the extent that they often felt part of the family unit.

The nurses’ emotional investment in caring for the dying was inestimable. They shared the grief of families, going from anticipation of loss to acceptance, in varying degrees, depending upon the relationship they had developed. The simple fact of being there or staying with a dying person and their family no matter what the relationship, still ensured the dying person the best gift of all; the gift of oneself.

The nurses worked within a supportive environment which appeared to facilitate their goal. They attempted to ease the suffering of others whilst being aware of their own and the organisation’s limitations. They identified with

patients as human beings and communicated in an open, honest manner. A primary concern for nurses was that patients were the focus of their care and that decisions rested primarily with the patient, or the family, for as long as practicable. As in any human relationship, disagreements occurred that were usually resolved by discussion or debate.

Past and current experiences, thoughtfully reflected upon, ensured that the nurses maintained a realistic perspective about what they could and could not do for patients. Most nurses were comfortable with the notion of death and all expressed a healthy concern for themselves. Personal loss had been experienced by most nurses and this, combined with the care of the dying, seemed to have a salutary effect such that some nurses had re-ordered their lives, maintaining a healthy balance between caring for others and caring for themselves.

### Themes

#### Being Transformed By The Experience.

Caring for the dying changes people. Nurses described how they had become more aware of their personal strengths and limitations; in effect, becoming more self-aware. Enhanced awareness of self was also seen by some nurses' as leading to a greater ability in giving of oneself and enhancing compassion for the patient and their family. Nurses seemed attuned to the needs of individuals within the context of caring for the dying. It appears that most of these nurses have come to terms with their own mortality, being largely unafraid of death, such that they are able to care for the dying, maintaining a unique human kindness. From nurses' descriptions, four initial emergent

themes were clustered under the common theme of personal feelings about the experiences. These included:

Developing a Realistic Perspective

Developing a Philosophy of Dying

Balancing Guilt and Compassion

Experiencing Loss and Acceptance

Developing a realistic perspective.

These nurses felt that being aware of what one can and cannot do for a dying person is influenced by one's own expectations of dying and death. The nurses' perceptions of the reality and inevitability of dying and death counter the romantic notion of a "good death". The fact of working with the dying, is knowing that the person is going to die, sometimes horribly, painfully and frighteningly. Also, the relief and sharing of grief experienced by some nurses was seen as quite realistic while still feeling compassion and empathy, both for the deceased and his/her surviving relatives. The nurses understood that being aware of and sharing emotions helped the family and the nurse only if individuals within the family unit could make sense of each other's experience:

I feel compassion and empathy, depending on how close I was to the person. One gets used to death. I'm not shocked. It's just part of the job. (H04)

Sometimes it can be more unhappy if they don't die. Death rounds off everything you've been doing and that's what you're working toward in a way. (P03)

Other nurses' proffered the suggestions that:

It depends upon who they are and what they want. I try to step into the person's shoes and see how it is for them. Even though life is finite, it's still a shame. (S08)

If you share your grief with the family it helps yourself. I like to grieve with people because I feel that helps them say goodbye. It's anticipation of how they (the family) are going to cope when that person dies. (C07)

These nurses seem to reflect a tendency to face facts and be practical rather than imaginary or visionary. In this way they remained realistic in their relationships with families while empathising with their loss.

### Developing a philosophy of dying.

To be aware of one's strengths and limitations, is to have insight into oneself which comes from reflecting on past and current experiences. Application of this insight to the care of the dying, the dead, (and oneself) may be seen in these nurses' comments:

I see life as a place where opportunities are offered and there is life to live. I see people living until they die. (S08)

Life is not endless suffering. (D05)

I feel as though I've learnt from the past. It helps form your character. (G09)

Something will come up and it will remind you of something in the past. don't dwell on it though. (M06)

Some nurses commented on the meaning of death, reflected in the following statements:

Death brings a sense of peace and release from pain for a person. (G09)

I feel relieved having "travelled with them" even for a short time.

They always look so peaceful. (S08)

I know that there is suffering which is not going to go on forever. People go somewhere better but I do not know where this is. (H04)

It's the end of life. I'm not sure if there's anything more. Death is inevitable. I believe it is a transition from this life to the next. (M06)



I've probably asked what's the point of it all because I think you have to come to terms with your own death before you can work here. (G09)

I think you become self-sufficient. It's really unhealthy to rely on other people for your own needs. (C07)

Since I've been working here it's changed. I had lots of goals before but now it's just enjoy yourself as you can. (X01)

These nurses seem to perceive life positively, and continuing up until the moment of death. The past is looked upon as influencing their character and present perspectives. The meaning of death in this context clearly brings forth a sense of peace, relief and freedom from suffering. The nurses seem to ascribe to a view that life continues after death in some form or other.

Their experiences in caring for the dying also seems to have changed their outlook on life and, interestingly, one nurse accedes to the proposition that one has to come to terms with one's own mortality before being able to care effectively for the dying. Overall, these nurses appear to feel comfortable in facing death, and have the requisite knowledge and personal strength to care effectively for the dying.

### Balancing guilt and compassion.

Personal development embodies deep compassion for others whilst maintaining a realistic and healthy concern for oneself rather than allowing guilt to introduce on their ability to care. These nurses understand that living can sometimes be more painful than dying. They are also able to afford themselves the respect and dignity they deserve. Nurses' comments reflected that they seek a balanced sense of self. This seems to reflect personal and professional maturation, as the following statements indicate:

I felt guilty in the past about making more of an effort, but I now realise it's just different priorities. Guilt means not being committed to what you are doing. (S08)

Initially, I used to think, why was I short with that person, I could have done this or that. I could have done more. But not now (G09)

I often think, "Thank goodness she's finally gone" (V02)

For these nurses, experience with dying, death and loss appears to have effected a significant change in attitude, in that they realise their limitations and are thankful that someone's suffering is finally over.

### Experiencing loss and acceptance.

Everyone lives, and everyone dies. Throughout life, nurses, as individuals and professionals, encounter loss in many ways, the effect of which may be accumulative in nature. Any loss, especially the loss of someone significant, changes an individual and nurses may be especially vulnerable to the effects of loss as they constantly care for dying people. Nurses gave very open and honest comments on experiencing loss and acceptance:

My perception on loss seems to be what drives me now. (S08)

I felt a sense of longing after he died, but I was relieved his suffering was over. (M06)

I felt sad when he died, it was hard to take at the time. (D05)

I felt devastated going through a normal grieving process, but I feel I came through it. (H04)

It hurts, it's like an open wound, almost like a pain I guess. But gradually it heals up and after a while the scar is there but it no longer hurts. (P03)

I was an absolute disaster, it was such a shock and very sad. I also felt very alone. Part of your history is gone. (V02)

The following nurses' comments offer a different view on loss. As they suggested:

**I think most people that work here have been through some experience where they've lost someone and I think that's why most people come here, because they want to do it better than what happened to them. (X01)**

**I know some people have felt that they have been sent here. Maybe it's those who have experienced a loss and maybe that's why they pick up that someone needs support. (C07)**

**True acceptance of loss was seen as follows:**

**It's becoming aware of, facing the changes and losses and coming to terms with them, making them part of you. (PO3)**

**I don't think you forget that person, but I think you get over them. You also have to go with the feeling for a while. (VO2)**

**The longing for someone doesn't go away, it stays there - and it's very useful in sitting/talking to people. (SO8)**

**Two nurses' comments reflected how acceptance of loss may be problematic:**

**If they're gone when you come back from days off it's difficult. It's good to say goodbye. Sometimes I think you find out in the death notices, so on your days off you scan the columns. (HO4)**

**Sometimes it's really disappointing if the patient doesn't die when you're at work because you feel like you haven't finished off your business. (CO7)**

**One nurse offered the insightful comment that:**

**With most people you don't need to resolve the relationship because its (death) is what you've been working towards. (GO9)**

**One suggestion appears to be that personal loss motivates some nurses to care for the dying as a means to expiate the suffering they may have experienced in the past. Other nurses described their feelings, which, although painful, appear to have been resolved such that they are at least able to proceed with the care of the dying. Other nurses seem to accept death as part of the work they do, their final goal.**

### **The Influence Of Context On Caring**

The nurses described the environmental setting within which they worked, in terms of either positively or negatively affecting the care of the dying. While all nurses acceded that working with the dying was a matter of choice for the individual, their everyday ministrations were either assisted or impeded by the physical structure of the environment, organisational philosophy, policy and procedures, formal and informal networks, organisational structure and organisational support. These factors were also seen in association with nurses taking responsibility for their own care, and their own actions with regard to patient care. The nurses' contribution to the caring environment and the influence of the environment on their approach to patients resulted in the emergence of two initial themes:

Teamwork

Conflicts

#### **Teamwork.**

One component of organisational structure voiced by some nurses as important was the notion of working as a team. Working with a group that has the same goal was seen as a rewarding experience, as the following comments indicate:

Most people have the same care philosophy. We try to make sure everyone's on the same wavelength. (H04)

The ability to work with a team accomplishes something. (P03)

I feel safe in this environment, so I'm not slow at coming forward and stating how I'm feeling. (C07)

I usually don't stew over things. You work together and you can usually turn around to do something and the other person is already doing it. We really care for each other. (X01)

### Conflicts.

Generally, nurses seemed to prefer open discussion or debate, in order to resolve differences and prevent conflict. Disagreements did arise however, as reported by the nurses, and centred mainly on the care of patients. Various comments from the nurses suggest differing views, as may be seen in the following:

I'm aware of patient needs, but sometimes frustrated by doctors. Sometimes you may not agree, but they (the doctors) may actually be right. (GO9)

It goes back to frustration because of the medical side of things. Sometimes people put up a brick wall and you can't see what's going on. It must be hard for them (the doctors) but they often give families a false sense of hope. (X01)

Yes we disagree, and they (the doctors) get angry with us - because we interrupt them. They're human. They are open to constructive criticism. (MO6)

A different perspective was offered by three nurses in that:

Obviously there are disagreements on the plan that we have for that person, but not generally. (HO4)

Sometimes a conflict may arise due to lack of understanding. Generally I don't argue with others, they argue with me. (SO8)

I do find the politicking and stress from inter-staff relationships does get me down. (PO3)

One nurse stated:

I don't recall any particular conflicts. I feel everyone has the same philosophy. We are an amazingly compatible bunch. (DO5)

From the nurses' accounts, conflicts mainly arise out of interpersonal relationships, and are usually resolved by open discussion.

