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**THE ESSENCE OF EXPERTISE
IN PALLIATIVE NURSING PRACTICE:
A HERMENEUTIC ANALYSIS.**

A thesis presented to the University of Dublin, Trinity College
for the Degree of PhD in Nursing

by

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FFNMRC SI.

VOLUME ONE

April 2004

THE EFFECT OF EXERCISE
ON PALATAL BURNING PAIN
A DERMATOLOGIC REPLY

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Title: The Essence of Expertise in Palliative Nursing Practice: A Hermeneutic Analysis.

SUMMARY.

Background: The nature of nursing practice and caring are phenomena that have received much attention in the nursing literature in the past. Phenomena that are central to nursing and caring have been addressed and both models and theories have emerged from these descriptions. The practice of expert nurses has also been explored, however, the nature of expertise in the practices of expert nurses caring for patients receiving palliative nursing care has largely been ignored. I addressed this gap in this research.

Aim: Palliative nursing practice is patient and family centred as patients and families progress through a living-dying trajectory. The aim of this study was to make explicit the practices of expert palliative care nurses as they care for patients throughout the palliative care phase of their illness and to develop a model of expert practice that depicts these practices. The research focused on nursing practice within in-patient palliative care units in the Republic of Ireland.

Methodology: This hermeneutic study was guided by the philosophies of Schleiermacher, Dilthey, Heidegger and Gadamer. Data were gathered from six hospice in-patient units in the Republic of Ireland. Respondents consisted of forty nurses who were considered to be experts working in in-patient hospice units and eleven patients receiving palliative nursing care within three of these units. Data were collected through interviews and observation of nursing practice.

Results: Expert palliative nursing practice may be understood through the conceptual framework of “Fostering an Optimal Functioning Self Through Living with Dying”. Expert palliative nursing care is delivered to patients as they progress through the living-dying trajectory. Nursing practice is centred on maintaining the patients’

personhood throughout this trajectory. This is practiced through the processes of “presencing”, “comforting in dying”, “journeying”, “preparing for death” and “family caring”.

Conclusion: Expertise in palliative nursing practice remains complex. Expert practice is centred on the personhood of patients and their families. The extent of nursing care that is required is influenced by the location of the patient and patient’s family in the living-dying trajectory. Nurses require the knowledge, skills and competencies to interpret both patients and families needs in order to foster their optimal functioning through living with dying.

Introduction.

The concept of expertise has been examined within the discipline of nursing by various authors. The work of Benner (1984) provided one of the first qualitative studies that provided insight in the nature of skills development, that from novice to expert. Benner (1984) concluded that experts possess a holistic grasp of the situation; they rely on experience and develop an intuitive response to clinical situations. Additional studies based on the work of Benner (1984) have sought to provide insight into the nature of expert practice in a variety of specialist areas of nursing, including public health nursing, psychiatric nursing and nursing practice in surgical wards. One such area that remains absent from investigation is that of palliative care nursing practice. The World Health Organisation (1990: 11) acknowledges the key aspect of palliative care involves the “total active care of patients whose disease is not responsive to curative treatment”. While a number of theories depict the nature of dying, much still remains unknown about the practices of expert palliative care nurses as they care for patients during the palliative care phase of their illness as they are progressing through the living-dying trajectory. Care required by patients at this time demands expert knowledge and skills from nurses to meet these needs. However, no conceptual framework depicts the practices of nurses who are considered to be expert palliative care nurses, as they care for patients who are dying. This thesis sets out to address this deficit so that a conceptual framework may be generated from the practices of expert palliative care nurses involved in this study.

Research Purpose.

The overall purpose of this study was to investigate the essence of expertise in palliative nursing practice. This study concerns the nature of professional nursing practice within palliative care and specifically, the practice of expert palliative care nurses caring for patients who are dying. It is based on the premise that the knowledge and skills used by expert palliative care nurses within in-patient palliative care units builds over time and is deeply embedded in their expert practice. It builds on the assumption that the practice of these experts can be shared with non-expert nurses so that ultimately it will facilitate these latter nurses to develop expert skills in caring for

the dying. The nature of nursing practice has been the focus of discussion by many nurse theorists as they attempted to clarify the comportment of nursing practice. Various theories of nursing have been postulated which views caring as being central to nursing practice. However, a research-based understanding of the nature of expertise in palliative care nursing practice is needed so that quality care can be provided to patients throughout the palliative care phase of their illness.

Background to the Study.

The questions and ideas that generated my interest in this area of research stem from my awareness of the distinctions between different levels of skills practised by nurses. As I was involved in palliative care nursing practice, the practice of nurses engaged in caring for the dying seemed to demonstrate variations in their skills. I considered that a number of nurses practised at a novice level, while others practised at an expert level. However, I questioned as to what constituted “expert practice” and how the knowledge of nurses, who I considered to be experts, was translated into practice. Furthermore, I considered that the development of expertise in palliative care nursing practice would also have a positive impact on the nursing care patients received. I felt that patients receiving palliative care deserved expert care so that their living-dying trajectory was made peaceful for them and for their families, hence, there was a need to identify what constituted expertise in palliative care nursing practice. This prompted me to question whether the nature of expertise in palliative nursing practice differed from expertise in generic nursing practice, as addressed in the literature on expertise. As much remains unknown about the nature and development of expertise in nurses’ day-to-day clinical practice in palliative nursing care, I questioned what knowledge they used in their caring and how this knowledge translated into practice so that the findings can be used in the education and practice of non-expert nurses caring for patients who are dying.

Research Aim.

The overall aim of this study is to explore and describe the essence of expertise in palliative care nursing practices in caring for patients who are dying and to develop a

conceptual framework that depicts the practices of expert palliative care nurses as they translate their knowledge of caring for the dying into practice. The study also aims to explore patients' perspectives on their experience of receiving expert palliative nursing care.

Research Question.

This study is guided by the following research question: What is expertise in palliative nursing practice?

Research Design and Methods.

This study was guided by the philosophy of hermeneutics. The works of Schleiermacher (1977), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975 / 1989) were influential in forming the philosophical basis of this study. Interviewing and observation provided the methods of data collection. Data were collected from a total of forty palliative care nurses working in in-patient palliative care units in the Republic of Ireland and eleven patients who were cared for by a cohort of these nurses.

The Format of this Thesis.

The thesis is presented in three sections. Section one contains chapters one and two. Chapter one presents a review of the associated literature. The nature of nursing is explored in an attempt to provide an overview of its constituents. As caring is an integral aspect of nursing, caring is explored from a theoretical perspective. A review of the literature that examines the focus of palliative care and the nature of palliative care nursing is also addressed. Chapter two presents a review of the literature that addresses expertise and expert practice, with specific reference to the nature of expert practice in nursing. As knowledge forms the basis of expertise, a review of the literature that addresses the nature of knowledge is addressed.

Section Two contains chapters three, four, and five. Chapter three describes the research methodology employed in this study. As hermeneutics provides the

philosophical basis for this inquiry, the work of Schleiermacher (1977), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975 / 1989) are explored. My interpretations of the literature of these philosophers are presented in an attempt to demonstrate how they influenced my thought processes, data collection and analysis. Chapter four provides an account of the methods used to generate the data for the study. A discussion on the appropriateness of interviews and observation as a means of data collection is presented, together with an account of access to the respondents, inclusion criteria and ethical issues associated with undertaking research in the area of palliative care. Chapter five presents an account of the data analysis process employed in hermeneutically analysing the data. Data from observation and interviews are used to demonstrate the transparency of the approach used in analysing the data.

Section three contains chapters six to ten. Chapters six to eight present the findings from the study. Five themes emerged from the data that accounts for how the nurse respondents in this study demonstrate expertise in their practice. Chapter nine contains a discussion of the findings in the context of current literature and provides a conceptual framework within which to view the practices of expert palliative care nurses in palliative nursing practice. The implications of these findings for education, clinical practice and research within the area of palliative nursing care are presented in chapter ten.

SECTION ONE

LITERATURE REVIEW

CHAPTER ONE

LITERATURE REVIEW

1.1 Introduction.

This chapter presents a literature review pertaining to four concepts central to this study. These are a) the nature of nursing, b) the nature of caring, c) the nature of knowledge and d) the nature of palliative care. Understanding the nature of caring provides some insight into its complexity and is considered by many authors to be the central practice of nursing. As this study is concerned with the nature of expertise, a review of the literature addressing studies of expertise is presented. As the possession and application of knowledge is central to expertise, an overview of the nature of knowledge is presented. The review also focuses on methodological issues pertaining to these studies. The final section of this review addresses palliative care and palliative nursing.

1.2 THE NATURE OF NURSING.

1.2.1 Introduction.

The nature of nursing is one that has been explored from numerous perspectives. Florence Nightingale is considered to be the founder of nursing. Stemming from her experiences in the Crimean War, Nightingale's views of what constituted nursing centred on health and illness nursing (Nightingale 1992). While attempting to highlight the difference between medicine and nursing, Nightingale emphasized that the central focus of nursing as being one of preventative and health-oriented care as opposed to curative care, which she considered to be the focus of medicine (Reed and Zurakowski 1996).

Throughout the mid-twentieth century, attempts were made to further clarify the discipline of nursing. Numerous nurse theorists attempted to define and describe nursing. Among these are Peplau (1988), Henderson (1991), Johnson (1990), Orem (1995) and Roy (1999). A brief overview of these theories is presented in an attempt to demonstrate the complex nature of nursing.

1.2.2 The Nature of Nursing: Theoretical Perspectives.

One of the first attempts to theorise the nature of nursing was presented by Peplau (1988), where nursing was considered to be centred on the notion of interpersonal relations. The goal of interpersonal relations is one where "...the nurse and patient respect each other as individuals, both of them learning and growing as a result of the interaction " (Belcher and Fish 1990: 44). Interpersonal relations consist of four phases, namely the orientation phase, identification phase, exploitation phase and resolution phase. Peplau (1988) considers that progressing through these phases in a nurse-patient relationship facilitates the patient to address and identify problems, then utilise the nurse in solving these problems. Finally, the resolution phase of the relationship signifies an ending of the patient's problems.

Describing the nurse's role as part of the interdisciplinary team, Henderson (1991) highlighted fourteen functions of the nurse in an attempt to help patients maintain independence. While Henderson (1991) acknowledged the role of the nurse in caring, she also highlighted this role as one that encompasses carrying out the physician's orders, while maintaining patients' individuality throughout this process.

Johnson (1990) views nursing as a discipline that is distinct from medicine. She considers nursing to be complementary to medicine and other health care professions, while making its own contributions to the care of the patient. According to Johnson (1990: 29), nursing is:

"...an external regulatory force that acts to preserve the organization and integration of the patient's behavior at the highest possible level under those conditions in which the behavior constitutes a threat to physical or social health, or in which illness is found".

From the above definition, the focus of nursing is on supporting a behavioural system when there is a disruption of the individual's ability to function or when prevention is needed to avoid a breakdown in an individual's functioning. The individual, within Johnson's (1990) view, is one that is composed of systems; hence the focus of nursing is to maintain functioning systems for patients.

Orem (1995) considered that the focus of nursing is that of assisting the patient to maintain self-care, where there is a deficit in the self-caring abilities of the patient due to illness. According to Orem (1995: 2-3), to nurse means to:

“...attend to and serve and to provide close care of a person, an infant or a sick or disabled person, unable to care for self with a goal of helping the person become sound in health and ‘self-sufficient’ ”.

Orem (1995) also considers nursing to be a human and a helping service, with the nurse’s focus specifically being on the patient’s continuing therapeutic care. The components of the nurse’s focus on patient care inherent in Orem’s (1995) view of nursing include: encompassing the patients and physician’s perspective on the health situation, the patient’s state of health, the health outcomes sought by the patient and the self care demands sought by the patient and the patient’s abilities to engage in self care activities.

Roy (1999) provided an alternative theoretical perspective on the nature of nursing when she considered that nursing is focused on helping the patient to adapt to illness. While a definition of nursing is not provided, Roy (1999: 54) describes the goal of nursing as “...to contribute to the overall goal of health care, that is, to promote the health of individuals and society”. Roy (1999) proposes that people are adaptive systems with an ability to adapt to changing situations in their health. Nursing practice, based on the focus of adaptation, is centred on helping people adapt in the physiological-physical mode, self-concept-group identity mode, role function mode and interdependence mode. Nursing care is required when there is difficulty between and within modes of adaptation.

While the above theoretical frameworks view nursing as it is embedded in the beliefs and values of the theorists, these, and other nurse theorists, have influenced nursing practice throughout the world. This is evident from the writings of Knight (1990), Haggart (1993), Nyqvist and Sjoden (1993), and Tolson and McIntosh (1996). However, the practice of nursing remains nebulous, and while various literature sources attempt to describe the practice of nursing, it continues to be a complex

phenomenon and one that requires further clarification. Savage (1998) provides a comprehensive review of the changes in professional role of the nurse outside Ireland in which she examined the practice of nursing and the role of the nurse. While Savage (1998) describes international trends and the professional role of the nurse, there continues to be disparity as to the nature of nursing and particularly the components of various levels of practice. In an analysis of nursing, Savage (1998) proposes that nursing encompasses numerous dimensions and utilises role theory as a framework to describe nursing. She proposes that nursing is considered to consist of a helper role, the teacher / educator role, patient care / manager role, a clinician role, the manager / leader role, consultant role, and researcher role. She concludes that "...the practice of nursing is a complex phenomenon and in the process of evolution" (Savage 1998: 29). As nursing is conceptualised as encompassing these multi-dimensional roles, it is important to examine the caring practices of nurses in detail, so as to make explicit the elements of nursing practice. Such an examination will contribute to the education and practice of nurses, ultimately affecting the outcome of patients in their care.