### **The Embodiment Of Caring**

The nurses experienced the burdens and benefits of caring for the dying in ways which counted for them and created possibilities for their patients.

Caring was not seen as a one-way process, as they gave and also received help or satisfaction throughout their interactions. Nurses valued, respected and recognised the vulnerability of their patients (as well as their own vulnerability), and remained accessible even if a particular situation was distressing or intensely emotional. The experience of caring was exemplified in five initial themes:

**Making a Difference**

**Recognising Limitations**

**Identifying with Patients**

**Communicating**

**Empowering the Patients**

#### **Making a difference.**

Within the hospice environment, nurses described what they felt could be achieved for their patients. One nurse recounted the story of how several nurses were involved in planning a helicopter ride for a patient, but on the day of the flight the weather was bad. Shortly after, the patient deteriorated and died, her wish unfulfilled. The point is however, that these nurses had tried to

make a difference regardless of the outcome. Other nurses described physical and/or psychological issues as making a difference.

This environment is challenging in that you're healing a lot of things, social, psychological or long stemmed family issues. I think we do a lot of good work and achieve a hell of a lot here. (C07)

People are living until they are dead, and you can make them comfortable. make sure they do all the things they want to do, so that they enjoy the time they've got. (V02)

Knowing that I've helped someone feel better, or to have a better time toward the end of their life. I believe that people should have lots of understanding. Lots of tender loving care. One also needs to work out what the person needs from you at that particular time. (H04)

One nurse described making a difference in more pragmatic terms, stating:

I want to be able to feel that I have done my job to the very best of my ability and be satisfied with my work. (P03)

While another nurse suggested that:

It means being intuitive, sensitive to someone's needs. Listening, absorbing, "awareness of the music". It comes from the way you view life. (S08)

This last nurse felt that prior to making a difference, one must first become aware of what a patient's needs were, such that a difference to their care or to their lives could be affected.

### Recognising limitations.

Being aware of what was possible, was described by nurses as part of, yet separate from, knowing the patient's, the nurse's, and the organisation's limitations. Nurses expressed their feelings in the following manner:

I'm aware of patients' needs, but sometimes frustrated by doctors. (G09)

It is difficult if the person has not accepted that they were dying or does not want to accept treatments. (D05)

I'd feel distressed if I couldn't help anyone - it's because I'm a human being. (H04)

If it's physical symptoms, that's distressing. In fact you never completely fulfil a dying person's needs. (M06)

Especially with younger patients. It can be very frustrating and dissatisfying when you feel that you have been unable to accomplish the goal you have set in your own mind. (F J3)

I get quite frustrated in seeing a dysfunctional family. (S08)

Nurses spoke of feeling frustrated or distressed even when aware of various limitations within the environment.

### Identifying with patients.

As in everyday life, this group of nurses tended to identify more with some patients than with others. They felt that the closeness and intensity of working with the dying, often for weeks or months, led to the formation of a strong bond or identification, that sometimes resulted in a mutual sharing of experiences.

It (age) tends to matter. One patient had a daughter the same age as me and I got to know the family really well. She really opened up a lot and gave as much as you - and I probably opened up to her as well. (C07)

If it's someone I've walked very closely beside in that journey along the way it becomes a connection, an identification, a 'to and fro' of experience which is related. (S08)

I feel sad when caring for someone my own age, I identify with the person and feel disbelief that they will be gone. (G09)

With young people you feel as though they're robbed more so of life than the elderly person. I've cried for someone I've nursed for weeks or months. They may have been a similar age, have had children or similar things to myself - so I may find it hard to detach. (H04)

One nurse held a slightly different view, suggesting:

Sometimes you're more in tune with somebody but I think you get attached to everybody who's been here for a long time. (P03)



The nurses' comments seem to suggest that age is an important factor in identifying more with some patients rather than others, while the final comment suggests that length of stay is important, regardless of age.

### Communicating.

All nurses were aware of the critical issue of honest, open communication with the dying. Differences in the attitudes' of nurses toward communication are reflected in the following comments:

I don't talk for the sake of talking. If the patient asks questions, I'll answer them. I won't bring up the subject of death unless the patient wanted to discuss it. (V02)

Most people. It is difficult sometimes especially if you've never met them before. But often it's a matter of time, getting to know them in the context of their family and friends. (M06)

I don't talk easily with everyone because I think that's unrealistic. (C07)

Alternatively:

I converse easily and I allow someone to prompt and they 'call the shots.' (S08)

Be honest. Listen to people. Find out what their needs are. Care for people as human beings. Listening actively to people is most important. (G09)

Some nurses appear to converse readily and easily with all patients, others are more reticent, acceding to some of the difficulties in communicating with the dying.

### Empowering the patient.

For these nurses, empowerment meant allowing the patient to choose what they felt was best for them, in planning for their future. Along with choice,

nurses also felt that the patient, or the patients' family should be the primary focus of care. Typical comments included:

The patient (or the patient's family) should have the final say. As far as possible they should be in control. The dying person is the focus. (M06)

Allowing the patient to live that part of their life the way they choose. Our philosophy is quality of life, so realistically, allowing them to have the best life they've got left. (H04)

The person should be able to maintain as much control over what's happening to them as possible and that they receive the best care we can give them. (P03)

To let them do it the way they want to, which is hard, as nurses can be very dogmatic people. (X01)

The issue of control, as the nurses have suggested, should lie in the patient's (or their families') hands, for as long as is practicable. The dying person is of central concern and they should be allowed to choose how they wish to live, until this is relinquished.

### Caring For The Family

The information provided by nurses suggests a commitment in caring for families as a whole, not simply the person identified as the patient. This seems to begin with the establishment of a rapport with family members such that nurses were cognisant of the experiences of family members, some or all of whom, may have been caring for a loved one over an extended period of time. Nurses recounted various experiences with family members, identifying significant relationships within the family unit, which implied some knowledge of family dynamics and the many socio-cultural factors that may impinge on care. Overall, these nurses' experiences with families reflects thoughtfulness and a

willingness to stand back, if need be, to give families time together, to express how they feel, to mend rifts and say goodbyes. For a brief moment in time, nurses are part of the family, experiencing the same emotions, conflicts, and also suffering a loss. From the nurses' experiences, three themes were clustered under the common theme of connecting with families including:

Enabling Decathexis

Easing Conflicts

Continued Support

#### Enabling decathexis.

Decathexis means detaching from and modifying emotional ties such that new relationships may develop. It does not mean forgetting the deceased person, rather, emotional investment may be re-channelled to others for emotional satisfaction. Nurses were aware of the necessity to remember and reconcile the experiences they had had with the deceased. One nurse's comment exemplified the shift in focus as:

You put your energy into the family, so you've still got someone living, so you don't lose everything. (GO9)

Other nurses responded similarly:

If you really work with the family, it helps to take away the subjectivity. (CO7)

If you know them fairly well, your concern goes away from them to the family. (VO2)

While, for one nurse, emotional and physical investment continued after death, she stated:

I often sit and hold their hand when they're dead. I talk to the essence of the person. (SO8)

### Easing conflicts.

The nurses' descriptions of conflicts with families were few. These occurred while they were intimately involved with a family unit under the enormous stress of seeing a loved one dying. As these nurses indicated:

Yes, we have conflicts with relatives, especially if the patient tells you that they want something and the relatives don't. Usually it's because they're not accepting that the patient's dying. They want us to do things that are completely unrealistic, but I don't react to it. You know that they're not actually angry with you. (HO4)

Yes, families get angry with you, but you don't take it personally. (XO1)

One nurse suggested she had:

No conflicts with families. I often get a hug from them. (SO8)

### Continuing support.

Further contact with and support for families may well be more apparent than the few comments given in this regard. Some nurses suggested that it was possible to become involved in bereavement services as a means of ongoing support, while two nurses' commented that:

Some survivors return, to help themselves (and sometimes the nurse). I tend to remember faces not names. (GO9)

Sometimes the relatives come back, maybe a year later and you did actually know that person quite well, but you just can't come up with their name. It's embarrassing. (HO4)

These two comments seem to suggest the importance of continued support for some survivors. Returning after a year may help the person and the nurse.

## **Coping**

These nurses strive to contend with many stressors and tension inherent in caring for the dying, as well as those of everyday life. In order to be helpful, nurses need to maintain a healthy balance between caring for others and caring for themselves. Ways of coping are myriad in nature; they may be internal or external, but all are defense-oriented serving to protect the individual from being overwhelmed. The choice of coping method seems to depend on external circumstances, the suddenness or chronicity of stress and tension, the resources available to the nurse and an individual's predisposition to one or another coping pattern. From the nurses' descriptions, four earlier emergent themes were clustered under the common theme of coping. These included:

Caring for Self

Keeping Work in Perspective

Managing Stress

Emotional Distancing

### **Caring for self.**

It would seem that the ethos of caring for people, is so instilled in some nurses that they remain "rescuers" often doing their utmost to save people from distress. From most nurses' comments however, the opposite seems to hold true in that:

I get away, leave the "stage" and everyone behind. I like to go bush and "veg" out. It's a means of self-preservation, maintaining self-esteem. You need to live every day. Observe nature. See the trees more clearly. (G09)

I like swimming, reading and sailing. Get on with the business of living. Enjoy life. Care. Add value and value others. (S08)

Pleasure. I do quite a bit of exercise. I also enjoy my children and I enjoy gardening. You've got to live your life for now and appreciate what you've got. (M06)

I live for today. I believe one can plan for certain things, but one never knows what's around the corner. (D05)

You need regular holidays, just time away. Do something a bit more normal. Generally, dealing with many deaths isn't a normal thing to do. Although I do receive something from the job itself. (H04)

One nurse tendered an alternative view:

I'm one of those who runs around and makes things everything alright with everybody else. I know I should be doing things for myself as well. I don't have a lot of time for myself. (X01)

These nurses appear perceptive to their own needs and know how to care for themselves. Most are perceptive to the necessity of having time for themselves and their strategies include physical, social, cognitive and emotional levels, or a combination, such that they preserve their self-esteem. This is self-interest, rather than selfishness, the two of which are often confused.