1.2.3 Summary.

In summary, the nature of nursing has been conceptualised by a number of theorists. Among these are include Peplau (1988), Henderson (1966), Orem (1995) and Roy (1999). While each theorist has provided a conceptual framework that depicts the nature of nursing, a lack of understanding persists regarding the nature and essence of nursing practice. Additionally, Savage (1998) has provided a comprehensive review regarding the nature of nursing, within an international context. This valuable work has succeeded in providing a broad description of the nurse role, highlighting its multi dimensional aspects. However, as Leininger (1984) points out, caring is synonymous with nursing. This indicates that there is an inherent quality in each theory of nursing proposed that is common to all theories of nursing. As the focus of this study is on the nature of caring in palliative care nursing, the following section provides an insight in to the nature of caring, in an attempt to clarify its constituents.

1.3 THE NATURE OF CARING.

1.3.1 Introduction.

This section provides an overview of a number of theories of caring as they have emerged in the nursing literature. Caring as a concept has received much attention in the nursing and philosophical literature. While it may appear to be a straightforward concept, it has been explored from a number of perspectives and has been demonstrated to be quite complex. The following section addresses a number of views of caring in an attempt to demonstrate its complexity. It will also be demonstrated that, due to the complex nature of caring as derived from the literature, there is a need to explore the nature of caring as it occurs in the context of caring for patients in the palliative care phase of their illness, in order for such practices to be understood within this specialist area of nursing practice.

1.3.2 Caring: A Theoretical Perspective.

While a number of theorists have attempted to provide a variety of perspectives on the nature of caring, the philosophical and nursing literature frequently makes reference to the diversity of interpretations offered by various authors. Four of these theories are presented in an attempt to compare their richness in quality. Additionally, they provide a synthesis of thoughts, feelings and actions that depict the practice of nursing. These include Mayeroff (1971), Campbell (1984), Noddings (1984) and Watson (1988). These were chosen for their wide spectrum of views of the concept, and account for the humanistic characteristics that are inherent in the practice of caring. The nature of caring for the dying is one that involves the development of relationships and supporting patients as they progress through the living-dying trajectory. The views of caring in those theories takes cognisance of the patient as being central to the caring interaction, which is fundamental to the caring interaction.

1.3.2.1 Mayeroff's (1971) Theory on Caring.

Mayeroff (1971) describes caring as helping someone else to grow and reach a stage of self-actualisation. He assumes that caring is "to care for another person, in the most

significant sense, ... to help him grow and actualise himself" (Mayeroff 1971: 1). Mayeroff (1971) contends that 'another' may include ideas as well as humans, however, in the context of nursing, the person is the focus of the caring relationship. Caring, as proposed by Mayeroff (1971) is compiled of a number of elements. These include: knowing and knowledge, alternating rhythms, patience, honesty, trust, humility, hope, and courage. Knowing and knowledge are necessary constituents of caring. Knowing, an essential element to the caring process, includes understanding of individual needs, an ability to respond effectively to these needs, an aptitude to determine what is conducive to personal growth as well as defining both personal and patient limitations. Knowledge, on the other hand, is considered to include information about the person, who forms the centre of the caring relationship. Alternating rhythms signify the necessity to review the individual's past and to implement changes in the caring act so as to maintain and / or modify behaviour.

Patience allows a sense of freedom, a degree of liberty where the person being cared for is allowed to lead the caring process. Mayeroff (1971: 17) considers patience enables "...the other to grow in its own time and in its own way". Honesty involves openness with the person being cared for and with the carer. It allows the caring relationship to grow and develop, where there is no dichotomy between the carer's thoughts and actions. "There must not be a significant gap between how I act and what I really feel, between what I say and what I feel" (Mayeroff 1971: 20). Trust promotes independence and responsibility in the person being cared for, while the carer also needs to have trust in himself / herself. Humility promotes learning as a reciprocal process between the carer and the person being cared for, while it also allows for the realisation of limitations in the process of caring. Hope "...is an expression of the plenitude of the present, a present alive with a sense of the possible" (Mayeroff 1971: 26). It facilitates growth between the carer and the person being cared for, while courage is necessary to face the unknown. Future actions are guided by what has been learned in the past as the unknown future is travelled. An adaptation of Mayeroff's (1974) definition of caring was presented by Blattner (1981: 70), who defined caring as "... the interactive process by which the nurse and client help each

other grow, actualise and transform towards higher levels of well-being". Blattner's (1981) view of the caring relationship requires an opening, a sharing of one self, trust, ideas and knowledge.

van Hooft (1987) is critical of Mayeroff's (1971) concepts of caring and presents a number of arguments that infer that there are limitations and difficulties associated with Mayeroff's (1971) theory of caring. These include: personal characteristics of the carer, lack of growth and the notion of constant replacement of the person doing the caring. van Hooft (1987) suggests that there are a number of patients who are not in a position to grow in the manner that is referred to by Mayeroff (1971). According to Mayeroff (1971: 33), "... a person who has suffered brain damage cannot be cared for in the sense of helping him grow". Such an exclusion from caring in the sense of growth, appears to be inappropriate as van Hooft (1987) suggests, the course of activities in caring for a brain damaged person may be considered to be caring. Such an interpretation of caring fails to take cognisance of the potential for growth, while it also appears to limit the different ways in which people can actually experience growth.

van Hooft's (1987) second criticism of Mayeroff's (1971) theory focuses on the idea that a caring relationship diminishes if there is a constant replacement of the carer by another. This suggests that there is a degree of permanence and irreplaceability involved which is unachievable in reality. Mayeroff (1971: 48) strongly supports the ideal of continuity of caring when he proposes:

"... the other for whom I care is a completion of my own being and as such is partially constitutive of my own identity. The other for whom I care is so important to me as to constitute an extension of my very self".

As van Hooft (1987: 30-31) suggests, such an assertion is unrealistic in that it requires those whom the nurse cares for to enter into "... the selfhood of the nurse".

1.3.2.2 Campbell's (1984) Theory on Caring.

Another interpretation of caring has been offered by Campbell (1984). Skilled companionship forms the centre of Campbell's notion of caring. Campbell's (1984) ideology of caring is one that views caring as the central focus of nursing. He suggests that:

“... what is required is an account of nursing which is not caught up in sexual stereotypes, which is professional without being distanced and manipulative, which is close to the reality of bodily care, yet also sees the personal potential of the patient, which protects the nurse from overwhelming demands, yet which gives every patient full consideration” (Campbell 1984: 49).

From the above description, it is evident that the centrality of caring is companionship. However, the companionship requires a balance between excessive and insufficient attachment in the relationship. He attempts to clarify the notion of companionship by suggesting that it is:

“...a closeness that is not sexually stereotyped; it implies movement and change; it expresses mutuality; and it requires commitment, but within defined limits” (Campbell 1984: 49).

The boundaries of companionship allow the carer to share freely without imposing on the other person while allowing the person to make their own journey. Like Mayeroff (1971), Campbell (1984) provides four components of companionship that are relevant to nursing. These are: bodily presence, helping the person to move onward, closeness of contact between the nurse and patient, and a commitment to limited companionship.

Nursing practice requires the establishment of a bodily presence throughout the process of caring. Skilled nursing care depends on sensitivities, so that “the body of the other person is handled in a way that overcomes embarrassment” (Campbell 1984:50). Tenderness and patience form a central element of bodily presence throughout the caring process. Bodily presence is necessary in order to allow for the eccentricity, individuality and peculiarity of patients.

Moving onwards towards health or death provides the second component of companionship. The role of the nurse in providing companionship throughout this

time is one that reduces the difficulties associated with the onward journey, and is guided by the nurse's knowledge of the journeying process and possible outcomes. Encouragement forms an essential component of companionship, particularly when the patient considers that all is lost and when difficulty in moving forward is experienced. Encouragement is necessary so as to offer new ways of accomplishing the patient's journey. This requires innovative ways to be implemented to help patients move onwards. Campbell (1984: 50) warns that:

“...the greatest destruction of nursing care is evident when routines prevent any change and patients are offered no future, but a state of living death”.

The practice of nursing brings nurses into close bodily contact with patients (Lawler 1991), and as such distinguishes nursing from other healthcare disciplines. According to Campbell (1984), the closeness of contact between the nurse and patient involves 'being with' in a special way and not just 'doing to' the patient. While companionship is less than friendship, it involves risk-taking on the part of the nurse, especially in interacting with demanding and ungrateful patients. Hence, the quality of 'being with' the patient is embedded in the skills of companionship.

Finally, Campbell (1984) advises that the type of companionship that is applicable to nursing requires a limited commitment. The commitment ceases as the onward journey proceeds to the restoration of health or to death. Campbell (1984: 50-51) advises against 'total dedication' in caring and adds:

“... we have seen the dangers - for both nurse and patient - in the idealized picture of nursing as total dedication. The nurse whose life outside the hospital or sick room has its own richness and satisfaction will offer a less demanding relationship to patients than the nurse whose whole fulfilment must be found in helping the sick”.

1.3.2.3 Noddings (1984) Theory on Caring.

Noddings (1984) developed a caring ethic in which she considered that intersubjective care cultivates the focus for self-care. She stresses mutuality, recognition and fostering self-care in the development of her theory. She defines ethical caring arising out of

natural caring as “that relationship in which we respond as one caring out of love or natural inclination” (Noddings 1984: 5).

Caring is considered to occur when the carer accepts the “natural instinct” to care for another being. Describing caring, Noddings (1984: 24) suggests it is

“... to act with special regard for the particular person in a concrete situation...the one caring desires the well-being of the cared-for and acts (or abstains from acting-makes an internal act of commitment) to promote that well-being”.

Elements of the caring relationship consist of “engrossment and motivational displacement on the part of the one caring and a form of *responsiveness* or *reciprocity* on the part of the cared for” (Noddings 1984: 150). Describing engrossment as the process of receiving the other person without judgment, the carer encounters the other’s experiences. While this may appear simplistic, Noddings (1984) describes how the above process is complemented by a motivational shift towards the person being cared for. She describes this as a displacement of motivational forces from the one caring to the one being cared for. Additionally, the caring relationship is a two-way process involving the one caring and the one being cared for. There is regard for the one caring to the person being cared for, while there is also some observable behaviour or action on behalf of the person being cared for.

There are benefits to both parties throughout this process, for the carer and the person being cared for. Noddings (1984: 150-151) describes the role of the cared for as follows:

“The cared-for contributes to the caring relation...by receiving the efforts of one-caring, and this receiving may be accomplished by a disclosure of his own subjective experience in direct response to the one-caring or by a happy and vigorous pursuit of his own projects”.

Noddings (1984) proposes that if it is possible, caring ought to be borne out of natural caring. If this is not possible, she contends that care should be undertaken out of a desire to be honourable. Bishop and Scudder (1991: 71) describe ethical caring from Noddings (1984) perspective as:

“... that which is done out of desire to be a good person, that desire being informed by the experiences of being a good person...affective recollection

empowers the caregiver to make the required shift from concern for self - being a good person - to engrossment with and motivational displacement toward the person needing care”.

1.3.2.4 Watson’s (1988) Theory on Caring.

Watson’s (1988) theory of caring complements that of Mayeroff (1971) and considers caring to be a moral ideal of nursing and a unique transaction between the nurse and the patient. Watson (1988) describes the foundation of care as being based on three motives, namely, the will to care, the intent to care and the caring actions. Influenced by Eastern philosophy, Watson (1988) adopts a transcendental position and deliberates the meaning of care as primal and universal psychic energy. She identifies caring as an art and science as well as an interactional process that occurs between a patient and a nurse. The caring process is paramount in that it assists individuals to grow, hence, drawing similarities to Mayeroff’s (1971) work. Watson (1988: 75) identified ten carative factors that constitute the process of caring. These include:

“(1). humanistic-altruistic systems of values, (2) faith-hope, (3) sensitivity to self and others, (4) helping-trusting, human care relationship, (5) expressing positive and negative feelings, (6) creative problem-solving caring process, (7) transpersonal teaching-learning, (8) supportive, protective, and/or corrective mental, physical, societal, and spiritual environment, (9) human needs assistance, (10) existential-phenomenological-spiritual forces”.

While Watson’s (1988) theory of nursing attempts to highlight the importance of caring in promoting growth that creates meaning and transcendence, it is not without its limitations. Morse et al (1990) consider that there is a broad gap between nurses’ caring processes and clinical reality where caring takes place. Furthermore, Morse et al (1990) suggest that true caring is not possible to achieve for short-term patients and patients who are unable to interact, or cognitively impaired, as a true caring relationship does not develop in these situations. Hence, it is questionable if caring is actually taking place where a caring relationship does not develop.

van Hooft (1987) describes two further elements that are requisites to the caring relationship, namely communication and compassion. He considers these as being

both emotional and spiritual in nature. While he argues that it is unusual to consider both of these as spiritual, he quotes Marcel (1971: 26) as saying:

“The person who is at my disposal is the one who is capable of being with me with the whole of himself when I am in need; while the one who is not at my disposal seems merely to offer me a temporary loan raised on his resources. For the one, I am a *presence*, for the other I am an *object*”.

van Hooft (1987) considers that the meaning of ‘presence’ in the above statement signifies a tool that gives way to communication which is not available in an ‘object’ like relationship. Compassion as an element of caring is considered to be a mundane form of interpersonal being that is based on an unequal relationship between the nurse and the patient. van Hooft (1987: 32) considers that nurses are not in the same unrestricted relationship as the patient. He refers to authors who:

“...in their talk of *mutual* growth and rapport seek to place the nurse and patient on an equal footing. While this may be admirable from the point of view of an egalitarian humanism, it flies in the face of the obvious fact that the patient is ill and the nurse is well. The patient is in need while the nurse is there to provide what is needed”.

Considering the above stance that patients and nurses are unequal in the relationship, van Hooft (1987) views compassion as the desire within the nurse to recognise this “superiority” and to attempt to restore parity in the relationship. This view of compassion however, seems to contradict the view of Mayeroff (1974) who considers compassion as an understanding of the other’s world as if the carer were inside it.

van Hooft (1987) also considers professional commitment as being encompassed in caring. He proposes that commitment is an ethical category that comes from an inner desire to act rather than being imposed on one from an external source. He defines professional commitment as:

“ ... an existential stance that has significant duration, through which the subject defines him or herself and in the light of which makes particular choices” (van Hooft 1987: 34).

The existential commitment, as identified in the above definition implies that the people define themselves in terms of the commitment made rather than by an

undetermined choice. Choice on the other hand originates from a superficial level and does not require an investment of the self. While the motivation for commitment arises from or expresses one's character, choice is more concerned with insignificant matters.

1.3.2.5 Summary.

The above review highlights the complexity of caring. Caring involves the facilitation of growth and actualisation that occurs through the nurse-patient interaction. Characteristics required to promote this process include the possession of patience, trust, and humility (Mayeroff 1971). Companionship, according to Campbell (1984), provides the genesis for the creation of attachment to patients through which the carer supports and directs patients in their journeying process. Noddings (1984) provides an alternative view of caring, as one that involves three aspects, namely, engrossment, attitude and observable action. These three aspects attempt to conceptualise caring process and actions; however, they provide little in proposing caring practices within her espoused theory. Watson (1984) provides three bases on which caring is created, namely, the will to care, the intent to care and the caring actions. In an attempt to clarify the process of caring, Watson (1984) provides a number of factors that impinge on the caring process. While those factors are valuable in providing insight into the nature of caring, Watson's (1984) theory never the less is limited in its application to caring for the dying. While no single theoretical perspective captures the diversity of practices that caring involves, the ill-defined nature of caring proposes difficulties for nurse theorists, educationalists and practitioners. As the focus of this study is on caring, caring by nurses within the context of patients who are dying in palliative care settings, the following section provides an overview of the nature of palliative care in an attempt to trace its development and its contribution to care of people who are dying.

1.4 PALLIATIVE CARE.

1.4.1 Introduction.

This section examines the nature of palliative care within the context of its philosophy. An overview of the development of the palliative care services in Ireland will be presented so as to place the study within the Irish context. Studies addressing the nature of palliative nursing will be presented in an attempt to highlight the specialist nature of palliative nursing practice.

1.4.2 Hospice Care: Meaning, History and Development.

The terms 'hospice care' and 'terminal care' are used synonymously with 'palliative care'. However, the Irish Association of Palliative Care and the Irish Hospice Foundation propose that terminal care is "...a continuum of palliative care which refers to the management of patients during the final hours or days of life" (Irish Association for Palliative Care and Irish Hospice Foundation 1996: 5). According to Clark and Seymour (1999: 80), the term palliative care is derived from the Latin verb *palliare*, which means "to cloak or shield".

The World Health Organization's (WHO) definition of palliative care considers that palliative care affirms life while regarding death as a natural process. It neither hastens nor postpones death. Palliative Care is defined as:

"... the total active care of patients whose disease is not responsive to curative treatment. Control of pain and other symptoms and psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable in the courses of illness in conjunction with anti-cancer treatment" (World Health Organisation 1990: 11-12).

In a recent review of the nature of palliative care, the WHO revised the definition of palliative care and expanded its focus. Key elements of this revised definition have been extracted by Sepulveda et al (2002) who propose that the nature of palliative care encompasses the following:

- provision of relief from pain and other distressing symptoms

- affirmation of life and regards dying as a normal process
- neither hastens or postpones death
- integrates the psychological and spiritual aspects of patient care
- offers support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The above key constituents of palliative care appear to mirror the notions put forward by Ahmedzi (1996) who considers palliative care to incorporate all treatment modalities that are both curative and palliative from the time of diagnosis to the terminal stage of illness. Palliative care interventions are also required as the individual enters the terminal stage of illness. Palliative care services have developed throughout the world with the development of services in some countries more advanced than in others.

The concept of hospice is derived from medieval times. Established by religious orders throughout Europe in the Middle Ages, hospices provided way-stations and shelter for pilgrims and travellers where they could find shelter, food and boarding on their journey (Roach 1997). The notion of providing a place of shelter for travellers extends back even further in history, to Egyptian times. Lodging houses known by the Greek word *xenodochia* were established to care for travellers, orphans the aged and poor Hebrew people (Jamieson, Sewell and Gjertson 1959). Dolan (1978) refers to hospices as places where medical and nursing care were provided to travellers due to

the inevitability of sickness. Throughout the Middle Ages, there was an increased demand for institutions to care for the sick as a result of illness such as bubonic plague, leprosy and syphilis across many European countries. These institutions became known as hospices where both the religious and secular orders cared for these people. While there appears to be some connection with these institutions and the hospices of the current era, Saunders (1993: vi) advises that the focus of care within these institutions and hospices ought not to be directly connected. She advises:

“...the medieval hospice was not primarily associated with dying people, and over the centuries it had come to welcome an impossible mix of patients along with travellers and pilgrims, orphans, and the destitute with varying degrees of segregation”.

A programme of research commenced in Britain in the mid 1990's known as “The Hospice History Project” in an attempt to compile the history of modern hospice and palliative care (Clark 2004). Data from this project traces the development of the hospice movement from its nineteenth century origins to the twentieth century. The nineteenth century witnessed the proliferation of hospitals throughout Europe. Throughout this era, death was considered to be a medical failure and sparked the development of institutions to care for those who were dying. These institutions were mainly managed by charitable organisations and philanthropists (Clark 2000). Two individuals in particular were of major influence in the development of the hospice movement. Jeanne Garnier, a young widow and bereaved mother formed L'Association des Dames du Calvaire in 1842 (Clark 2004). Following her death, six additional hospices were founded both in Paris and New York. The second influential individual in the development of the hospice movement is Mother Mary Aikenhead, who founded the Irish Sisters of Charity. Her work inspired the opening of Our Lady's Hospice in Harold's Cross a number of years after her death.

The next major development in hospice care occurred around the mid twentieth century. Dame Cicely Saunders, a nurse, social worker and doctor, established St. Christopher's Hospice in England (Hallenbeck 2003). This was the first teaching and research based unit to be established and is considered to be the first stage of the

international development of the hospice movement (Clark 1998). As Saunders continued to develop the hospice movement through practice, research and publications, her work:

“set out the principles of a new approach to the care of dying people which would harness together medical innovation in pain and symptom management with wider concerns for practical and social needs of patients and families, as well as a responsiveness to spiritual matters (Clark and Seymour 1999: 72).

The opening of St. Christopher’s Hospice generated a model of care that included home care, family support system, bereavement and follow up services (Saunders 2004). Clark and Seymour (1999: 72/73) attribute three factors to the success of Saunders in pioneering the hospice movement in the mid twentieth century. These include:

“...her sense of personal calling ... the pursuit of goals concerning the professional issues which relate to care of the dying ... the social networks which had to be exploited to gain support for St. Christopher’s”.

Since 1967, there has been a global spread of hospices (Hockley 1997). Evidence suggests that the benefits achieved through the development of palliative care services are worthwhile and point to the necessity to continue its development. These benefits include increased quality of life for patients, greater family satisfaction with care and bereavement support (Cooley 1992; Wakefield and Ashby 1993; McMillan and Mahon 1994; Kristjanson et al, 1997) Australia has witnessed the development of dedicated in-patient units, hospital consultancy services and home care services, while the status of hospice development in Eastern European countries remain at an early stage of development (Hunt and Maddocks 1997; Luczak 1997; Tropiano and Walsh 2000). Developments in hospice services have also been ongoing in the Republic of Ireland in tandem with England and other countries. As this study is based within the Irish health care context, an overview of the palliative care services in Ireland will be presented.

1.4.3 Development of Hospice and Palliative Care in Ireland: Policy Influences

The Irish health care structure consists of both public and private healthcare institutions. The government funds approximately 75% of health care while the remainder is covered by private health expenditure (O'Hara 1998). The Department of Health (1993) acknowledged the necessity to further develop palliative care services in Ireland and in an attempt to provide a co-ordinated approach to its development, it provided guidelines for the development of a palliative care service within Ireland. This document highlighted the role of various bodies involved in setting up palliative care services, together with recommendations for personnel and training initiatives within palliative care.

In 1994, the Department of Health published the document "Shaping a Healthier Future", in which it outlined proposals for reorganising the Irish health care services (Department of Health, 1994). This document presented a number of initiatives in order to widen the inclusiveness in health care provision and availability. It also provided the impetus of further evaluation of the cancer services within Ireland. As a result of the above publication, an additional document published in 1996, "Cancer Services in Ireland: A National Strategy" (Department of Health 1996), highlighted the need for inclusiveness of palliative care service for people with cancer. Since then, however, palliative care has widened its focus to include the provision of care for people with Motor Neurone Disease and AIDS (Hayes and McDonnell 2001).

While the above recommendations highlighted the need for including palliative care to be an inclusive aspect of all clinical practice, there was a need for direction in this development. In an attempt to provide such direction, the Irish Association for Palliative Care and the Irish Hospice Foundation (1996) presented a position paper and made recommendations regarding issues such as funding, standards, education and training and the scope of palliative care services. Additionally, recommendations were made to establish a National Advisory Council for hospice and specialist palliative care services. The first publication to arise from the development of such a

committee was in 2001 by the Department of Health (2001). This report has traced the ongoing developments in palliative care in Ireland while making recommendations for future development of palliative care services. These include: access to services, aids and appliances, counselling, bereavement and support, education, practice and financial support, respite care and communication.

1.4.4 Development of Hospice and Palliative Care in Ireland: Hospice Services

The establishment of the first Irish hospices has been influenced by the work of the Irish Sisters of Charity. Many of these sisters were nurses who devoted their time and skills to caring for the poor and terminally ill (Butler 1980). Hospice care in Ireland has its origins in the late 19th century with the establishment of Our Lady's Hospice, Harolds Cross and St. Patrick's Hospice, Marymount, Cork. The need for the establishment of hospices in Ireland is evident from the number of people requiring care as they approach death. Hospice services in Ireland consist of in-patient units, home care services, day care services and palliative care services in general hospitals.

The first day-care service was established in 1993, and this number has now risen to four, which are attached to in-patient palliative care units. There are thirty-one home care teams that are mainly nurse led services in partnership with the primary care team. There are also six in-patient units, four consultant led specialist palliative care services in general hospitals and one paediatric oncology/palliative home care team in the Irish Republic. The principles of palliative care on which the Irish palliative care services are based are in keeping with the W.H.O. recommendations of service development and are also endorsed by the Department of Health and Children (2001). Many of the palliative care services in Ireland are extended from focusing solely on cancer related symptoms and now include Motor Neurone Disease and AIDS. The continued development of the hospice services in Ireland is evident from the contribution of the Irish Cancer Society, the Irish Hospice Foundation, regional health boards and health authorities and the Department of Health and Children (Department of Health 1994; Irish Association for Palliative Care and the Irish Hospice Foundation 1996; Department of Health and Children 2001). With the continued development of

palliative care services in Ireland, palliative care nurses continue to make an important contribution to caring for clients within all areas of the palliative care services. This has resulted in the demand for practitioners with specialist knowledge as well as a palliative approach to care (Hayes and McDonnell 2001).

1.4.5 Palliative Care Nursing within Ireland.

The development of palliative nursing in Ireland has not occurred in a vacuum. It has developed in tandem with a variety of health services over a number of years, as outlined in section 1.4.3 and 1.4.4.

According to Hayes and McDonnell (2001: 779) palliative care nursing in Ireland has:

“...a belief in and nurturance of the soul and spirit of the patient; a desire to serve and to help alleviate suffering of the patient; and a deep compassion and love for the patient, whether a patient or family member”.

While the above ideal of the attributes of Irish palliative care nurses appears to encompass essential elements of palliative nursing, there is a dearth of literature that explores the role of palliative nurses in Ireland. Larkin (1998) however, undertook a phenomenological investigation of the meaning that palliative care nurses derive from working with the dying in Ireland and how this was reflected in the Irish culture. The themes captured the expression of Irish palliative nursing from sixteen palliative care nurses working in a home care setting. These were expressed as closeness (*dluchairdreamh*); soul-friend (*anam cara*); loving (*gramhar*); caring (*aire*) and spirit (*spioraid*). While Larkin (1998) succeeded in describing the lived experience of palliative nursing from a home care team perspective, the findings of the study may be limited in that the Irish language was used to provide meaning and structure to the expression of palliative nursing, meaning may be lost through the process of translation. Despite this however, the study is unique in that it is the first and only study of its kind in Ireland that has attempted to capture the lived experiences of Irish palliative care nurses. Findings described by Larkin (1998) are comparable to the understanding of palliative care nurse as advisor, supporter and counsellor as described by Quint-Benoliel (1995) and Webber (1993). However, findings from these

studies raise the questions as to what constitutes the field of palliative care nursing and how this differs in essence from other areas of nursing care.