#### Keeping work in perspective.

Few nurses alluded directly to any technique whereby they were able to exit the area of work and keep it completely separate from home. However, all these nurses tried to keep work in perspective. Nurses stated succinctly that:

I reflect on past events/people when overloaded or worn out. I "mull" things over on the way home. (S08)

I have a "switch-off" point on the way home. (X01)

I always leave my work at work. But I love my work. Never retire. (G09)

The use of a technique which enables the nurse to maintain a clear separation between work and home appears to be utilised by these nurses. These nurses have other roles in life (such as wife, mother, friend), which are equally, if not more important than the role of a nurse, and are necessary for the maintenance of a distinct identity. Taking feelings home may impede the ability for care for oneself and impinge too much on personal life, to the detriment of the individual.

### Managing stress.

Most nurses know that they need to recognize and respond to their own signals of stress or tension. The emotional pain and suffering that these nurses experience in the care of the dying requires extra attention. Feelings need to be expressed such that the individual continues to live with what is, instead of continuing with what was. The nurses offered various ways of dealing with stress, as may be seen in the following comments:

I've sometimes felt that because of personality, I've let other people do things for a patient rather than myself. But this does not stop me if no-one else is available. (D05)

You do get angry with patients sometimes. If you've got someone who's irrationally demanding, you may need time out. (M06)

I can usually discuss with the other girls if I'm upset or cross about something. In the work situation it goes away. (X01)

You have the opportunity to talk to other staff members or get involved in bereavement services. (M06)

I think everyone here is aware of just supporting people if they need it and we give pats on the back quite regularly. (P03)

One nurse stated that:

Humour saves my life, it helps me focus, to put things in perspective. Even the potentially tragic may be avoided by use of humour. (S08)

As individuals, nurses will experience personality clashes, in which event, it seems reasonable to let someone else take over. Organizational support in the form of time out and open discussion at the time when someone is feeling stressed, rather than waiting, does much to assuage feelings and maintain a sense of equilibrium for the person. Support and encouragement from colleagues who have experienced the same feelings and can empathize will also assist an individual in expression of feelings and maintaining a realistic perspective. Involvement in bereavement services may allow for resolution of feelings with other survivors, again enabling the nurse to come to terms with the losses inherent in caring for the dying.

### Emotional distancing.

The usual understanding of maintaining physical or emotional distance from patients suggests a negative attitude on the part of the nurse or that the nurse may be suffering "burn-out" which often leads to blaming the victim. A different view was offered by some nurses who stated that:

I believe I do have barriers. I think we have to have a certain distance that the patients and families aren't aware of, I suppose I mean emotional distance. (P03)

It's unhealthy if you cry with every patient, because then I think you've got to look at what's happening here and what you're not coping with. (C07)

Sometimes I want to be alone, like when you've just had enough. (X01)

You do get to know people very well, but you maintain a professional barrier. (V02)



**Maintaining emotional distance** may well serve a protective function for the nurse in avoiding over-involvement or assisting in the process of decathexis, which occurs during the last few hours of life for the patient. Similarly, for some nurses it may well be unhealthy to cry with the loss of every patient nor, is there anything inherently wrong with wanting to be alone. All may serve a protective function provided they are not taken to the extreme.

### **The meaning of caring for the dying.**

The meaning of caring for the dying for nurses is expressed on a continuum and is linked throughout their personal and professional lives. Meaning is embedded within a contextual, interpersonal process which occurs over time, awareness of which is relatively unrecognised. The experiences of these nurses engenders insight into what death means for them, having had many previous encounters with dying, death and loss in both private and professional circumstances. The meaning of caring for the dying within the overall context of care is manifested by a deep sense of compassion and concern for the dying, resulting in a mutual sharing of experiences with the dying person and his/her family. The ability of nurses to care effectively for others reflects an extension of their ability to maintain a healthy balance between the meaning of life and death. The nurses in this study appear comfortable in facing death, suggesting they have come to terms with their own mortality, as far as is humanly possible.

### Summary

This chapter has presented an interpretive account of nurses' experiences with the dying. Thematic analysis identified five key themes and eighteen emergent themes which structure these nurses' experiences. The essence of this experience is that these nurses perform caring work as a process of personal and professional interactions with the dying. These interactions are influenced by the hospice setting, which fosters a holistic, personalised, transformative process wherein patients, their families, and the nurses themselves are profoundly affected on a deeper level than that typically expected in the nurse - patient grieving situation. They develop a range of coping skills to deal with the intensity of the relationship and the processes, such as anticipatory grief, embodied therein.

## CHAPTER 5

### Discussion Of Findings

#### Introduction

This discussion addresses the salient issues of this study as they relate to the current state of knowledge relevant to nurses caring for the dying. Analysis of data was conducted on information provided by nine (9) participants who were selected purposefully on the basis of their knowledge and experience. Five key themes were identified from the information provided by participants and these themes formed the descriptive basis for the lived experience of nurses caring for the dying. These themes included:

Being transformed by the experience

The influence of context on caring

The embodiment of caring

Caring for the family

Coping

The results of this study support, in part, similar findings in published literature. However, the findings of this study identify previously unrecognised areas of concern in relation to nurses caring for the dying. Previous notions of how nurses continue to care effectively for dying people on a constant basis, are also challenged.

### Discussion of Themes

Nurses described the importance of their encounters with the dying, discerning the value and significance of often shared and cherished goals, aspirations, hopes and dreams with their patients. Nurses often realised and found meaning from their experiences as they reflected on the totality of living with the dying.

The experience of constant interaction with the dying also necessitated confrontation with the reality of death, rather than defensive posturing. Thus, the ability of these nurses to work with the dying was directly related to the degree to which they risked being emotionally accessible to them. Working with the dying forced nurses to confront and come to terms with their own mortality, as well as acceptance of past, current and future, potential loss; primarily loss of self.

The greatest impediment to this then became the distinction between the nurse as a nurse and the nurse as a human being. What appeared to blur the boundary however, was that nurses were able to relate to patients on a level that bridged the nurses' and patients' experiences of caring for the dying such that the nurse-patient relationship became one of "I am you, and you are me." These nurses appeared to be experts who, as Benner (1983, p.32) has suggested, have:

An enormous background of experience ... an intuitive grasp of each situation and (can) zero in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions.

Nurses shared the pain of the dying, because they empathised and identified with patients as human beings. These nurses typified La Monica's (1981) operational definition of empathy which states that:

Empathy signifies a central focus and feeling *with* and *in* the client's world. It involves accurate perception of the client's world by the helper, communication of this understanding to the client, and the client's perception of the helper's understanding (p.398).

Nurses conferred with their patients, were there for them, affording patients time and the gift of presence.

Caring for people, as people, also involved the recognition that these nurses always faced complex emotional issues involving not only the person a patient but also the family as patient. Crossing the boundary of the family as a unit redefined communication and interaction among family members. Nurses occasionally became part of the family unit, and such integration allowed for continued support of the family and maintenance of a sense of identity and self-worth amongst individual family members. Involvement with the family placed an increased burden on nurses but also allowed for increased sensitivity to the needs of various family members, as well as allowing for continued support following death. This does not mean that nurses became enmeshed in family systems. As Minuchin (1974, p.55) suggests, "enmeshment ... refers to a transactional style ... not to a qualitative difference between functional and dysfunctional." These nurses usually maintained clear boundaries within the family subsystem but were occasionally affected by the behaviour of individual family members who had not accepted that a loved one was dying.

These nurses also recognised the need to redirect the emotional investment they had had with a particular person, such that they retained some memory of the deceased in order to reconcile the experiences they had had with them. This shift in emotional focus usually moved to the family of the deceased, depending upon the significance of the relationship between the nurse and the deceased.

Caring for people as they did however, meant that for this group of nurses, they cared for themselves first. Most nurses were able to maintain a healthy balance between the demands of work and their private lives. Caring for the “self” was the rule, rather than the exception, which served to strengthen, or at least maintain the positive self-image nurses had of themselves. In caring for themselves first, nurses ensured that they could continue to emotionally invest in the care of others.

### Being Transformed the Experience

These nurses' perceptions of the reality and inevitability of dying and death counter the romantic notion of an appropriate death which, “means dying in the best possible way ... with minimal distress and few intractable symptoms ... in effect, an appropriate death is one we can live with” (Weismann, 1988, p.67). Some nurses were relieved when a person died, especially when a person had perhaps lingered too long and was suffering. Nurses' knowledge and experience

also forewarned them that emotional “closure” with a dying person was not always possible.

This realism in dealing with dying and death suggests that nurses recognised the futility in “fighting back”, in doing everything they could to prevent death. Nurses realised that even though death was inevitable it was still sad, but they were not traumatised such that they were unable to care for others, nor, was the reward in caring for the dying diminished.

Previously, Thompson (1985, 1986) found that independent of the work setting, the older, more experienced nurses were inclined to view their work with the terminally ill as rewarding. Stoller (1980) suggested that with increased work experience in caring for the dying, most nurses became uneasy and they minimised contact with the dying. Significantly, accumulated negative experiences and nurses’ early losses associated with dying patients was also seen as a cause of uneasiness. This may be true, as experience does lay down sets of reactions and contributes to individual coping methods. This contrasts with Reisetter and Thomas’s (1986) view that experience of the death of a significant other sensitised nurses towards the needs of the dying and enhanced their skills in caring for them. Most nurses in the present study had experienced death in personal and professional circumstances and it appears that experience of dying, death and grief may have also sensitised these nurses, enhancing their skills in caring for the dying.

However, this also suggests that the cumulative effect of caring for the dying may lead to a subtle form of guilt, which; in turn, leads to over-giving as a kind of penance for remaining well (Lorenz, 1991). Similarly, some nurses admitted feeling that they had been, “sent”, to work in hospice in order to make the experience (of caring for the dying), better for others than it had been for them.

In this study nurses were also able to afford themselves the respect and dignity they deserved. Their comments also suggested that their self-esteem was constantly maintained, and that they had matured personally and professionally. Davies and Oberle (1990) also found that:

The nurse maintains self-esteem by looking inward, by valuing personal worth, and by acknowledging and questioning personal behaviours, reactions, and needs (p.32).

Such reflective awareness appeared to stem from a culmination of nurses’ knowledge and experience in working with patients and families rather than working in isolation. As Thomas (1983, p.26) asserted, “the ultimate reward of hospice nursing, and the most difficult to accept, is the personal growth that results from interaction with the patient and family.”

Interestingly, many nurses acceded to the proposition that one had to come to terms with one’s own mortality before being able to care effectively for the dying. Samarel (1989) also identified that nurses, “had given considerable thought to their philosophies of life and death and expressed feelings of acceptance of their own death” (p.324). Previously, it has been suggested that, “professional caregivers... employ a variety of defenses to avoid confronting their



own personal death" (Rando, 1984, p.274). For this group of nurses however, what appears to have changed is their outlook on life in that for some, their goals in life have changed, they are more self-sufficient and tend to take each day as it comes. To work with the dying means experiencing some of the same feelings as patients and their families.

Personal loss appeared to motivate some of these nurses to care for the dying as a means of resolving the suffering they have experienced in the past. This does not appear to take into account any losses they may currently be experiencing, or future, anticipated loss which may be significant. Loss may not necessarily involve only death. It may mean lost opportunities or loss of lifestyle, or the content may be in terms of loss of hopes, aspirations or plans for the future (Rando, 1986). The acceptance of loss for some of these nurses was achieved as they continually cared for the person, for others it was making loss part of oneself, not forgetting the person and allowing time for resolution of feelings.

The significance of loss has been addressed by Benoliel (cited in Schoenberg, Carr, Kutscher, Peretz, & Goldberg, 1974, p.223) where:

The significance of a patient can also be tied to a heavy investment in comfort-oriented care, such as happens with cancer patients whom the nursing staff gets to know over a prolonged period.

Such a death means the loss of a socially integrating relationship of some importance in nurses' professional lives (Benoliel, cited in Schoenberg, et al., 1974). To negate such a loss is to avoid one of the basic postulates of human

relationships contributing to personal well-being and social integration. Yet, nurses in this study appeared to accept the reality of loss rather than deny it.

What was denied by nurses however, was the suggestion that loss (and grief) may be accumulative. This appears contradictory to nurses' previous suggestions about acceptance of loss. It may be that, as Davidson and Jackson (1985) have suggested, the nurse is not directly involved in a life-threatening situation and is in fact only witnessing the catastrophic events taking place in other peoples' lives. This appears to contradict Kastenbaum's (1969) assertion that nurses who take emotional risks and form bonds with patients, in serial fashion, may become subject to bereavement overload, possibly being overwhelmed by loss and grief, especially if these have not been worked through.

Additionally, Rando (1984, p.431) suggested:

If accumulated grief is not worked through, the caregiver is every bit as vulnerable to all the malignant sequelae of unresolved grief as is any other individual who has suffered a loss but failed to complete... grief work.

A further complicating factor is that as nurses experience loss of a significant patient, whether serially or in isolation, this often results in the resurgence of many of the nurses' own thoughts, feelings, memories regarding personal loss (Rando, 1984).

As Weigart and Hastings (1973) suggested:

From the symbolic interactionist and phenomenological viewpoint, it is theoretically necessary that a socialised self, invested in a particular biographical family, experience the sense of loss, not only of the other person, but also of that part of the self constituted by the relations which were anchored in that other person (pp.7-8).

If loss and grief never really “die” then nurses will experience long-term sequelae, which may only be mitigated by the nurses’ personality, self-esteem and the experience of sharing grief.

Sharing grief with families was one of the adaptational tasks of these nurses. Permitting nurses and families to grieve together, only made sense however if individuals within the family unit were able to understand the grief that others were experiencing. This kind of interaction elicits, “emotional responses in nurses which can be very intense, cross the boundaries of professionalism, and touch on our humanness, vulnerability and finiteness” (Rando, 1986, p.72). Where death is a long anticipated fact, as in hospice, nurses may get caught up in the lives of the patient and the family to such an extent that they also grieve the loss of family members no longer available to them.

For these nurses, caring for someone who is dying meant feeling and experiencing something beyond professional duty. It is essential therefore, that nurses understand their own feelings about dying and death, the need for which has long been recognised. In a remarkably insightful editorial in, “Nursing Outlook” (1964) cited in Rando (1984, p.432), it is suggested that:

A nurse faces two very grave responsibilities, when her patient is dying. She must give life measures - including emotional support... she must reassure, understand, and, in a sense, share the grief of those who love the patient. *Before she can do justice to either, she needs to resolve her own feelings* [italics added]. (p.23).

As a group, nurses in this study appear to have attended to their feelings as far as possible. In the case of personal loss, it may be that nurses, as human

beings, never really get over the loss of a significant person. As one nurse suggested "It's like an open wound, almost like a pain I guess. But gradually it heals up and after a while the scar is still there but it no longer hurts."

It may also be the case that for some nurses in this study, the resolution of personal feelings may not be complete, and may well be a motivating factor in caring for the dying. If painful memories still exist, caring for others may detract from having to look to one's own feelings, resulting in repression of affect.

Additionally, Rando (1984) suggested that:

Professional caregivers... employ a variety of defenses to avoid confronting their own personal death anxiety generated by the patient, as well as their own frustrated desires to take away the pain of loss... at times these are cloaked in the desire to 'protect' the patient... which also serves to protect them from having to deal with someone who is in pain from having to face loss and death (p.274).

For nurses in this study it appears that no matter which, if any, defenses were used (consciously or unconsciously), all were forever changed by the experience.

### The Influence of Context on Caring

The structural organisation of any health/illness-oriented system may impede or promote nurses' ability to care effectively for patients. Nurses in this study felt that one important notion was the ability to work with a team, which was generally felt to be rewarding as most members had the same goals and care philosophy. A team approach offers all professionals the personal support that is necessary in a situation which evokes anticipatory grief reactions. People may

need permission from others, to take the time and space necessary to care for themselves. More importantly perhaps is the assertion that roles are blurred in hospice nursing and professional territory becomes unimportant (Walker, 1981). In an ideal situation this may well be the case, but working within a team may still generate conflict, especially where medical staff retain primary responsibility for the patient.

One aspect of working with a team noted to be problematic was team communication problems, identified as the single biggest stressor, the major manifestation of which was staff conflict, power struggles and rivalry associated with, "sharing some of the glory with other care providers" (Vachon, 1987, p.187). A team approach does, however, provide for an effective, individualised programme of care for patients. Communication between professionals may be enhanced and options explored. Team members have access to the same information and care may be seen as an integrated whole, thus preventing misunderstanding and reducing stress.

Teamwork was evident amongst nurses and was a source of support for, and by nurses. However, differences did arise amongst professionals, mainly doctors. There may have been conflicts from intra-professional relationships but these appeared of secondary importance. Doctors entered the working environment of nurses from acute-care settings and, in a sense, were "outsiders". Some may have had a cure orientation to what is generally seen as a cure-oriented profession, and it appears that for some of these nurses, the cure-

orientation often gave families a false sense of hope, with which they disagreed.

Weismann (1981, pp.161-162) suggested that this was the protocol caregiver whereby:

Patients are asked only to cooperate; they do not need to be understood as individuals... the only real issue is compliance and effectiveness, not a doctor-patient relationship.

Weismann (1981) was not minimising protocol, as it represented the “organic” tradition in medicine. However, protocol “avoided imponderables, putting aside other aspects of care” (p.163).

Nurses seemed to suggest that doctors incompletely addressed the needs of patients and families, in maintaining a balance between over-reliance on medical intervention and failure to recognise when medical treatment was necessary, either physical or psychological (Rando, 1984). Other nurses suggested that conflict arose out of misunderstanding (or the fact that doctors are also human), but the overriding inference was that hospice was basically the nurses’ “turf” and while medical management was the doctors’ responsibility, patients (and nursing care) were the responsibility of the nurse. Also, nurses were assertive, knowledgeable and patient advocacy was a primary concern. Sawyer (1988) suggested that advocacy evolved as a result of unequal doctor/patient relationships; whereas Abrams (1978) saw the need for advocacy as a result of the failure of the health care system to function as it should. However, Jameton (1984) implied that nurses focussed their emotional responses and frustrations onto doctors, making them “scapegoats”, at the same time reinforcing medical

dominance, probably because doctors still think that nurses are there to support them in their role. Nurses may also foster an unequal nurse/patient relationship however, which is as oppressive as medical dominance, the results of which may well be projected onto doctors in order to assuage the nurses' feelings of guilt.