1.4.6 Palliative Care Nursing and Research

To date, palliative nursing research has addressed a variety of issues pertaining to the practice on palliative nurses. These include: perceptions and definitions of the contribution of the palliative care nurse to the care of the dying (Davies and Oberle 1990; Herring, Wilson-Barnett and Ball 1995; Nebauer et al 1996; Taylor et al 1997). The skills required to deliver palliative nursing care have also been the focus of attention by Quint (1967), Mc Corkle (1982), Degner and Gow (1988), Gibbs (1995), and Heaven and Maguire (1996). As caring for families and patients occur in different settings, a number of researchers have explored the components of the caring process (Davies and Oberle 1990; Copp and Dunn 1993; Webber 1993; Larkin 1998; Rasmussen and Sandman 1998). James (1986) explored if hospices achieved the idealistic aims they set themselves, together with exploring how nurses manage the care of the dying relative in hospice ideals. Furthermore, caring for patients in the palliative care phase of their illness within a home care situation has also received attention (Beaver, Luker and Woods 2000; Pooler et al 2003).

The role of the palliative care nurse as a support to the dying was addressed by Davies and Oberle (1990). The respondent consisted of one nurse who cared for ten patients, their spouses and other family members. This was a retrospective account of the palliative care nurse's role, which was undertaken five years following the caring activities. Analysis indicated that the supportive role of the palliative care nurse consisted of six elements, namely: valuing, connecting, empowering, doing for, finding meaning and preserving one's own integrity. These dimensions formed a model of supportive care, where each role was interwoven to provide support for patients and their families in a pain and symptom control clinic. While this study adds valuable insights into palliative nursing practice, it is limited in its findings. As the study was a retrospective account, the accuracy of the accounts is questionable and

challenges the truthfulness of the data. Furthermore, as there was just one respondent, the generalisability of the findings is limited.

Degner, Gow and Thompson (1991) report on a study of ten educators and ten experienced palliative care nurses who undertook a qualitative study that explored the critical nursing behaviours in caring for the dying. Results indicate that these behaviours consisted of the following: responding during the death scene, providing comfort, responding to anger, enhancing professional growth, responding to colleagues, enhancing the quality of life during dying and responding to the family. Data were supported by exemplars and rich descriptions of the nurses' accounts of practice to support their findings.

Dobratz (1990) describes the role of hospice nurses as one that encompasses intensive caring, collaborative sharing, continuous knowing, and continuous giving. These activities highlighted the complex role that palliative care nurses undertake within their work in caring for the dying. Research from a family caregiver's perspective was undertaken by Hull (1991) in an attempt to describe the caring behaviours of hospice nurses as perceived by family caregivers in a hospice home care programme. Analysis, using a constant comparative method of fifty-five interviews indicated that the caring behaviours centred on a 24-hour accessibility and availability, effective communication skills, accepting and non-judgemental attitudes and clinical competence.

Studies have also addressed the effects of death education on fear and attitudes towards death and life (Leviton and Frets 1978); the responses of nurses to death and dying in general hospital settings (Stoller 1980); and nurses' responses to death (Hare and Pratt 1989). The nature and effect of palliative nursing practice was described by Taylor et al (1997) as one that involves dealing with death, making connections, acting as advocate, making contracts, building interpersonal relationships, facilitating breakthroughs and acceptance, facilitating support, being involved in issues, and finding solutions. These authors consider that in order to deliver care within this

framework, nurses need to achieve a comprehensive level of understanding of the dying person's inner life so as to improve the human transition from life to death.

While caring for the dying occurs in hospice settings, it also occurs in a variety of health care settings. However, it is questionable if caring for the dying in out of hospice environments mirrors that of caring for dying within hospices. Field (1984) provides a comprehensive account of nurses' experiences, attitudes and problems caring for terminally ill patients on an acute surgical ward, medical ward, coronary care unit and in patients' homes. Data were gathered through interview and observation from eighteen nurses over a nine week period. Guided by the theoretical perspective of symbolic interactionism, data revealed that caring for the dying centred on work organisation, doctor-nurse relationships, the role of the ward sister, disclosure norms, patient contact and emotional involvement.

Work organisation either promoted the involvement of nurses with patients and their families and influenced the degree of satisfaction and reward which nurse experienced in caring for dying patients. Teamwork in end of life care is paramount in order to address the multiplicity of needs which dying patients present (Ajemian 1993). There was evidence that teamwork, or its absence, between doctors and nurses provided both inhibitors and facilitators of practice and autonomy for nurses in this study. Findings suggest that the healthcare team, of which the respondents in this study participated in, presented with similar difficulties identified by Payne (2000). These include relationships, team member support and responses to users' needs. Similar to the finding of Samarel's (1991) and Smith's (1992) studies, it was difficult to avoid emotional involvement with patients and their families. However, Field (1984: 133) considered that "...emotional involvement by nurses in this study with dying patients was more likely to be positive than a negative feature for both nurse and patient". The findings suggest that the respondents in this study did not identify stress as an outcome of emotional involvement or the nature of their work in caring for the dying. While stress has also been described as burnout, compassion fatigue and chronic grief (Saunders and Valente 1994; Welsh 1999; Payne 2001), however, the respondents

found that unexpected deaths were more difficult to cope with than those which were expected. This may be due in part to the context in which death occurred, as opposed to deaths occurring in a hospice setting.

While Field's (1984) study provides valuable insights into caring for the dying and its impact on the carers, there is a danger that "...the tyrannies of niceness" as described by Street (1995:30) may lead to distortion of the realities of palliative care practice. Additionally, Aranda (2001: 12) is critical of the "ideological stagnation" associated with palliative care, suggesting that such an ideology impedes carers' abilities to be self critical and reflective in their practice. It may also be argued that there is a danger of contradiction between work expectations and work realities in caring for the dying within the carers in an attempt to sustain practice within this ideology. There is also a risk that the emotional aspects of caring for the dying and their families may negatively impact on the caring practices of nurses. James's (1986) seminal work on "Care and Work in Nursing the Dying", provides valuable insights into the challenges facing nurses caring for the dying in a continuing care unit as they strive to deliver care within modern hospice ideals. She highlights the range of difficulties that nurses encounter as they attempt to provide a wide range and quality of nursing skills to dying patients, as follows:

"...the 'emotional labour' of talking about dying, of learning to be involved without being overwhelmed by it, and of watching someone in pain without immediately being able to relieve it ... which was threatening because it made them feel inadequate" James (1986: 180).

Emotional labour as a concept is described by James (1989: 15) as "...the labour involved in dealing with other peoples' feelings, a core component of which is the regulation of emotions". Within hospice care, James (1989) highlights the difficulties in addressing emotional labour at work and its impact on the carers, and argues that 'emotional labour' is integrated within the caring practices of staff. She suggests that work is frequently considered incomplete by nurses if the emotional aspects of caring has not been incorporated into caring. While the workplace may not be considered to be a place where emotional expression is considered appropriate, James (1989) supports the notion that emotional labour is congruent with the philosophy of hospice

care. This requires nurses to possess the capacity to maintain a balance between the demands of caring, the emotional labour associated with caring for the dying and an ability to successfully adapt to the challenges which caring present (Aranda 2004).

While there are numerous additional studies that have explored nurses role in caring for the dying (Watts, Jenkins and Back 1997; Lindop and Read 2000; Hopkinson and Hallett 2002; Steele 2002) none of these explore the practices of palliative care nurses, practicing at expert level, within palliative nursing practice.

While the above studies have contributed to the knowledge base regarding the nature of palliative nursing practice, the respondents within these studies, the level of experience, knowledge and skills of the respondents has varied. There still remains a lack of understanding regarding the manner in which expert nurses in palliative nursing practice engage in the process used to implement their knowledge base in order to support patients throughout the dying process. As such, the nature of expertise in palliative care nursing practice remains unknown. The aim of this study is to address the gap in this area so is to illuminate the practices of expert palliative care nurses within the specialty of palliative nursing practice, so that a conceptual framework that depicts these practices can be generated.

1.4.7 Summary.

This chapter has presented an overview of the nature of caring. The review highlights the complex nature of caring as a concept. Theoretical perspectives of caring were presented, however, much uncertainty remains regarding its nature. This literature has addressed caring in a number of contexts; however, there is a dearth of literature that addresses the nature of caring by expert palliative care nurses. Hospice care and palliative care are terms that have been used synonymously. A review of the development of hospice and palliative care services within the Republic of Ireland places the study in context.

1.4.8 Conclusion.

While the literature indicates that palliative care has been explored from various perspectives, there appears to be a lack of consensus as to what constitutes expertise within this specialty. This study sets out to address this deficit, while it also attempts to develop a model of expert practice that depicts expertise in on practice. Expertise is based on the possession of specialised knowledge and skills. The seminal work of Carper (1978) provides the basis for much discussion regarding the nature of knowledge used by nurses in their practice. The following chapter explores the nature of expertise and the nature of knowledge for nursing.

CHAPTER TWO

LITERATURE REVIEW

2.1 EXPERT PRACTICE AND NURSING.

2.1.1 Introduction.

This section provides an overview of the literature related to expert practice. An attempt is made to demonstrate its complexity and Benner's (1984) seminal work, which is based on the experiences of twenty one pairs of beginning and expert nurses working in acute and critical care units in three hospitals, has been utilised as a basis for exploring the attributes of expertise. Further studies that have been based on Benner's (1984) model are addressed, together with additional studies that have attempted to describe the nature of expert practice in nursing.

2.1.2 Expert Practice.

Expert practice and clinical expertise are concepts that are linked to advanced nursing practice. Manley (1998) considers that developing expertise in nursing practice is not a straightforward task, but one that encompasses the roles of educator, researcher and consultant. Expert practice is a concept that has attracted much discussion in nursing literature, however, there appears to be little agreement regarding the nature of expertise and how it is attained. Furthermore, there appears to be limited knowledge regarding the manner in which expert nurses deliver nursing practice in an attempt to achieve patient outcomes for the patients in their care.

2.1.2.1 Attributes Of Expertise.

"Expert" is defined in the Collins English Dictionary (2000: 196) as "a person with extensive skill experience or knowledge in a particular field". From this definition there appears to be four key attributes present that provide the hallmarks of expertise, namely skill, knowledge, experience and particular field. It appears from research undertaken on the nature of expertise (Benner 1984; Benner Tanner and Chesla 1992; Walters 1992; Cutliffe 1997) that these criteria are used extensively to identify expert practitioners. Jasper (1994) considers that while these attributes are plausible, it appears these characteristics are based on subjective interpretations in order to identify experts. She concludes that there are four key attributes that define an expert and these

are the possession of a specialized body of knowledge and skill, extensive experience in the field of practice, highly developed skills of pattern recognition and acknowledgement by others. Woods (2000) acknowledges the difficulties associated with the concept of expertise and its related attributes. He considers that expert practitioners are recognized by what they do and what they know rather than by a set of definitive characteristics. Despite this assertion however, there appears to be an over reliance on Benner's (1984) work as forming the basis of studies on expertise. The following section provides an overview of Benner's (1984) work and highlights a number of concerns related to her study.

2.1.2.2 Benner's (1984) Novice To Expert Model Of Expertise.

Benner's (1984) seminal research investigated the stages of skill acquisition in registered nurses working in acute and critical care units in three hospitals. Her study involved interviews with highly skilled and experienced clinicians who related critical incidents from their practice to her in order to identify levels of competencies. The outcome of her study indicated that nurses move through a five-stage process, namely novice, advanced beginner, competent, proficient and expert. Another outcome of her study was that Benner (1984: 46) identified a number of functions associated with the domains of practice. These include: teaching-coaching; helping; diagnosing and monitoring; and managing rapidly changing situations, administering and monitoring therapeutic interventions and regimens, monitoring and ensuring quality the quality of health care practices and organizational and work-role competencies. An overview of the stages in the context of Benner's (1984) study will be presented together with a critique of issues related to her study.

Novice.

Skill acquisition at novice level is gained through instruction. The novice learns to recognize the objective facts and features and acquires rules for determining actions based on those facts and features. The elements of the situation that identify the problem are so clearly and objectively defined that the novice can recognize these elements without reference to the overall situation in which they occur. The rules that

are applied to these facts in this stage of skill acquisition are absolute and context free. Within nursing practice situations, Benner (1984: 21) describes the actions of the novice practitioner thus:

“The rule-governed behaviour typical of the novice is extremely limited and inflexible. The heart of the difficulty lies in the fact that since novices have no experience of the situation they face, they must be given rules to guide their performance. But following rules legislates *against* successful performance because the rules cannot tell them the most relevant tasks to perform in actual situations”.

It appears from Benner’s (1984) description of the actions of the novice nurses that they are novices in terms of length of time since registration or length of time in a new clinical situation. It is debatable however, if nurses experienced in other “disciplines” of nursing would rely on the “rule governed” practice when confronted with a new clinical situation. Additionally, the roles of knowledge and clinical decision-making skills of the nurse do not appear to have been considered during this phase of development.

Advanced Beginner.

Following on from the novice stage, Benner (1984) proposes that nurses reach the stage of the advanced beginner. However, there appears to be marginal differences between the skills of the novice practitioner and that of the advanced beginner. Benner (1984) considers the main attribute of the advanced beginner is that of building on skills and prior experience that are developed in the novice stage in order to cope with new situations as they arise. It appears from Benner’s (1984: 25) description of the advanced beginner that experience forms the main focus of development for the nurse, while there continues to be a need for support and guidance “in setting priorities” as they continue to learn “meaningful patterns” in patients’ behaviour.

While the above description appears plausible, there appears to be no time frame recommended by Benner (1984) to indicate the period of advanced beginner performance. There is no acknowledgement of the quality of the experience and the structural support provided during the period of being an advanced beginner.

Similarly, there is no account taken of the intellectual ability of the nurse to facilitate the transition between novice to advanced beginner.

Competent.

Benner (1984: 292) describes competence as consisting of "... deliberate planning ... evidenced by an increased level of efficiency". The competent stage of skills development is marked by a notable increase in the nurse's ability to use his/her analytical ability when addressing clinical decision situations. Unlike the two previous stages of development, exposure to similar practices for two to three years is identified as being a hallmark in developing competency. The competent performer has moved from a detached state to one of involvement that occurs as a result of decisions reached. The competent stage of performance remains as a conscious decision process. Despite this assertion regarding length of time in a speciality area, there appears to be no justification or rationale relating to the number of years experience. Furthermore, no exemplars of practice or interview data are provided in order to substantiate the findings from this group.

Proficient.

Performance in the proficient stage is characterized by the use of maxims. These are defined by Benner (1984: 296) as "... cryptic description of skilled performance that can benefit one who has enough skill to recognize implications of the instructions". Proficient nurses are in a position to view the situation in its entirety, anticipate changes in patient care situations and change nursing actions and plans accordingly. Intuitive decision-making processes based on past experience of similar situations are used to guide the proficient nurses' thought processes.

As in the analysis of the competent stage of skills acquisition, Benner (1984) fails to provide exemplars from the study to support her distinctions made between that of competent to proficient nurse. Furthermore, the expected length of time it takes to reach the stage of being proficient is not addressed. The use of educational processes

in promoting the nurses' analytical ability throughout the proficient stage appears to be absent from the description of this stage of development.

Expert.

For Benner (1984: 32), the expert nurse is one who has:

“... an enormous background of experience, now has an intuitive grasp of each situation and zeroes in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions”.

Benner (1984) considers the characteristic of intuition as being that which separates the expert from other levels of skill acquisition. Analytical rules or maxims are not relied on when considering a patient situation. Experience also forms the basis of reaching decisions, without having to consider a range of alternative solutions. While the expert may have limited use for analytical thinking in clinical situations, Benner (1984) acknowledges that when experts are confronted with new or different situations, they are required to use analytical problem solving approaches to deal with the situation.

2.1.2.3 Criticisms of Benner's (1984) Study.

While the seminal work of Benner (1984) has provided a milestone in exploring the process of skill acquisition in nursing practice it is not without its critics. An overview of these will be presented in the context of what is offered by Thompson (1990); English (1993); Farrington (1993); Cash (1995) and Crotty (1996).

Hermeneutics as a Foundation for Inquiry.

Thompson (1990) praises the work of Benner (1984) in that it provides an insight into the knowledge and wisdom that is embedded in nursing practice. She notes that Benner (1984) maintains a distinction between the wisdom of nursing and the knowledge for practice, which she does not equate with technical proficiency. The importance of meaning and the influence of context on meaning are central to hermeneutics (Mulhall 2000). Reference is made to the context of nursing and its influence on the importance of meaning. It is debatable as to whether the context of

practice of a nurse in critical care is similar to that of a nurse working in an area outside of critical care, and as such it appears Benner (1984) has omitted to recognize context at a micro level within an organisation. This suggests that there is more than one contextual standpoint that needs to be addressed in relation to wisdom and knowledge for practice.

At a macro level, Thompson (1990) argues that Benner (1984) has failed to recognise the cultural influence on the context of practice. The inclusion of culture as an influence would provide insight as to how the social and political contexts influence, either positively or negatively, the development of nursing practice or wisdom. In addition to the above limitations, Thompson (1990) expressed concern regarding the methodological ambiguity of Benner's (1984) study. This ambiguity arises from two standpoints, namely the hermeneutic stance taken in the study and secondly, the methods of analysis. As far as Thompson (1990) is concerned, Benner's (1984) research is not clearly objectivist hermeneutics, Gadamerian hermeneutics or critical hermeneutics. While such a division in hermeneutics may provide clear direction regarding methods, Benner (1990: 284), in response to this criticism, suggests that while her study does not "fit the three categories", she justifies her work as being based on the writings of Heidegger, which allows her to "... study naturalistically the habits, skills, practices and meanings of people". This approach allowed Benner (1984) to go beyond the subjectivism and objectivism of objectivist and critical hermeneutics. However, Crotty (1996: 130) contradicts Benner (1984) who argues that the use of Heideggerian phenomenology is not evident in her study:

"... this is not phenomenology. It is a form of social inquiry that is in continuity with the American intellectual tradition but owes nothing to phenomenological movement. It relates to symbolic interactionism emanating from the thought of George Meade rather than to phenomenology, whether transcendental or existentialist".

Such a statement supports the criticism presented by Thompson (1990) in relation to methodological ambiguity; however, Crotty does not offer any further criticism of this study from a methodological perspective. The analysis of data was undertaken by means of thematic analysis, analysis of exemplars and the search for paradigm cases.

While this in itself does not appear problematic, Thompson (1990: 273) is critical of the fact that Benner (1984) has presented the findings, based on this process of analysis "...without situating the researcher in relation to the practices". Thompson (1990) suggests that such an absence appears to be consistent with an objectivist stance, while it is not evident from the study how the coding schemes were constituted. This may have been overcome if Benner (1984) made her reasons explicit for choosing specific exemplars of practice.

Other Methodological Concerns.

The use of the critical incident technique as a means of data collection has been the subject of a number of criticisms of Benner's (1984) work. Cash (1995) considers that an ambiguity exists as to what constitutes a critical incident. She focuses on limitations of the use of the critical incident technique and argues that incidents may be selected because they are typical, instead of being critical. Cash (1995: 531) further suggests that: "... the more one goes towards the atypical the more one gets away from... the background practices, that one is trying to expose". This raises the question of the validity of the critical incident technique as a means of data collection.

It is interesting to note that the critical incident technique was also used by Reed (1994), who acknowledged the strength of the critical incident technique as used in numerous studies, including Benner's (1984) study as a means of data collection. However, she also points out that this technique is not without its problems, as she encountered in her study. Despite this however, it emerged that the critical incident technique failed to capture the phenomenon of "expertise" in long-term care in the context of Reed's study. Reed (1994: 340) suggests that the use of this technique "...may have some advantages as well as disadvantages, especially when used in areas where work is not so clearly episodic". This may account for its failure to capture "significant incidents" in this study, while there appears to be more significant events occurring in critical care areas. Despite Reed's (1994) acknowledgement of the use of the critical incident technique in Benner's (1984) study, Farrington (1993: 228) considers that the central theme of Benner's (1984) work "...hinges on the notion of

using story telling exercises to demonstrate excellence in clinical nursing practice, i.e. the critical incident technique". Farrington (1993) considers that the use of critical incident technique in Benner's (1984) study is flawed and uses the work of Smith and Russell (1991) to support his viewpoint. Farrington (1993) appears to have ignored the positive elements as described by Smith and Russell (1991: 289) who suggest:

"Students often express appreciation at being given the time and freedom to share concerns, experiences and feelings, providing them with the opportunity to increase understanding of their own and others' responses to situations encountered during nursing practice and which in turn enhances their sensitivity to others' needs".

It appears from the above feedback on the use of the critical incident technique that it provides a valuable method to students in heightening their awareness of the complex skills in nursing. It appears from this critique that the critical incident technique was the only approach used to collect data. Farrington (1993) does not make any reference to the fact that Benner (1984) utilized the interview and observation of practice as a means of data collection in an attempt to capture the essence of expertise in nursing practice.

The role of intuition as an attribute of expertise and nursing knowledge has been the focus of ongoing discussion and criticism. Cash (1995) is critical of the role of intuition as described by Benner (1984) as being purely within the realm of the expert practitioner. Cash (1995: 533) contradicts this notion and suggests that "... an amateur in scientific thinking can still have intuitions, and those intuitions can be wrong". Furthermore, Cash (1995: 533) considers the value of intuition in nursing is also lessened because of the nature of "epistemological power" in professional relationships. In a counter argument regarding the relationship between intuition and power, he considers that instead of intuition giving power, it actually needs it. The support for this assertion is evident from the following:

"The physicians have control over the clinical situation, the nurses power is negotiated with them. Intuition, because it lacks immediate confirming evidence relies therefore for its status on the perceived epistemological power of the person having the intuition. Because generally nurses have less power than physicians, the status given to nurses' intuition will be less". (Cash 1995: 533)

English (1993) presents a challenge to Benner's (1984) claim regarding the nature of intuition of expert nurses. He is critical of the assertion that intuition is a legitimate source of knowledge in clinical decision-making available only to experts. He suggests that to consider intuition as an obscure or latent talent is incorrect. He supports this assertion by considering that non-expert and student nurses as well as patients also experience intuition. Building on this assertion, English (1993: 390) considers intuition to be a "...subjective and questionable entity and hence, until empirically and unequivocally validated, has limited applicability in a nursing profession". In an attempt to redefine intuition, English (1993) endeavours to apply a model of cognitive psychology that would provide a more distinct account and an objective measurement of intuitive responses. While this may be plausible, it may present with difficulties because of the complexity of skills involved in nursing practice.

English's (1993) assertions are supported by Effken (2001), who suggests that intuition may be perceived as "direct perception" that is information based, when viewed from the perspective of ecological psychology. According to this view, "intuition is an observable, lawful phenomenon that is measurable, potentially teachable and appropriately part of nursing science" (Effken 2001: 252). The basis for this assumption by Effken (2001) is that the underlying environmental informational sources are used instead of perceptual and conceptual processes in making decisions in practice. It may be argued that this view of intuition is credible and simplifies the nature of intuition as used in practice as a process of information processing and knowledge for practice.

2.1.2.4 Additions to Benner's (1984) Novice to Expert Model.

Benner, Tanner and Chesla (1996) extended the research undertaken by Benner (1984) in an attempt to provide a more detailed examination of the nature of expert nursing practice. The study involved one hundred and thirty-five registered nurses working in intensive care units and general floor units in eight general hospitals in America. The nurses varied in the number of years experience and were classified as follows:

twenty-five nurses with less than one years experience, thirty-five nurses with at least two years and less than five years experience, forty-four nurses with greater than five years experience and regarded as being expert and twenty six nurses with five or more years experience and considered as being experienced practitioners. Data were gathered through the use of narrative interviews and observation of practice. Observation of practice was undertaken on forty-eight nurses on three different occasions, during which time conversations were recorded. Rich descriptions of practice are provided in text to support the analysis of data and provide exemplars of practice associated with the different stages of development. It is interesting to note the absence of the novice stage of development within this study. There was no reason provided for the omission of this stage. Unlike the previous study by Benner (1984), there are numerous exemplars from practice to support the data analysis, which strengthens the credibility of the findings.

The Advanced Beginner Stage.

The aim of practice of advanced beginners is marked by a series of tasks to be completed within a particular time frame. With the focus on tasks, these are guided by a set of unit protocols, unit procedures and by physicians' orders. While undertaking these tasks, nurses often consider that they are being tested on their capabilities to deal with a particular clinical situation. It is not unusual for them to make "lists" of tasks to complete, as opposed to viewing the clinical situation in its entirety. These clinical situations, however, provide the advanced beginner with the opportunity for learning in practice, while linking the practice to their theoretical knowledge. Benner, Tanner and Chesla (1996) suggest that nurses working as advanced beginners often worked in situations that are beyond their capabilities. This is described by Benner, Tanner and Chesla (1996: 57) as "... a period of stark terror in which they recognize they are in over their heads, and lose all capacity to plan or act".

The Competent Stage.

Nurses practising at the competent stage invariably have two years experience in the specialist field. Unlike the nurse at the advanced beginner stage, there is no longer a focus on completing a set of tasks within a specific time frame. Instead, the nurse demonstrates an ability to anticipate possible eventualities in practice that is indicative of the development of a greater understanding of each clinical situation. Experiential learning and formal modes of study form a major role in the nurses' development as they strive to develop a greater understanding of clinical practice. As the competent nurses' skills develop, they are in a position to practice outside the realms of protocols and guidelines so as to deliver care that is specific to individual patients and their families. There is also an increase in the nurses' emotional response to clinical situations where there is evidence of a deep sense of involvement with clients and their families at an emotional level.

Increased clinical understanding, technical skills, organisational abilities and the ability to anticipate likely course of events provide the hallmarks of this stage of practice. This is a marked progress from the advanced beginner stage where practice was undertaken and guided by a list of tasks to perform within a specific timeframe. The competence state is also marked by a reduction in the level of confidence in other nurses and physicians. Benner, Tanner and Chesla (1996: 101) describe this situation as a period where "... nurses are experienced enough to recognize that not all health care workers are reliable, but they may not accurately discern the complexity and novelty of the situation". As a result of this lack of confidence in other nurses and physicians, a sense of heightened responsibility in practice situations is created.

The Proficient Stage.

Experiential learning forms a major aspect of learning at this stage. Organisational and technical skills continue to improve, while the value of experiential learning is evident through improved clinical reasoning abilities. Benner, Tanner and Chesla (1996) identify the major hallmarks of the proficient stage as an increase of the perceptual ability and responsiveness to patient situations, resulting in a change in clinical

performance. The use of reflection allows proficient nurses to develop their understanding of patient situations so that they can focus on the salient issues of the situation. There is an increase in the emotional attunement to patient situations, while there is evidence of an increased involvement with patients and their families. Nurses practising at the proficient level are also in a position to prioritise nursing actions and make decisions as to what is important in each situation. This is also accompanied by a reduction in the nurses' anxiety related to practice outcomes. Flexibility in practice is increased and they can act in situations without direction. As experience in the proficiency stage increases, so too does the level of responsibility increase. This is indicated by Benner, Tanner and Chesla 1996 (1996: 129) who suggest that:

“The heightened skills of perception and judgment, coupled with the experiential learning that allows for missed signs and symptoms, make this a time when the nurse confronts the full level of responsibility inherent in the work”.

The Expert Stage.

Nurses practising at this level appear to have an immediate and comprehensive grasp of the patient situation. This is accompanied by the ability to see the complete picture together with the ability to manage a number of tasks and issues at one time. There is an attunement to recognise the salient issues in patient situations and these nurses have a “... practical understanding of what to expect for the patient population, and often know the particular patient's patterns of response” (Benner, Tanner and Chesla 1996: 157). There is also a strong commitment within the expert to guide others in making a decision regarding patient care issues so that an appropriate treatment plan may be implemented. There is an increased sense of responsibility for patient well-being at this level.