### The Embodiment of Caring

Achieving something which made a difference to the lives of dying people for some nurses in this study involved a healing of complex psychosocial issues, for others the difference simply meant making people comfortable and giving tender loving care. Most nurses implied that in order to make a difference, the patient's needs must first be ascertained, but only one nurse stated this explicitly. The major notion of all nurses however, was centred on the concerns of the patient, as the nurses understood them, be they large or small. As Weismann (1981, p.167) suggested, "A little goes a long way; the least contribution is the one... with the best chance of making a difference, however small." This does not imply doing as little as possible for a patient; on the contrary, it means doing a little more than may be expected which may make quite a significant difference overall.

Occasionally, nurses in hospice care for dying patients over a long period of time which may result in the establishment and maintenance of a close nurse - patient relationship. In this instance Weismann (1981, p.163) suggests that:

Any caregiver who has a sustained relationship with a patient implicitly promises to fulfil or contribute something to good management and care...

as a rule, the caregiver's contribution to management is to offer *safe conduct* in one form or another beyond treatment itself.

From the nurses' descriptions, there is a large amount of emotional and physical investment with someone who is cared for over an extended period of time. The burden of care may rest primarily with one nurse, but it is evident that the burden is shared such that the primary nurse is not overwhelmed in the process, and contributions to making a difference in patients' lives could also be shared.

These nurses were knowledgeable with regard to care of the dying and organisational support appeared sound. Lyons (1988) suggested that whether or not nurses had been adequately prepared to interact with the dying and bereaved, this still posed a dilemma for nurses. However, Benoliel (1977) offers a salutary view in that she suggests that nurses are in positions, far more than is true for physicians, to influence the social milieu of the dying and to set priorities based on the patient's stated wishes.

The closeness and intensity of working with the dying, occasionally led to the formation of a strong bond with a particular patient, resulting in the mutual sharing of experiences. These nurses seemed to identify more with someone their own age although similar family structure and length of stay in hospital were also important for some nurses. One nurse asserted that "with young people you feel as though they're robbed more so of life than the elderly person." This appears to be a commonly held belief amongst nurses (and the population in general). However, while the young person may be filled with rage and anger at being



“cheated” of life, this also holds true for the elderly person. As Thomas (1983, p.25) notes:

It is not true... that the older persons are more accepting of death than younger people... some of the elderly are content to die. Others are resentful, fearful, or anxious to negotiate for a little more time.

Rando (1984) concurs, one primary difference being that the elderly probably think about death more often than the young, and that the elderly have often planned for their demise, but not in the immediate future.

It appears that the identification by some nurses with patients of the same age is more likely to be a reflection, as one nurse suggested, “That could be me, leaving my children,” increasing the immediacy, in principle, of one’s own death. Alternatively, Raphael (1984) points out that working with patients who are dying heightens mutual empathy and identification. This is because the experience of loss (and grief) is so universal, as is its inability to be controlled, to any great extent. The need for self-awareness cannot be over-emphasised and:

A useful construct to facilitate this may be ‘the bereaved child in each of us’. Those feelings that are aroused but do not come to conscious perception when working in loss/separation/death situations, are most frequently related to childhood experiences of separation, loss and death or to fantasies thereof. When emotional pain, anxiety, depression, helplessness, anger and guilt arise... and when blocks or other counter transference manifestations occur, it is well to seek the internal bereaved child (Raphael, 1984, p.161).

Therefore, the previous statement of “that could be me, leaving my children,” then becomes, “that is me, experiencing my bereaved child.” Self-awareness is not easily achieved however, and it appeared much easier for many

of these nurses to deny their feelings and concentrate on intellectualisation, rationalisations, or repression.

All nurses were aware of the importance of honest and open communication with the dying. However, some nurses appeared to converse readily with all patients, others were more reticent, acceding to the difficulties inherent in communication. Some nurses expressed preference for the patient to initiate conversation, especially on the topic of death, which may have been a reflection of the nurse's private concerns on the topic.

Ufema (1991) suggests that nurses are prepared to ask questions and communicate easily with the dying because of nurses' natural sensitivity (much like doctors natural compassion). The problem is that fear of saying the wrong thing may get in the way, which may apply to some nurses in this study.

Previously Verwoerd (1966, p.29) suggested:

In keeping with the goals of therapeutic communication, it is a general principle to avoid making the patient more anxious... the principle of 'first, do no harm' is a cardinal rule: the patient's defenses should never be heedlessly stripped away.

The complexity of communicating with the dying patients is further revealed by the suggestion that repeated requests may be made of nurses, obtusely, in order to secure their attention, instead of directly asking nurses to sit down and talk (Rando, 1984). This is often done without conscious intent on the part of the patient, and must be inferred by the nurse being aware of and responding to non-verbal cues. Glaser and Strauss (1965) also suggested four types of possible interactions and awarenesses in the context of communication between patients

and caregivers. These include a closed awareness context in which caregivers keep information from the patient. Secondly, a suspicion awareness context, where caregivers know the truth and the patient suspects they are dying. Thirdly, a mutual pretence awareness context, where both caregiver and patient are aware of the implications of the illness, but pretend they are not. Finally, an open awareness context, in which there is shared knowledge about the patient dying. Only the latter context allows for a frank exchange, which provides optimum conditions for completing unfinished business and continued interaction with significant others.

It becomes obvious therefore, that interactions and awareness of communication may be consciously or unconsciously driven. With regard to the latter, Freud (1918) maintained that the unconscious does not know death and that no person believes (honestly) in his/her own mortality. This appears to suggest that denial may play a large part in blocking out of consciousness, anxiety-producing aspects of awareness related to dying and death.

Denial serves as a protective function and may be an issue that underlies all others. Depending on the resolution of this process, other tasks and issues may be faced such that a balance was maintained in order to, "continue functioning with a sense of purpose and meaning, while making necessary changes and accommodations to meet the needs of the dying" (Cohen & Cohen, 1981, p.186).

Nurses in this study largely promote an open awareness context, although some appear to promote either a suspicion awareness, or mutual pretence awareness context (Glaser & Strauss, 1965). It may be that knowledge, experience, and nurses' personal concerns about dying and death determine the context within which nurses are willing and able to communicate with the dying, accounting for some of the differences described by nurses in this study.

Nurses felt that the issue of control for patients meant allowing the patient or the patient's family, as a single unit, to choose what they felt was best for them, in planning for their future. The dying person was the focus of care and empowerment fostered choice for the patient, however large or small. This enabled the maintenance of the patient's self-esteem, and helped to assuage feelings of helplessness, frustration and guilt arising out of dependency (Rando, 1984).

Davies and Oberle (1990) also found empowering as one of eight key concepts in the supportive role of the nurse in palliative care. Empowering was described as:

Enabling the patient and family to do for themselves, to do whatever has to be done, to meet their own or others' needs. Empowering is neither tangible, nor task-oriented, but strength-giving and innervating (p.90).

For these authors, empowering encompassed five dimensions, including: facilitating, encouraging, defusing, mending and giving information. Empowering was also seen as a two-way process whereby there was an exchange of energy in

which the nurse gained and was “energised” by the connection with patient and family (Davies & Oberle, 1990).

Empowering patients and their families also meant that there could be the possibility of rejection of advice from nurses, even where a nurse was seen as part of the “family”. Acceptance of patients’ and families’ decisions is also seen to a far greater degree in hospice than in most other nursing situations (Thomas, 1983). Overall, empowering patients for nurses in this study was seen as a critical obligation. Any rejection on the part of the patient or the family did not appear to over-ride the nurses’ intent, nor did it result in the nurse withdrawing from the patient or family. However, by empowering the patient, the real issue of ultimate control, especially with regard to affective expression, rested in the hands of the patient, not the nurse or the doctor.

### Caring for the Family

When one person dies, as in the case of a patient, the nurse needs to re-invest emotional energy from the deceased. New attachments must be established based on the absence of the deceased. This is what is meant by moving from a relationship of presence to one of memory. In psychoanalytic terms, this movement of detaching and modifying emotional ties such that new relationships can be established is called, “decathexis” (Rando, 1984, p.19). This does not entail forgetting the deceased, rather, emotional satisfaction is re-

channelled toward others. A new conscious perspective must develop in order to assimilate what has been lost and what may be gained as a result of the loss.

Interestingly, these nurses seemed to intuitively recognise this important process. It may be that constant interaction in caring for the dying allows for a constant process of cathexis (emotional investment) to decathexis (detaching and modifying emotional ties), but not to the same extent as in "nuclear" family members. Alternatively, nurses may not have to undergo the whole process depending on the significance of the relationship with a patient at a given point in time, and the degree of mourning which the nurse actually undergoes.

Rando (1984, p.76) also suggests that:

Too often... caregivers focus solely on the reactions to the external world (ie. emotional responses to the separation... ) and not enough on the changes in the inner world (ie. decathexis, development of a new relationship with the deceased, and formation of a new identity).

However, this is also dependent on how much of a mental representation of the deceased the nurse has retained in his/her own mind, as it is from this introjected image that the "mourner" (if this be the case for the nurse) must withdraw emotional energy. Consequently, all the thoughts, feelings and memories which bond the nurse to the deceased are gradually worked through and loosened, over time. Perhaps these nurses underwent the process of decathexis by remembering the deceased, in context, as someone who lived and died, but the memory, as such, is effectively repressed.

Further contact with and support for families was addressed by some nurses in this study. The most interesting suggestion was that some survivors

return to help themselves (and sometimes the nurse). It may well be impractical however, for all nurses to provide continued support for families and/or themselves, which may be mitigated if a nurse availed him/herself of the opportunity to work in bereavement services.

There is more understanding of continued support for bereaved family members and the sequence of loss (Berardo, 1968; Glick, Weiss, & Parkes, 1974; Stroebe & Stroebe, 1983), than there is for nurses (Davidson & Jackson, 1985; Gray-Toft & Anderson, 1981). The nature of the supportive role in palliative care for nurses has also only recently been addressed (Davies & Oberle, 1990; McWilliam, Burdock & Wamsley, 1993), and concentrates only on the role of the nurse within a caring setting.