2.1.2.5 Benner's (1984) Model as a Basis for Examining Expert Practice.

A number of studies have been conducted that have used Benner's (1984) model of expert practice as a basis for their study. It is interesting to note that these studies have been based in a number of specialties, including ambulatory care nursing, psychiatric

nursing, critical care nursing, public health nursing and nurses working on surgical wards.

Brykczynski (1989) undertook a qualitative study on the nature of clinical judgment of twenty-two nurse practitioners in an ambulatory care setting. Based on the work of Benner (1984), findings highlighted aspects of practical knowledge, domains and competencies of nursing practices within the ambulatory setting. Utilizing phenomenology as a research methodology for the study, three themes emerged from the data, and include (1) “discretionary judgment as a central aspect of ‘know-how’ ”; (2) “background knowledge is of considerable importance in skill development” and (3) “the nature of practice skills is experience-based” (Brykczynski 1989: 82). While the findings from this study appear to concur with that of Benner (1984), Brykczynski (1989) has succeeded in expanding the knowledge, domains and competencies of the practice of expert nurses in the ambulatory care setting. However, there appears to be little acknowledgement of the limitations associated with Benner’s (1984) work and as such the findings from Brykczynski’s (1989) study supports Benner’s (1984) findings as opposed to generating an additional perspective on expertise.

Mc Elroy (1990) undertook a study, the aim of which was to uncover the clinical knowledge used in the practice of expert psychiatric nurses. Using a Heideggerian phenomenological approach, Mc Elroy (1990) utilized Benner’s (1984) framework, together with that of Benner and Tanner (1987) and a Skill Acquisition Model. Ten expert psychiatric nurses were included in the study. It was interesting to note that their peers and the investigator chose the experts. The inclusion criteria were: a minimum of five years practice in psychiatric nursing, but a minimum educational requirement was not specified as inclusion criteria. The education level attained by the experts was varied, and they ranged from diploma, associate degree, and baccalaureate up to doctoral level. Paradigm cases were obtained from the respondents through unstructured interviews and these were recorded and transcribed to compose the text for analysis. The practice settings varied from in-patient units to nurses practising in private settings. Findings from the study indicated that the clinical knowledge of the

respondents was consistent with competencies in all of Benner's (1984) seven domains of practice. Additionally, a constructive pattern emerged which was identified as "The Primacy of the Nurse-Patient Relationship in Psychiatric Nursing Practice" (McElroy 1990: 81). This consisted of three relational themes which were a) uncovering danger in psychiatric nursing, b) acknowledging and marking boundaries and c) reflection on practice. Mc Elroy (1990) provided exemplars of these themes in an attempt to explicate the knowledge embedded in psychiatric nursing practice. While the study provides rich accounts of practice, the nurses involved relied on memory to recall a significant nursing situation that stood out in their memories and was meaningful to them. The accuracy of recall as forming the basis of data for analysis is questionable and limits the findings of the study.

A major strength of this study is the evidence of exemplars from practice to support the experts that help in confirming Mc Elroy's (1990) interpretation of the findings. However, had the researcher adopted the "etic" view of undertaking observation of practice, then possible inconsistencies between what the respondents said they did and what they actually did may have been uncovered. It was interesting to note how Benner's (1984) framework depicted more than the action skills of the expert nurses in this study.

Walters (1992) presented an interpretive study of the clinical practices of eight expert critical care nurses. Utilizing a modified version of Benner's (1984) inclusion criteria, Walters (1992) observed and interviewed eight clinical nurse specialists caring for patients in an intensive care unit. Data were analysed according to Benner's (1984) research design. Themes that emerged from the data analysis included "business", "focusing", "comforting", and "balancing" (Walters 1992: 321). Descriptions of practice that depicted these themes included reducing pain and anxiety, balancing caring for the patient as a person as opposed to the technical equipment, and empathising with the patient and family members. Further to the above themes, the ontological qualities that depicted the clinical practice of these nurses include "being-in-the-world", "being-with-the-technology" and "being-in-the-world-of-the-patient".

Practices associated with the above themes included the nurses' skills to use technology as part of their caring role, dealing with the patient and families as they experienced their trajectory through the ITU experience. The study provides valuable insights into the practices of expert critical care nurses, however it may be argued that using peers to nominate experts may lead to an element of bias in the sampling process used.

Mc Murray (1992) conducted a qualitative study of expertise in public health nursing. Data were gathered through observation, interview and written retrospective accounts of clinical episodes from thirty-seven nurses; twenty-seven of whom were considered to be experts while the remaining ten were considered to be novices. The expert group demonstrated a greater level of motivation, self-confidence and receptivity than the novices involved in the study. Additionally, the experts had engaged in a wider range of educational programmes, acted as role models and capitalised on clinical experiences to enhance and develop their practice as compared with the novice group. While the process of data analysis was guided by the constant comparative method, Tanner's (1984) model of diagnostic reasoning guided the development of a model of expertise in community care nursing. While this in itself is not problematic, the over reliance on Tanner's (1984) model restricts the analytical process to Tanner's (1984) framework and possibly limits the interpretation of findings.

A study was undertaken by Logan and Boss (1993) in an attempt to articulate the transition involved in proceeding through advanced beginner to expert practitioner. The study was based on the responses of eight registered nurses working on a specialized surgical ward. Like Benner, Tanner and Chesla's (1996) study, these researchers commenced at the level of advanced beginner, omitting the novice stage of skill development. Findings indicate that trust, advocacy and relationships capture the essence of learning in practice across the transition from advanced beginner to expert practice. In the advanced beginner stage, technical procedures and tasks formed the focus of nursing actions, so that these were completed before the end of the nurse's shift. However, as the focus on task completion diminished and centred itself on

meeting patient needs, the nurses were considered to have advanced to the competent stage of development. The competent role was characterised by an ability to partake in the domains of the helping role, teaching and coaching role and the diagnostic and monitoring function, as exemplified by Benner (1984). This was also accompanied by a focus on the overall plan of care of the patient as opposed to considering nursing interventions in isolation. There was also an increase in the nurses' skills related to patient care at this level. Meanwhile the expert nurses demonstrated a higher level of diagnostic and monitoring function and were in a position to manage rapid changes in patient condition effectively.

It is evident from this study that Logan and Boss (1993) have adhered to Benner's (1984) analytical framework in analysing the data obtained from the interviews. While this has potential to provide convincing findings, and a methodologically sound framework for analysis, it may be argued that valuable insights as to the practice of these nurses may have been lost. A notable difference in the findings of this study is that nurses appeared to use intuition as a function of decision-making in a much earlier stage than those identified by Benner (1984). Part of this may be attributed to the fact of the smaller number of respondents in this study and also to the complexity of the nurses' role in a surgical unit as opposed to a critical care area.

King and Macleod Clark (2002) undertook a comprehensive study of nurses working on surgical wards and critical care units. The aim of the study was to explore and identify levels of nursing expertise found through focus on a practice event-that of nurses' postoperative assessment of patients returning from major surgery. Another aim was to compare the findings with those of Benner (1984) and Benner, Tanner and Chesla (1996). Data were collected using interviews, retrospective reporting of critical clinical incidents associated with postoperative assessment of patients. This was combined with the observer-as-participant form of observation. Three research sites were used to generate the data, and consisted of thirty nurses working on surgical wards and thirty-one nurses working in critical care units. A purposive sample was used to select nurses for the study. Unlike other studies on expertise, there was only

one criterion for inclusion used, which was that they were working in the field of Intensive Care or a surgical ward and their experience ranged from newly qualified to those with many years of experience. The other criterion was that the nurse was allocated to a patient who had consented to participate in the study. While the focus of the above study was limited to nursing assessment in the postoperative phase, it highlighted interesting differences from Benner's (1984) and Benner Tanner and Chesla's (1996) studies. The findings emerged from observation and interview data on one clinical episode: that of post-operative assessments as opposed to a number of nurse-patient interactions throughout a full working shift. It was interesting to note that nurses with very little post registration experience, as little as one month, were considered to be advanced beginners, despite such limited experiences. It is questionable as to whether it is possible for a registered nurse with such a limited clinical experience to reach a competent level of practice. The inclusion criterion for this study is also a cause for concern and appears to be based on patient care demands as opposed to the skills of the nurse being identified as ranging from advanced beginner to expert. Unlike Benner's (1984) study, a clear audit trail was presented that provided the reader with a clear view as to how data were analysed. Exemplars from practice also supported the themes that emerged from the data. The use of observation as a means of data collection enabled the researcher to view nursing practice as it occurred as opposed to relying on the retrospective accounts of nursing actions, which may be influenced by the passage of time.

This study highlights a number of important issues that influence the development of nurses' expertise along a continuum from advanced beginner to expert. These include motivation, theoretical and experiential knowledge, the synthesis of these forms of knowledge through reflection and learning from role models in practice. Benner, Tanner and Chesla (1996) however, make no reference to motivation as an influential element in knowledge development or nurse-patient relationships.

In a qualitative study by Brykczynski (1998), clinical exemplars of expert nursing practice were identified and described from ten registered nurses working in a large

teaching hospital in the USA. Data were obtained through observation of practice and interview. Brykczynski (1998) utilised an interpretative approach based on the work of Benner (1984), Brykczynski (1989) and Benner, Tanner and Chesla (1996). Findings revealed an additional sixteen new competencies using Benner's (1984) domains of practice. These include "thinking critically about collecting data", "coaching other nurses"; "role modelling", "participating in significant intimate life events" and "preventing unnecessary technological intrusions" (Brykczynski 1998: 354). While the findings are useful in supporting the work of Benner (1984), Brykczynski (1986) and Benner, Tanner and Chesla (1996), both the criteria for selection and the area of nursing practice in which the respondents practices is not clear from the study. Despite this, the study is useful in its contribution to the development of nursing knowledge regarding the nature of expertise.

While the above studies have contributed to describing the nature of expert practice in a variety of settings, there are a number of issues that arise from these studies. Firstly, criteria for the selection of respondents in the study have varied widely between studies. This has ranged from eighteen months to five years experience in the clinical setting. This casts doubt as to whether expertise is dependent on years of experience or on the quality of experience. Secondly, educational attainment of the respondents has varied from diploma education to masters prepared nurses. This raises the question as to whether expertise develops as a result of theoretical knowledge in combination with experiential knowledge or whether it is influenced solely by experiential knowledge. The use of Benner's (1984) model as a basis of exploring expertise in practice ignores issues such as motivation, mentorship and the quality of role modelling as influencing factors in the development of expertise.

2.1.3 Additional Studies on Expertise.

A limited number of additional studies have explored the nature of expertise in various practice setting which have not utilised Benner's (1984) model of expertise as a framework for inquiry. These include studies by Butterworth and Bishop (1995), Conway (1996), Cutcliffe (1997) and Langley (1997).

Butterworth and Bishop (1995) sought to identify the characteristics of optimum practice within a variety of practice settings, including midwifery, health visiting, community psychiatric nursing, mental handicap nursing, children's nursing and adult general nursing. The respondents, who were considered to be expert nurses, were invited to complete an open-ended questionnaire regarding the nature of optimum practice. Responses were sought regarding their views as to the constituents of optimum practice, their contribution to its development, their description of optimum practice and the ingredients needed to create optimum practice (Butterworth and Bishop 1995: 27). Findings indicate that optimum practice by expert nurses consists of eighteen key characteristics. These range from innovation, leadership, personal qualities, and positive communication skills to involvement with teaching/education, political awareness and attention to human support services. Butterworth and Bishop (1995) argue that achieving a state of expertise in practice lends itself to providing optimum practice. The study's strength lies in the insight it offers into the development of an environment for the optimum delivery of patient care through the practices of expert nurses.

Conway (1996) examined the nature of knowledge that expert nurses used in practice. A total of thirty-five respondents who were considered to be experts by their managers, nurses and link educationalists participated in the study. The respondents included nurses from anaesthetics, critical care, surgical wards, oncology, cardiac care and accident and emergency units. Data for the study, which was guided by ethnography, hermeneutic phenomenology and grounded theory, were gathered through the use of observation and interview. Findings indicate that expertise "...develops in response to the 'world view' held by the expert" (Conway 1996: 14). Conway (1996) classified the world views of the experts as consisting of technologists, traditionalists, specialists and humanistic existentialists. "Anticipatory knowledge", "diagnostic knowledge", "know-how knowledge" and "monitoring knowledge" formed the basis of technologists' practice (Conway 1996: 15). Traditionalists focused on the completion of tasks and were limited in the amount of time spent reflecting in or on their practice. Specialists extended their roles and

challenged medical decisions that were made which influenced their practice. Humanistic existentialists maintained a "...strong nursing focus to care" (Conway 1996: 16). While the findings from Conway's (1996) study provide additional insights into the nature of knowledge used by expert nurses in their practice, the usefulness of applying terms such as those highlighted above is questionable, due to the variety of meanings that may be attached to each term. Additionally, it is questionable as to whether it is possible to practice solely within one 'world view'.

A study by Cutcliffe (1997) explored the nature of expert psychiatric nursing practice and focused on the beliefs and principles of psychiatric nurses working in a psychiatric unit. Data were collected through the use of focus group interviews and analysed using the constant comparative method. While Cutcliffe (1997) notes that the respondents were ward managers who were considered to be experts, there is no indication as to the number of respondents involved in the study or the criteria used to decide on the expert status of the respondents. Four categories emerged from the analysis that described the nature of expertise in psychiatric nursing care. These include 'attitude/philosophy', 'knowledge', 'skills' and 'roles' (Cutcliffe 1997: 325). These findings offer valuable insights into the constituents of expertise in psychiatric nursing. However, as the number of focus groups or number of respondents from which the data were generated is not clear, the transferability of the findings to other expert nurses is limited.

Langley (1997) completed a phenomenological study on the nature of expertise in public health nursing. The sample included nineteen public health nurses who were considered by their nursing colleagues to be experts. Data were generated through demographic survey forms, description of written narratives from their practice and interviews. Diekelmann's (1992) seven step interpretative process guided the data analysis. Findings indicate that expertise in public health nursing consists of five processes: experiential, educational, ethical, organisational and personal. These processes combine to form a constitutive pattern, which Langley (1997: 183) terms "Expert Public Health Nursing As Interpretive Practice: Building Past to Future".

This study offers findings which are important to the understanding of the intricate nature of expertise in nursing practice. Each process presented by Langley (1997) depicts the interconnectedness of skills that are necessary to practice at the level of an expert and provides further support to the notion that expert practice is a complex phenomenon.

2.1.4 Summary.

This section has presented a review of the literature on expertise in nursing. Benner's (1984) model of expertise provided the basis for further studies on the phenomenon. While Thompson (1990), English (1993), Cash (1995) and Crotty (1996) have been critical of her work, Benner (1984) has highlighted the need to examine expert nursing practice in the midst of uncertainty regarding the nature of caring in nursing practice. Furthermore, Benner (1984) provided valuable insights into the importance of knowledge of practice within the realm of expertise. While a number of studies have attempted to explore the nature of expertise in nursing practice, the majority of these studies have been mainly influenced by the work of Benner (1984) and Benner, Tanner and Chesla (1996). The limited number of studies that did not rely on the work of Benner (1984) and Benner, Tanner and Chesla (1996) provide valuable insights into the nature of expertise but have lacked a focus on palliative care; hence, there is a need to address this deficit. The following section addresses the nature of knowledge that is an essential component with expert nursing practice and presents a review of the theoretical literature related to the nature of knowledge for practice.

2.2 KNOWLEDGE USED IN NURSING.

2.2.1 Introduction.

The development of expert nursing practice is based on the possession of knowledge. According to Benner (1984), expertise develops as a result of processing and refining theoretical and practical knowledge within specific clinical situations. While the nature of nursing knowledge has been the focus of academic debate for a number of years by various authors, the work of Carper (1978) has provided the first major examination of the types of knowledge used in nursing. Since then, other authors,

including White (1995), Silva, Sorrell and Sorrell (1995) and Liaschenko and Fisher (1999) have added to the debate regarding the nature of knowledge used in nursing. In order to gain an understanding of the attributes of each type of knowledge, an overview of the four patterns of knowing will be presented. Furthermore, additions to Carper's (1978) work will be presented: this includes the work of Silva, Sorrell and Sorrell (1995), White (1995), and Liaschenko and Fisher (1999). Nurses draw on various forms of knowledge to guide their practice, however, there is a dearth in the literature that provides an insight into how expert palliative care nurses implement their knowledge for practice when caring for the dying in practice. In an attempt to provide the context for this study, this section of the review provides an overview of the various forms of knowledge from which nurses utilise in practice.

2.2.2 Carper's Ways of Knowing.

Carper (1978) presented seminal work that addressed the nature of nursing knowledge. She suggests that knowledge utilized in nursing practice is essentially composed of four "patterns" or types of knowing. These include empirics, ethics, aesthetics and personal. While four patterns of knowing are presented, they are not mutually exclusive and each pattern is used interchangeably in practice.

2.2.2.1 Empirics.

Carper (1978) views the empirical way of knowing as being compiled of scientific or propositional knowledge and consists of theories and models that can be empirically tested. It is a type of knowledge that is objective, factual, generalisable and publicly versatile since its purpose is to describe, explain and predict. Studies to test knowledge in this area need to involve experimental and control groups and have pre and post-test measurements. Edwards (2001) considers empirical knowledge is factual, acquired by development through the senses, and verifiable. While the use of empirical knowledge is essential to nursing practice, Nolan, Lundh and Tishelman (1998) challenge the notion that the knowledge used in nursing needs to be unique and proposes that the use of scientific knowledge for other disciplines needs to be incorporated into nursing practice and knowledge development. Jacobs-Kramer and Chinn (1988), supported by

McKenna (1997) further expand on the work of Carper (1978) and suggest the use of replication as a means to assess for credibility in the process and context of developing empirical knowledge.

2.2.2.2 Ethics.

Ethics as a form of knowing is concerned with moral duty and is expressed through moral codes and ethical decision-making (McKenna 1997). According to Carper (1978: 20) ethical knowledge "...includes all voluntary actions that are deliberate and subject to judgment of right and wrong". Inherent in the above notion of ethical knowing is that nurses need to have an understanding of a range of moral theories and perspectives from which they can draw to make moral decisions regarding practice. However, the possession of such knowledge is not always adequate when challenged with ethical dilemmas in practice. The development of ethical knowledge for practice, from the perspective of Jacobs-Kramer and Chinn (1988), arises from the process of reflection on contextual circumstances of the ethical problem together with the process of decision-making. In an attempt to simplify this process, these authors identify the components of ethical knowledge and consider that the "...assessment dimension of ethical knowledge draws on rightness, justness and responsibilities" (Jacobs-Kramer and Chinn 1988: 293). It is through these processes that a new perspective may arise that informs nurses' ethical knowledge for future practice. White (1995) supports the work of Carper (1978) in relation to ethical knowing and draws attention to the necessity of linking ethical ways of knowing to personal knowing.

2.2.2.3 Aesthetics.

Aesthetics as described by Carper (1978) consists of the art of nursing. The first step in the development of aesthetics as a pattern of knowing is made visible in practice through meeting the needs of the patient in order to deal with particular circumstances. In order for nursing actions to encompass an aesthetic quality, nursing actions need to be reflected on by the nurse so that meaning is interpreted into appropriate nursing actions. Jacobs-Kramer and Chinn (1988) advance this notion further and suggest that aesthetic knowledge development requires the skills of engagement, envisioning the

whole, followed by interpretation. In order to maximize this process, a deep understanding of the client situation is necessary, together with the use of other forms of knowing, namely empirical, ethical and personal knowing. White (1995) adds to the debate regarding the nature of aesthetics as a form of knowing and highlights the necessity of context-specific experience as an attribute to its development.

Silva, Sorrell and Sorrell (1995) also contribute to the work of Carper (1978). Describing the ontological relations between aesthetics and the nature of multiple realities in practice, these authors highlight the necessity to look beyond the aesthetic aspects of knowing. While acknowledging that there are multiple realities, looking beyond aesthetic knowing helps to "... find new meanings in everyday experiences" (Silva, Sorrell and Sorrell 1995: 6). This assertion highlights the importance of using multiple ways of knowing and supports the idea that there are multiple forms of knowledge utilised in practice.

2.2.2.4 Personal Knowing.

Carper (1978) considers personal knowing as the most problematic, the most difficult to master and the most difficult to teach. Personal knowledge concerns the manner in which nurses view themselves combined with interpersonal processes, and involves interactions, relationships and transactions between the nurse and the patient. White (1995: 80) acknowledges the values of personal knowing and suggests that without personal knowing, "... nursing is only a technical assistance, not involved care". Jacobs-Kramer and Chinn (1988) also note the value of personal knowing and suggest the innovative dimension of personal knowing is enhanced through reflection of the private and public self. Silva, Sorrell and Sorrell (1995: 8) draw on the value of narrative as a way of articulating personal knowledge as used in practice. These authors advocate the use of narrative so that "...we can glimpse the multiple realities that can come from personal knowing". While Carper (1978) has been influential in articulating the nature of knowledge used in nursing practice, White (1995) considers another form of knowing that is used in practice, namely socio-political knowing.

2.2.2.5 Socio-Political Knowing.

Socio-political knowing provides the context of people and their interactions within the environment. White (1995) suggests that there are two levels of understanding of this knowing, namely, socio-political context of the patient and the socio-political context of nursing as a practice profession. The former concerns the cultural identity of the person, while the latter refers to society's understanding of nursing and nursing's understanding of society. The characteristics of the socio-political form of knowing according to White (1995) are comprised of a number of issues. The essential element of assessment in socio-political knowing involves the identification of whose voice is heard and whose voice is silenced, while credibility is attained through shared governance, enlightenment and a movement towards equity in the delivery and distribution of care. Including this pattern of knowing widens the perspective of nurses in the delivery of care and heightens their awareness of issues previously taken for granted regarding socio-political elements affecting health care (Kennedy 1998).

2.2.2.6 Inexplicable and Unknowable.

Silva, Sorrell and Sorrell (1995) acknowledge the valuable contribution of Carper's (1978) work to understanding ways of knowing in nursing. However, these authors merge epistemological and ontological views in an attempt to provide meaning to the concepts of inexplicable and unknowable as additional forms of knowing in nursing. Silva, Sorrell and Sorrell (1995: 10) describe a knowable and inexplicable experience is one that "... goes beyond our ability to directly understand it or to describe it, yet it is so vivid and powerful that one cannot help but know it". Because of the uniqueness of this experience, these authors affirm that this makes the experience one's own. On the other hand, the unknowable is situated outside the individual's views and perceptions, yet it has a direct influence on the individual.

2.2.2.7 Case Knowledge, Patient Knowledge and Practice Knowledge.

Liaschenko and Fisher (1999) propose a framework that theorises the interaction between knowledge and nursing actions. They suggest that nurses utilise three forms of knowledge that are connected by a form of social knowledge. These consist of case

knowledge, patient knowledge and practice knowledge. Case knowledge is considered to be that knowledge that consists of anatomy, physiology, pathophysiology, disease processes and therapeutics. This knowledge is considered to be controlled by medicine and is concerned with nursing actions that involve monitoring the disease processes and responses to therapies. Liaschenko and Fisher (1999: 34) consider this type of knowledge is uncomplicated and “serves as a code or cue that sets up expectations about actions that will be necessary”.

Social knowledge that links case knowledge to patient knowledge is considered to involve knowledge of the social factors involved in work. Knowledge of the skills and work patterns of these individuals shapes nurses’ actions in order to meet individual preferences for care. This type of knowledge however, appears to ignore the needs of individual patients. Patient knowledge is a complex form of knowledge. It is multi faceted and consists of “... knowledge of the individual’s response to treatment, knowledge of how to get things done for the individual within and between institutions, and knowledge of many others who are involved in providing services across time and space” (Liaschenko and Fisher 1999: 35). The value of this knowledge is that it provides the nurse with a blueprint so as to match the care delivered with the appropriate provider. This knowledge is often referred to as “knowing the patient”, (Jenny and Logan 1992: 254) and is considered to be an essential element of effective nursing practice.

Social knowledge linking patient knowledge to person knowledge is the knowledge that develops over a period of interacting with the patient and involves the subjectivity of the nurse. It is similar to the socio-political knowledge previously described by White (1995) in that it involves having knowledge of the social conditions of the client, the individual’s ability to function in society and the impact of culture on functioning with a particular illness. Knowledge of these factors can guide nursing actions to facilitate a smooth return to the client’s role in society. Person knowledge involves the subjectivity of the nurse in order to gain an understanding of the patient as an individual as they progress through the illness trajectory. Nurse-patient

interaction is an essential element in developing this form of knowledge in order to promote patient advocacy and support nursing actions that may be in conflict with the health care organisation.

2.3 Summary.

The work of Carper (1978), Silva, Sorrell and Sorrell (1995), White (1995) and Liaschenko and Fisher (1999) provide an overview of the ontological and epistemological issues that underpin a number of views regarding the nature of knowledge used in nursing practice. The works of the above authors provide valuable insights into the nature of knowledge used to guide nursing practice. Nurses base their practice on the amalgamation of different types of knowledge, however the manner in which practice emerges from this process remains unclear.

2.4 Conclusion.

A variety of studies have addressed the nature of expertise in nursing practice. Findings from these studies indicate that nurses, who are considered to be practising at an expert level, utilise a wide range of skills and competencies. Experts engage in a variety of role functions and draw on a wide knowledge base to guide their practice and decision making process. However, with the exception of one study by Davies and Oberle (1990), palliative nursing practice has not been represented in this body of research, hence there is a need to address this deficit so that a conceptual framework may be developed in order to conceptualise the essence of expertise in palliative nursing practice. The following section addresses the research methodology employed in this study.

SECTION TWO

**RESEARCH DESIGN, RESEARCH METHODS
AND DATA ANALYSIS**

CHAPTER 3

RESEARCH DESIGN

3.1 Introduction.

In this chapter I will explore hermeneutics from the perspective of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996). Following this, I will demonstrate how these philosophers have influenced the data collection and analysis in order to explicate the composite of expertise in palliative nursing practice. As the overall purpose of this study was to explicate the composite of expertise as it is revealed through the everyday practices of expert palliative care nurses, the study is focused on persons as situated within the context of their experience, that is, palliative care nurses who are considered to be expert in delivering palliative nursing care. As understanding and interpretation are the primary concerns of hermeneutics, the task of bringing the text to understanding is central to hermeneutic philosophy. While the work of Heidegger (1927 / 1962) and Gadamer (1975) played a major influence in informing the methodology for this study, the works of Schleiermacher (1977, 1990) and Dilthey (1990) also influenced my thoughts and analysis. As Geanellos (1997) has acknowledged, various authors have translated these philosophers' work and they have grappled to present their interpretation and understanding of the original texts. These translators include Kisiel (1969), Linge (1976), Thompson (1985), Weinsheimer (1985, 1991), and Munhall (1994). This is in itself problematic as these authors were unable to confirm the outcome of their work with the original authors. The result of my understanding of hermeneutics arises from my interpretation of various authors' interpretations, while the readers of this thesis will provide yet another level of interpretation. Furthermore, Ricoeur (1981) contends that there is no universal strategy for exegesis; hence there are disparate rules for interpretation. This places the responsibility on the interpreter to make clear the influences that interplay when interpreting texts in order to maintain transparency throughout the interpretive process.