Nursing studies in particular do not take into account the effects of anticipatory grief which is defined as, "knowledge beforehand that death is probable, or inevitable in the near future (and) may affect both the dying person and those close to him" (Raphael, 1984, p.50), either within the context of a nurse's role up until the time of death; nor, the mitigating effects of anticipatory grief for nurses as survivors. It is important to note Rando's (1984) assertion that there seems to be an "optimum amount" of anticipatory grief. Parents whose children had illnesses ranging from six months to eighteen months, were the most prepared for death and adjusted better following death. Sanders (1982-1983) also found that survivors of death from an illness of less than six months duration, fared better than those from either a sudden death or long-term chronic illness.

Nurses in this study seemed to care for people within a short timeframe, apart from the occasional patient who was nursed for months. It may be therefore, that in the case of caring for someone over a shorter period of time, nurses may also fare better in terms of less and long-term sequelae.

Nurses' comments reflected very few conflicts with families which does not necessarily imply that other nurses in this study did not also have conflicts. Nurses were astute enough however to realise that while they may be the brunt of feeling from families, they did not take these feelings personally. It seems that more often than not, anger was displaced onto nurses because family members had not accepted that their loved one was dying, or that they were under enormous stress watching a loved one dying, or both.

These nurses appeared to have the necessary insight into family dynamics at this time and seemed to use their communication skills to good advantage, especially assisting with the processes of grief, anger, remembering, longing, (and denial), which need to be worked through for decathexis to occur.

Feelings of helplessness and lack of control amongst family members may also be a source of their frustrations. How families cope with their frustrations is dependent on a variety of mechanisms including denial, sublimation, repression, reaction-formation, displacement, projection, and introjection (Rando, 1984). Unwittingly, nurses are at the "forefront" of these mechanisms and their emotional or behavioural concomitants.



Further catalysts to anger and frustration are, “disappointments over unfilled ambitions and unfinished business and expectations that will never be realised” (Rando, 1984, p.345). It is essential therefore that nurses identify these reactions in order to be aware, and not accepting of projection onto themselves, rather than being targets for such feelings. It is also essential that nurses recognise they may well be experiencing the same reactions.

### Coping

Most nurses were perceptive of, and responded to their own needs as human beings. Nurses’ self-interest (not selfishness) was reflected in a generally positive image of their individual “selves” and engagement in “life-affirming” activities (Rando, 1984, p.443). Activities took the form of physical exercise, either aerobic or anaerobic, gardening being a common activity. Other ways of caring for themselves included spending time with their families, friends or doing just what they wanted to do. Some preferred time on their own, going “bush” to escape the noise and pace of city or suburban life. All nurses recognised the need for holidays, to do something “normal” as one nurse suggested.

In effect, nurses did not think of themselves as selfish while engaged in the care of the dying. They did realise their limitations and, as Rando (1984, p.441) states, “we must acknowledge the fact that sometimes we must only ‘be, not do’; we must be realistic about how much we are truly capable of accomplishing for the patient.”

Nurses were also knowledgeable regarding their work and some had completed post-basic education and/or were pursuing further study. Rando (1984) suggests that increased awareness (of thanatological research) does much to allay feelings of stress as well as filling gaps in knowledge. This, combined with these nurses' personal strengths, experiences and positive self-image seems to suggest continued development and growth, while remaining "true" to themselves.

Taking feelings home may impede the ability to care for oneself and impinge too much on personal life, to the detriment of the individual. Nurses have roles in life which may be seen as competing or complementary, the transition from which has been defined by Morris (1979, p.636) as, "A process of change from one activity or form of activity to another." Role transition occurs when a nurse leaves the work setting and resumes the role of spouse or parent (Samarel, 1989).

In balancing personal and professional careers, Ross, Rideout and Carson (1994) suggest that:

Feelings of control are important to feelings of satisfaction at home and at work. Confidence and competence, involvement in decision-making, and a sense of flexibility in (the) workplace all contribute to a positive work experience (pp. 55-56).

Support and help at home, open communication, realistic expectations among family members and good health were also seen as necessary for a satisfactory home life (Ross, et al., 1994). No nurse in these authors' study identified any clear separation from work, whereas three nurses in the present study alluded directly to a technique whereby the separation between the work

and home environments was quite distinct. This separation included what Rando (1984, p.442) has termed, "decompression routines." These routines are activities which allow the nurse to relax and forget about their jobs, as well as clarifying the distinction between personal and professional responsibilities. One nurse alluded to "mulling" things over on the way home, while another had a "switch off" point, and a third nurse always left her work, at work.

Rando (1984) suggests activities such as physical exercise, a walk in the park, meditation, or a hot bath, to forget the cares of the day, thus relieving stress and tension. The necessity for such routines may well be necessary in all nursing specialities, perhaps none more so than in the nursing care of the dying, such that identity and roles may be kept distinct.

This group of nurses seemed very adept in knowing when they were stressed and what best befitted them in managing stress. Also, being stressed meant different things to different nurses. One nurse honestly admitted to "getting angry with patients" occasionally, and proffered the suggestion of needing time out. Another nurse admitted to personality clashes, in which event, another nurse took over, if one was available. All nurses felt that there was always the opportunity to talk with their colleagues, which was facilitated by organisational support.

One nurse utilised humour (sometimes to the annoyance of her colleagues) to avoid what she saw as the potentially tragic, and stressful aspect of caring for the dying. As Herth (1990) has found, humour is essential, if not more essential,

during the terminal phase of an illness than at other times during illness and health. Herth also suggests that nurses should attach more significance to humour in caring for the terminally ill and to consider the potential of humour as an intervention strategy that could be utilised by nurses in a hospice setting.

Killeen (1991) presents a pragmatic approach to the use of humour in hospice care. One overriding concern pertains to staff who deal with the everyday stress and loss in working with the terminally ill. Killeen (1991) suggests that colleagues share levity, have planned activities and "theme days", humour bulletin boards and even engagement of a humour consultant. Such activities would of course, need to be handled with sensitivity. What is humorous to one person may be offensive to another, nurse or patient.

The enormity of stress inherent in caring for the dying cannot be underestimated and the nurses in this study seemed well aware of that fact. Nurses expressed some important views on maintaining emotional (and physical) distance from patients which run counter to previous notions that this is a reflection of a negative attitude on the part of the nurse or that the nurse was suffering "burn out." Nurses were in fact so attuned to the needs of the patient and family that they knew when to stand back, in order to give the family time together, without making it obvious to the family.

Some nurses did maintain a professional barrier and/or a pragmatic stance in caring for the dying, which appeared to serve a protective function for the nurse in avoiding over-involvement with patients or their families, or assisting in the

process of decathexis (Rando, 1984; 1986). Similarly, some nurses simply wanted to be alone at certain times, either to be on their own or express their feelings privately. In both cases, there is nothing inherently wrong with this behaviour and any suggestion to the contrary appears to be a misreading of the nurses' intentions.

Benoliel (cited in Schoenberg, et al., 1974) suggested that while anticipatory grief may serve as a protective function in family members, "the phenomenon of anticipatory grief in nurses may function to keep them emotionally detached from situations which are high risk in matters of personal and professional loss" (p.226).

This contrasts with Rando's (1986) view, admittedly more than a decade later, that the anticipatory grief of "families" includes nurses who may not experience the phenomenon as intensely as members of the nuclear family, but should nevertheless experience some of the protective functions of anticipatory grief in the same manner as for families.

Weismann (1981) also suggests that when caring for the dying:

It is wholly possible to remain matter-of-fact and keep a healthy respect for the patient and oneself without distorting reality or lapsing into empty efforts to encourage (pp. 165-166).

Therefore, the emotional distance maintained by some nurses in this study is not seen as negative. In essence, it is a protective function which prevents the nurse being overwhelmed by intense emotions, as they are experienced by the nurse in interaction with patients, and not as detached observers.

## **CHAPTER 6**

### **Summary of Methodology, Limitations, Implications, Recommendations and Conclusions**

#### **Summary of Methodology**

The purpose of this study was to provide information on nurses' perceptions and understanding of caring for the dying and how it affects them. No identifiable study has specifically sought to explicate the meaning of caring for the dying and the fundamental problem of anticipatory grief for nurses, despite the assertion that nurses are a very important group who are increasingly involved in and affected by the processes inherent in caring for the dying.

Given that the effects of these processes amongst nurses has largely been ignored, the present study sought to focus on nurses' perceptions of caring for the dying. This study focussed specifically on hospice nurses, whose everyday experiences necessitates constant and consistent involvement in the care of the dying. Nurses' experiences within the environment of hospice offered the potential of greater insight into caring for the dying rather than traditional acute-care hospitals.

These processes must be examined in the context of what they mean for the nurse, as they are experienced. Therefore the present study attempted to identify and describe the effects of caring for the dying amongst nurses in order to broaden conceptual understanding of the manifestations of caring for the dying in clinical practice.

**Specifically, the study attempted to answer the following objectives:**

**To describe nurses' experiences of caring for the dying.**

**To interpret the shared meanings nurses have in caring for the dying.**

**To use this information as a contribution to knowledge which may be utilised for improving nursing practice.**

**As this study was concerned with the tacit world of nurses as it is experienced, an interpretivist paradigm was followed, in order to understand the world of nurses as it was, and to create a dialogue whereby the lived experience of nurses could emerge in their fullest complexities and perspectives. The study also followed the existential phenomenological method of Colaizzi (1973, 1978), in order to pursue the search for meaning and describe and interpret nurses' experiences.**

**The strategy for sampling was purposeful in that participants were selected according to the needs of the study. This resulted in a group of nurses who were assumed to hold similar views and had similar experiences. While the sample size was small (nine participants), the power of purposeful sampling lies in selecting information-rich cases from which one can learn a great deal about issues of central importance to the purpose of the study.**

**Data collection, analysis and validation occurred concurrently. The raw data for analysis were transcripts from interviews with participants along with the researcher's personal diary, the primary purpose of which was to code the data such that themes may be recognised and analysed. Transcripts were interpreted both within and across individual accounts in order to capture contextual information and allow for constant comparison. This allowed for the**

emergence of initial themes and subsequent clusters of themes such that a comprehensive picture of the experiences' of nurses caring for the dying emerged.

The researcher's assumptions regarding care of the dying were "bracketed" prior to coming to grips with the significance of the phenomenon, in order to reduce bias. Also, the researcher used in-depth interviewing, transcripts, a personal diary and equivalence tests in an attempt to further reduce bias.

### Limitations of the study

In seeking to understand lived experience utilising phenomenology as a philosophy and as a method, the findings of this study cannot be generalised. The accuracy of the participants' accounts can sometimes be seen as a limitation. However, there was no evidence to suggest participants were defensive or guarded in any way, nor did they appear to respond to the researcher in any other manner than one which was honest.

It may be argued that evidence for care of the dying amongst nurses is limited in that the phenomenon is not an end-point, in and of itself; or, it may be that nurses have become sensitised to dying and death. This makes the determination of concurrent processes such as anticipatory grief more difficult and may also be seen as a limitation.

All participants in this research are female and the lack of experiences from a male point of view may be viewed as a limitation. Also, all participants were Caucasian females such that the experiences of different cultural groups were not included in the study.



### Implications for Nursing Practice

The major implication is that nurses, as people in interaction with people who are dying need an awareness and understanding of the effects of caring for the dying and concurrent processes such as anticipatory grief, *as it affects them [italics added]*. Increased awareness and understanding of caring for the dying offers nurses a means by which to promote the care of themselves, one consequence of which is an increased awareness and understanding of how caring for the dying may be affecting their peers.

The study findings also indicate that the effects of caring for the dying amongst nurses should not be undervalued or treated as secondary to patients' concerns. This is not denying patients care, the assumption is that care for patients will improve. Also, nurses *must [italics added]* attend to their own emotional responses, recognise what they can realistically achieve for patients and consciously recognise and accept their own mortality. Such recognition and attention to these aspects will further enhance nurses' level of awareness of "self" and maintenance of self-esteem.

Nurses should also have a supportive network, both within the environment of work and at home. No-one can work in isolation no matter how good a nurse's self-esteem appears to be. Peers, mentors and family can do much in sharing the burden, being supportive, or just providing "a good ear" to assist in ventilation of feelings. Friends not associated with work (or nursing) may be helpful in at least providing distraction from the cares of the carer.

Most importantly, in developing a shared understanding of the experience of caring for the dying, it is important to recognise that nurses may gain insight into the patients' lived experience. Nurses appreciation of patients lived experience of dying is necessary to enhance acknowledgment of caring for the patient as a person. Such understanding of the patients lived experience may then allow the nurse to foster appropriate therapeutic interventions by a common understanding of the patients' (and families) perceptions.

### Recommendations For Further Research

Several important areas for further research are suggested from the findings of this study. The most important appears to be replication of this study in similar settings to clarify the experiences' of nurses who care for the dying on a consistent basis.

Other studies should be designed to include different populations who care for the dying including enrolled nurses, volunteers and medical staff. Such studies may highlight significant differences of the effects of caring for the dying from those of registered nurses. Other studies should be designed to assess the effects of caring for the dying amongst carers who work in long-stay institutions such as nursing homes, where there is prolonged contact with patients who do not appear to have a reasonable chance of recovery.

Further studies should assess the influence of caring for the dying amongst carers who have intermittent contact with dying patients, rather than consistent contact, such as nurses in psychiatric hospitals.

Comparative studies amongst hospice, palliative care, oncology and acute medical-surgical units should also be designed to assess the effects of caring for the dying amongst nurses working in these settings on either a consistent or intermittent basis.

Comparative studies should be designed, if possible, to explore the effects of caring for the dying where all, or a majority, of carers are male in order to identify if gender may be a significant factor in the manifestations of caring for the dying.

Death education programmes should be designed with caring for the dying as part of the curriculum and compared with programmes where caring for the dying is not integral to the curriculum. This may help to explain, in part, why death education programmes have generally been unsuccessful in improving nurses' attitudes toward dying and death or exploring the meaning of death for nurses.

Further research is also necessary amongst nurses from different cultural groups in an attempt to analyse whether culture alone may have positive or negative effects on the processes of caring for the dying.

### Conclusions

This study supports, in part, findings from published literature. Conceptual analysis extends previous research in providing an analysis of the shared meanings amongst nurses caring for the dying. Being transformed by the experience, the influence of context on caring, the embodiment of caring,

caring for the family and coping are new areas of concern, with the context of caring for the dying, for further inquiry.

The experiences of this group of nurses and the previously identified issues should be examined in order to determine whether they can be substantiated as part of the total experience of caring for the dying. This study contributes to nursing practice by providing the basis for further research of the effects on caring for the dying amongst nurses.

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## **APPENDIX A**

### **CLUSTERS OF COMMON THEMES:**

**BEING TRANSFORMED BY THE EXPERIENCE**

**THE CONTEXT OF CARING**

**THE EMBODIMENT OF CARING**

**CARING IN THE CONTEXT OF THE FAMILY**

**COPING**



## **APPENDIX B**

### **SAMPLE OF SIGNIFICANT STATMENTS**

#### **BEING TRANSFORMED BY THE EXPERIENCE**

- G09 Death brings a sense of peace and release from pain for the person.
- S08 I feel relieved having "travelled with them" even for a short time. They always look so peaceful.
- D05 I don't feel an awful lot. I remember how the person was. What's left is an empty house. Sometimes I think it's unfair, especially someone who has younger children and all their life in front of them.
- P03 Sometimes it can be more unhappy if they don't die. Death rounds off everything you've been doing, and that's what you're working towards in a way.
- V02 I often think, "Thank goodness she's finally gone."
- G09 I feel dying is age dependent and that dying is part of living. It's upsetting, but offset if they are comfortable.
- S08 It depends upon who they are and what they want. I try to step into the person's shoes and see how it is for them. Even though life is finite, it's still a shame.
- M06 I always feel it is a tremendous loss. All the things that person has is suddenly gone. It depends how well you've known them.
- D05 Dying is not the foremost thing on my mind. Most of the time is concerned with alleviating particular problems.
- H04 I feel compassion and empathy, depending on how close I was to the person. One gets used to death. I'm not shocked. It's just part of the job.
- S08 I felt guilty in the past about making more of an effort, but I now realise it's just different priorities. Guilt means not being committed to what you are doing.
- G09 When I was in palliative care I cried for myself, cried because I was alive. Now I control my feelings unless I'm attached to the person.

- S08 I'm selective in over emotion. I often cry when someone lives! Seeing the love for someone wither makes me sad because the richness between people is fading.
- S08 My perception on loss seems to be what drives me now.
- M06 I felt a sense of longing after he died, but I was relieved his suffering was over.
- D05 I felt sad when he died, it was hard to take at the time.
- H04 I felt devastated going through a normal grieving process, but I feel I came through it.
- P03 It hurts, it's like an open wound, almost like a pain I guess. But gradually it heals up and after a while the scar is there but it no longer hurts.
- V02 I was an absolute disaster, it was such as shock and very sad. I also felt very alone. Part of your history is gone.
- X01 I think most people that work here have been through some experience where they've lost someone. And I think that's why most people come here, because they want to do it better than what happened to them.
- C07 I know some people have felt they have been sent here. Maybe it's those people who have experienced a loss and maybe that's why they pick up that someone needs support.
- G09 I feel that 'you choose to live and die.' My life now. It's what I'm doing because I'm going to die.
- C07 I feel as though I've been there, it's peaceful. Once you die it's as though all your problems are gone.
- M06 I think working here is making it (death) easier because it's something you think about.
- D05 Dying to me is a way out for most people. I don't think that that's the end. I think that's one thing that sort of helps me with the idea of all these people dying.
- H04 Every human has a certain fear of death because it's an unknown thing. We still tend to think of it as something that will happen in the future.
- P03 Death holds no fear for me at all. It will mean me going from here into something far better.

- V02** I live with hospice. I see so many people who plan their future retirement, and then they die.
- G09** I feel as though I've learnt from the past. It helps to form your character.
- M06** Something will come up and it will remind you of something in the past. I don't dwell on it though.
- P03** You tend to remember your patients a lot. We reminisce.
- X01** Sometimes if something similar happens or things jog the memory, I do tend to reminisce.
- G09** I've probably asked what's the point of it all because I think that you have to come to terms with your own death before you can work here.
- S08** I see life as a place where opportunities are offered and there is life to live. I see people living until they die.
- D05** Life is not endless suffering.
- H04** Your perspective on life is coloured by how hard you are working and how much personal time you are getting.
- G09** Dying is part of living. It's a certainty.
- M06** It's the end of life, I'm not sure if there's anything more. Death is inevitable. I believe it is a transition from this life to the next.
- V02** As an experience, it's like giving birth or getting married (hopefully better than getting married). I'm sure there's life after death.
- X01** I'm a bit frightened about it because I don't know what's going to happen after dying. But I see it as part of living as well. There's something afterward but I'm not sure what.
- S08** I feel great, also humble - because of having some control over life and health. Happy to be contributing.
- C07** I think you become self-sufficient. It's really unhealthy to rely on other people for your own needs.
- P03** Interesting. I think it would be a natural thing to be glad it's them and not you.
- V02** I guess it's good to be a survivor. Working here, you're much more aware of your own mortality and the importance of enjoying life. You don't worry about the silly, little things. Live for the

moment. Do it now, go into debt and leave it for somebody else to pay.

- H04 I know that there is suffering which is not going to go on forever. People go somewhere better but I do not know where this is.
- X01 Since I've been working here it's changed. I had lots of goals before but now it's just enjoy yourself as you can.
- G09 The goal of a dignified death is not always possible.
- D05 I wouldn't like to be told I was dying. It must be devastating.
- P03 I wouldn't like to have a long, slow, incapacitating illness.
- V02 I would like three months off to finish the things I want to do. I'd prefer people to be the way they are to me today, as they would be the day before I die.
- G09 I feel positive about myself. I feel that there is something inside, an image which is not quite apparent. Others see me as strong.
- S08 I feel I have grown, but I have a lot more to do yet. I'm quick to anger - then it's gone. I have high expectations of myself. I'm humble, ordinary. Others see me as creative, helpful, a good listener and a good carer.
- C07 I don't know. Something happened last year and I just really changed how I felt about myself (and my family) and I think I've been going through a real period of adjustment.
- M06 I'm a reasonable sort of person. I'm fit, healthy, appreciate life and what I've been given.
- H04 I think I have a caring side to me. Generally I'm fairly patient.. I'm usually described as fairly quiet.
- V02 I'm basically a quiet happy person. Happy to do my own thing.
- X01 I care for people. I like to do the right thing.
- G09 I don't feel trapped by a mortal body. I've learnt how to leave my body and fly around (or communicate through the "mind"). It usually happens when I'm quite relaxed.
- S08 I started dreaming about dying when first having children (I'm the seventh child of a seventh child).
- C07 I've had a near death (clinical death) myself and I sort of feel like I've been there. I was thirteen and I grew up pretty fast. It just

feels really good but it was really sad because I was told to go back.

- X01 I dream about other people dying, and I'm usually right. I believe I may be psychic. I've also seen patient's ghosts. Whether they're actually there or in my mind I'm not sure.
- G09 Nurses are intuitive, knowledge of death comes with experience.
- C07 You just know. I think it's an aura. It's more spiritual but there's just something.
- M06 You don't always know when someone is going to die. Sometimes they'll tell you.
- D05 Sixth sense. One just gets a feeling about someone, even if they seem OK.
- H04 It's mainly based on physical signs and symptoms, but I think there's a degree of intuition involved.
- X01 I usually get a gut feeling about it, at work and in personal situations. It's intuition, something that's built in.
- D05 If I've got to know the family really well, I can go in and give everybody a hug. There's a lot more physical contact here than anywhere else.
- C07 If you share your grief with the family it helps yourself. I like to grieve with people because I feel that helps them say goodbye. It's anticipation of how they (the family) are going to cope when that person dies. It really helps me in the same situation.
- MO6 Seeing the family usually makes me cry. I feel really sad for them.
- X01 I feel relief for the family and for the person and also for me. The stress is relieved. I feel comfortable in hugging the family.
- G09 The nurse is often the brunt of a mass of emotions, usually anger. I just listen, because they are usually angry at their loss or the person.
- H04 Sometimes you feel as though someone has punched you in the stomach - and it's usually because you're dealing with them in terms of family.
- PO3 It's becoming aware of, facing the changes and losses and coming to terms with them, making them part of you.

- VO2 I don't **think** you forget your relationships but I **think** you get over them. You also have to go with the feeling for a while.
- XO1 I don't think you forget that person. I think you learn to live with it. I don't think you get over it. I think it would be sad if you did.
- MO6 Time usually, and if I feel grief or sadness I express those. I also talk to people. I accept what's going to happen to the person because you know they are going to die.
- SO8 The longing for someone doesn't go away. It stays there - and it's very useful in sitting/talking to people.
- GO9 With most people you don't need to resolve the relationship because it's (death) is what you've been working towards.
- DO5 Knowing that they're going to die anyway - it's just as bad as the fact that they actually do. Once they die I see it as a release for them (and for myself in a way).
- HO4 If they're gone when you come back from days off it's difficult. It's good to say goodbye. Sometimes I think you find out in the death notices. So on your days off you scan the columns.
- CO7 Sometimes it's really disappointing if the patient doesn't die when you're at work because you feel like you haven't finished off your business.
- SO8 Sadness mainly. It doesn't happen very often as you're doing a lot of that work when you're walking beside them. You survive.

## **APPENDIX C**

### **LETTER OF INTRODUCTION**

Dear Colleague

I am conducting a study in a Hospice setting, and I wish to investigate the phenomenon of anticipatory grief amongst nurses caring for the dying, as part of my Master of Nursing at Edith Cowan University. This study is important because we need to understand nurses' experiences as they impinge directly on nurse-patient relationships and the quality of such relationships.

I request your participation in this study but if you do not wish to take part, or wish to withdraw from the study at any time, you are free to do so. Non-participation in this study will not reflect on you either personally or professionally.

Should you agree to participate in this study, you will not be asked to identify yourself, nor will your name appear on any form, tape transcription or report. Confidentiality and anonymity will be preserved at all times.

There are no risks involved in this study although there may be no direct benefits to you individually. Potential benefits may contribute to a greater understanding of anticipatory grief leading to increased awareness of patients' needs and enhanced quality of care of the dying.

If you agree to take part in this study, you will be asked to participate in an interview which will be tape-recorded. This interview should take no longer than one hour, according to your needs.

Thank you for your attention and consideration.

Yours sincerely

DAVID M BYRNE

**APPENDIX D**

**CONSENT FORM**

**ANTICIPATORY GRIEF REACTIONS AMONGST NURSES CARING FOR THE DYING**

I \_\_\_\_\_ am willing to participate in research concerning Anticipatory Grief Amongst Nurses Caring for the Dying. The research consists of a tape recorded interview by the researcher who will ask questions regarding my thoughts and feelings about experiences related to the care of the dying. I understand that the interview is likely to take no longer than one hour.

I am also aware that data contained in the researcher's diary will contain observations of interactions during the course of my normal duties. I understand I will have full and free access to the researcher's diary, should I wish those observations pertaining to me deleted.

My participation in this study is voluntary and I realize there may be no direct benefits to me. I understand there are no risks involved in this study although information I give may contribute to a greater understanding of Anticipatory Grief amongst nurses which may assist nurses in the future.

I may stop the interview at any time and I may decline to answer any question. All information I give is confidential to the researcher and my identity will not be revealed on any report or tape cassette. I am aware that the tape cassette will be erased on completion of the study.

I have read the information and any questions I have asked have been answered to my satisfaction. I agree to participate in this study, realising that I may withdraw at any time without penalty.

I understand that research data gathered for the study may be published provided my name is not used.

Participant's  
signature.....Date.....

Researcher's signature .....Date.....



**APPENDIX E****DEMOGRAPHIC INFORMATION**

Please indicate the appropriate answer by placing a number in the box provided.

1. Are you:

(1) Female

(2) Male

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2. Are you:

(1) Married

(2) Single

(3) Divorced

(4) Widowed

☐

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3. (1) Were you born in Australia?

(2) Elsewhere (Please specify) \_\_\_\_\_ ☐

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4. Is English your first language?

(1) Yes

(2) No (Please specify) \_\_\_\_\_ ☐

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5. Are you presently employed:

(1) Working Full-time

(2) Working Part-time (Please specify) \_\_\_\_\_ ☐

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6. Please state years of practice in Hospice care.

(1) 00-10

(2) 11-20

(3) 21-30

(4) 31-40

☐

## 7. Please state years of practice in present employment:

- (1) 00-1
- (2) 2-3
- (3) 4-5
- (4) 6-7
- (5) 8-9
- (6) 9-10
- (7) 10-15
- (8) 16-20
- (9) 21+

☐8. What was your initial nursing qualifications?

- (1) Registered Nurse
- (2) Registered Midwife
- (3) Registered Mental Health Nurse
- (4) Enrolled Nurse
- (5) Nursing Assistant
- (6) Please Received

Please specify

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☐

## 9. Type of initial nurses' training:

- (1) Hospital Based
- (2) College Based
- (3) University Based

☐

## 10. Post Graduate Qualifications

Completed

Current

- (1) Degree in Nursing

☐☐

(or related field) please specify

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☐

- (2) Post Graduate

☐

- (3) Masters in Nursing

☐

- (4) PhD

☐

- (5) Post-basic courses:

Please specify

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## APPENDIX F

### Excerpt from the Researcher's Diary

5 May 1994

The usual trepidation I feel when coming into the hospice didn't seem to be with me this time. But I still have the feeling, or is it the sense, when entering a place or a room where someone is dying, that there is an aura or certain something which demands attention. Perhaps it's a reflection of my own experience with dying and death, the memories are still vivid. There is so much bustle here and I expected everything to be quiet - seems like the past again.

As usual I feel very drained, sad, the perennial invasive sadness, and it's always when you've stopped, and have the time to sit and think. So let's think about the interview. I think this nurse has a very special aura, it almost hits you when you meet her. Has piercing eyes and an open lively face, very expressive and expansive. Obviously loves life (although nothing is obvious apparently), loves living and enjoying herself. Loves her work. Seems very perceptive, warm, open personality. Has a great feeling for people. Is a fighter, has a job to do, and when it's done that's it. But it's rich (nice phrase). But the grief is there, as it always seems to be. Maybe that's the motivation. Seems to be working for something, not the "right" answers, but certainly something.

Has a great deal to say, which is good. Very detailed. Knows where she's been, where she's at? and where she's going? I was looking for something here. She seems quite "armoured" at times, then loosens up again. Has had lots of experience with loss, in hospice and privately. You walk into someone's life and then you walk out again. Only thing is, if you stop and really think about it, you're sunk. And I think I'm rambling, probably because I'm tired. What else is there. It's the honesty of people that really hits you. People bare their hearts and minds to a perfect (sic) stranger. Anyway, this is a good story. I think it captures just about everything. Should be interesting to listen to the tape and read between the lines.