This study is guided by the philosophy of hermeneutics. Section One of this chapter provides an account of the development of hermeneutics in an attempt to place this study in the context of philosophical hermeneutics. I will explore the work of

Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) in order to identify an interpretive methodology for generating nurses' and patients' actions and voices that will make explicit the composite of expertise in palliative nursing practice. The writings of Palmer (1969), Tuttle (1969), Bontekoe (1987), Benner and Wrubel (1989), Mueller-Vollmer (1985), Draper (1997), Bowie (1998), Moran (2000), Mulhall (2000) and others will be drawn upon in order to identify how I will proceed with this hermeneutic inquiry that is aimed at understanding the composite of expertise in palliative nursing practice. Section Two presents a critique of the work of nurse researchers who have used hermeneutics to inform their methodology and methods. I also present an overview of the contribution of these philosophers to this research study in order to make explicit the influence of these philosophers on the process of data collection and data analysis. As the thesis develops, it will be seen that hermeneutics offers an appropriate methodological framework for this study and how it informs the findings.

SECTION ONE. HERMENEUTICS.

3.2 Origins Of Hermeneutics.

Hermeneutics is considered to be a philosophy of interpretation of meaning (Bleicher 1980, Grondin 1994). Hermeneutics is derived from the Greek word "*hermeneuein*", which means to interpret. As an art and a science, hermeneutics strives to comprehend the meaning embedded in the written word (Taylor 1971). Dating back to biblical and classical literary interpretation, the basic tenet of hermeneutics is to "...reveal meaning by analysing the interpretative relationship of segments of textual material within the greater context of the whole (the text)" (Peden-McAlpine 2000: 196).

Palmer (1969) highlights the value of hermeneutics in its focus on philosophy, theory and practice of interpretation by making something that is foreign and strange familiar, current and understandable. Originally, hermeneutics was developed in an attempt to interpret biblical texts, however, since its original initiation, the domains of hermeneutics have expanded to include "...a science of linguistic understanding, a

methodological foundation for the human sciences, a phenomenology of existential understanding and a system of interpretation” (Allen and Jensen 1990: 241).

Over time, hermeneutics developed as a systematic means of interpreting oral and written texts and into a general philosophical methodology for the human sciences. Key developments of the hermeneutic movement include the work of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975). An outline of the work of these philosophers follows in an attempt to demonstrate the appropriateness of their philosophies as an interpretive research methodology for this study.

3.2.1 Schleiermacher (1977, 1990): Hermeneutics as the General Art of Understanding.

Hermeneutics as the art of understanding owes its origin to Friedrich Schleiermacher (1768-1834). As a German theologian and a translator of Plato, Schleiermacher (1977, 1990) was critical of the lack of a clear understanding as to how Christianity appeared to those who received the oral Gospel. Hermeneutics for Schleiermacher (1977, 1990) was concerned with the reconstruction of the author’s intended meaning. He considered an essential element of the art of understanding was the presence of misunderstanding. This laid the foundations for a series of reconstructions to take place in order to reach understanding. According to Moran (2000), Schleiermacher (1977, 1990) argued that there was a need to uncover the original meaning of texts through revealing the intentions of the authors. In order to uncover these intentions, there was a need to peel back the layers of misunderstanding in order to make the truth explicit. Texts contain two essential elements, a psychological explication and a grammatical explication.

The psychological element consists of attempting to get into the mindset of the author so as to create an understanding of what has been said and what has been written. Schleiermacher (1977, 1990) proposes that this process allows the reader to discover the individuality of the composition of the text in relation to the whole of the text. This is broken into the task of finding an inner unity or theme of the work and secondly to

find a distinctive element of the whole (Bowie 1998). Schleiermacher (1977, 1990) considers that in order to do this, both empathy and psychological nearness are required if accuracy is to be achieved. However, Moran (2000: 275) is critical of this approach as he considers "...distance is a necessary precondition for understanding, not something to be overcome; what is completely assimilated does not come into focus for understanding".

The grammatical explication is presented in two canons that are related to the language used by the author and the original audience. Bowie (1998: 30) describes the first canon as: "Every given utterance which requires a more precise determination may only be determined from the language which is common to the author and his original audience", while the second canon is described as: "... the sense of every word in a given location must be determined according to its being-together with those that surround it"(Bowie 1998: 44).

While the use of both the psychological and grammatical interpretations are necessary in developing the art of understanding, Schleiermacher (1977, 1990) recognises that there are inherent difficulties in forming a complete understanding of what has been said and what has been written. Bontekoe (1987) acknowledges that the possibility of gaining a complete knowledge of the language of the author is impossible as Schleiermacher (1977, 1990) laid down no rules in order to move between the grammatical and the psychological side of explication. In anticipation of such a criticism of his work and as a means of developing a pathway and guide to move between these two strands of interpretation, Schleiermacher (1977, 1990) advocated the use of two interpretative strategies, namely the comparative method and the divinatory method.

The comparative method enables the interpreter to understand the author in terms of the text and to identify distinctive traits associated with the author. The comparative strategy is complemented by the divinatory strategy, a process that "transforms oneself into the other person and tries to understand the individual" (Bowie 1998: 92). In

effect, the divinatory strategy facilitates the development of intuitiveness into the mind of the author in order to facilitate the development of a complete understanding. While Schleiermacher (1977, 1990) presented both psychological and grammatical explications separately, both are of equal importance, they are constantly changing and are in constant interaction with each other. While the art of understanding is guided by the principles of grammatical and psychological elements, Mueller-Vollmer (1985: 84) makes reference to a key development to hermeneutics in the work of Schleiermacher (1977, 1990) when he suggests that "Complete knowledge always involves an apparent circle, that every part can be understood only out of the whole which belongs, and vice versa". This statement indicates that Schleiermacher (1977, 1990) referred to the hermeneutic circle in the development of hermeneutics, which was further developed by Heidegger (1927 / 1962) and Gadamer (1975) in later years. The hermeneutic circle in the context of the work of Schleiermacher (1977, 1990) allows for suspiciousness, questioning, misunderstanding, dialect, intuition, experience, communication, grammatical structure, psychological elements and individual assertions to interact so that the act of understanding can develop and progress (Muller-Vollmer 1985).

The work of Schleiermacher (1977, 1990) is not without criticism. Gadamer (1975) (1989) is critical of the notion that the past and original meaning of text and language can be recovered through a sense of the past and of us as individuals. Furthermore, he is critical of the notion of empathy and psychological nearness as being necessary attributes in finding the individuality of the author in the text. Gadamer (1975)'s argument is contrary to this when he argues, "...understanding actually involves an irremovable distance" (Moran 2000: 275). The work of Schleiermacher (1977, 1990) was influential in setting the scene for further development of hermeneutics, particularly by Wilhelm Dilthey (1990) who reawakened the interest in Schleiermacher's (1977, 1990) development of hermeneutics in the mid-nineteenth century.

3.2.2 Wilhelm Dilthey: Hermeneutics as Foundation of the *Geisteswissenschaften*.

Following the death of Schleiermacher in 1834, there was a lapse in interest in the development of hermeneutics. However, Dilthey (1990), a German philosopher undertook the task of further developing the work of Schleiermacher (1977, 1990). He was interested in a group of sciences called *Geisteswissenschaften*, which includes history, art, literature, and sociology. He attempted to describe the method through which valid knowledge could be created in these disciplines. Dissatisfied with Kant's critique of the world of knowledge, Dilthey's goal was to write a critique of historical knowledge. For Dilthey (1990), life and history were inextricably linked. He claimed that this was necessary in order to identify the methods used to generate valid knowledge (Draper 1997). His concern was epistemological in that he focused on what it means to understand. He considered understanding to be "...a dialogue in which interpretation always occurs with reference to the personal, shared and historical position" (Todres and Wheeler 2001: 3). For Dilthey (1990), individuals have a *Weltanschauungenlehre* (world view), that is grounded in life and that is what guides our actions, thoughts and feelings. These are necessary pre-requisites for the generation of knowledge (Tuttle 1969; Bambach 1995). In other words, the worldviews ground the individual in reality.

A central focus to Dilthey's (1990) writings was that of life. He considered man as having an internal and an outer world; the inner world being self-awareness, feelings, thinking and evaluating, while the outer was awareness of external material and nature (Young 1983). He viewed life as the totality of inner experience as it is lived and considered this to be the subject of historical inquiry. According to Tuttle (1969: 15), Dilthey's description of life is summed up as follows:

"All life is a coherent whole of parts. The parts take their meaning only with respect to the whole, and the whole is what it is only by reference to the parts".

Furthermore, for Dilthey (1990):

"Life... is a self forming system always in process, and inseparable from the process of human life are the episodes whereby life constantly interprets and reinterprets itself. This interpretation takes place within the social-historical context through which we live". (Young 1983: 139).

The value of positivism for Dilthey (1990) as a basis for understanding life was limited as he considered these values did not take account of the subject matter, namely the human being with a life and a worldview. As such, life is not considered to be comprised of a series of mechanical categories or movements, but a cycle of individual moments that are unique to each individual, both in the context of their inner and outer worlds (Palmer 1969). For Dilthey (1990), the human sciences made available to the study of man a possibility of understandings within the context of individual life experiences and expressions that were absent from the natural sciences. Dilthey's (1990) notion of hermeneutics was composed of three elements, namely experience, expression and understanding. Experience is equated with the immediacy of life as it occurs combined with the totality of the life, which also projects to future happenings. Rickman (1979: 113) described experiences from Dilthey's (1990) perspective as:

“...not merely awareness of mental images; if it were, we could, indeed think of ourselves as spectators at a show. Instead we are involved as participants because what we experience helps or hinders us...gives us assurance that we are confronting reality”.

Expression following from experience is considered to be language or ideas that depict the inner and outer forms of life. While language and ideas form a central element of expression, Hodges (1969) clarifies Dilthey's (1990) notion of expression as consisting of three varieties. The first is one that all expressions convey ideas, secondly, expression comprises of human actions while the third form of expression is one that depicts spontaneous utterances that arises “...out of lived experience” (Hodges 1969: 22). Understanding is the mode of comprehension of the living human experience (Palmer 1969). This understanding is influenced by the way in which we interface our own lives with that of the lives of others and understanding takes place through the transference from our own inner lives to the lives of others (Lamb 1978).

Similar to Schleiermacher (1977, 1990), Dilthey (1990) expanded the notion of the hermeneutic circle in an effort to maintain a connection with the past, bringing it to the present and guiding thoughts to the future. Historical events for the individual may change as the hermeneutic circle develops when a previous event may be significant,

but when considered in the context of current events, it may become meaningless. In other words, events are considered within the sense of the whole and the whole is considered in the context of the events of life (Young 1983). For Dilthey (1990), developing a hermeneutic analysis of history, life and experiences, involved becoming a part of the hermeneutic circle. While he did not refer to it as a hermeneutic circle, it is described as the interpreter moving:

“... from the text to the historical and social circumstances of the author, attempting to reconstruct the world in which the text came to be and to situate the text within it - and back again (Crotty 1998: 95).

This is an ongoing process and as engagement with the hermeneutic circle continues, there is an ongoing development of historical and valid knowledge.

In summary, Dilthey's (1990) work expanded on the work of Schleiermacher (1977, 1990) and reinforced the necessity of engaging in the hermeneutic circle. Developing an understanding of human beings and expressions of being are drawn from life and from this comes a major source of valid knowledge generation.

3.2.3 Martin Heidegger (1927 / 1962): Hermeneutics as the Interpretation of Existence.

The work of Edmund Husserl was influential in the development of Heideggerian phenomenology. Heidegger (1927 / 1962), a student of Husserl, was dissatisfied with the epistemological focus of Husserl's work and considered that it was essential to focus on the ontological foundations of understanding. While Husserl conceptualised people as detached subjects existing in a world of objects, Heidegger (1927 / 1962) refuted this notion as being unacceptable. Instead, he proposed that it was not possible to understand the person in isolation from his/her world. Instead, the most fundamental way of understanding the world is from a practical point of view, rather than being detached from it. Heidegger (1927 / 1962) provided the analogy of an expert carpenter using a hammer to clarify practicality in the world. He argued that a carpenter uses a hammer without consciously thinking about it, and uses it in an appropriate way, at the appropriate time and under appropriate circumstances. From

this, he proposes that much of individuals' contact and interaction with the human world is of this nature, in other words:

“it is not always that of a conscious subject directed towards an independent object” (Reed 1994: 337).

The central tenets of Heideggerian phenomenology include *dasein*, temporality, structure of the question, pre-understandings, interpretation and understanding and the hermeneutic circle.

3.2.3.1 Heidegger (1927 / 1962) and *Dasein* and Temporality.

Dasein forms a central component of Heideggerian phenomenology. Translated to mean 'being-there', *dasein* is considered by a number of writers as encompassing "human-being" (Cooper 1990; Dreyfus 1991). It is also concerned with the 'being' of what is under investigation, which is first brought to consciousness through experience, in this case, the experience of the researcher. Leonard (1994: 46) advocates that the nature of *dasein* arises out of the question "what does it mean to be a person"? A preliminary understanding of the nature and structure of 'being' is clarified and it is made explicit how 'being' will be investigated in order to reach a final understanding of 'being' so that an everyday understanding of 'being' is clarified (Mulhall 2000). This is what Heidegger (1927 / 1962) terms '*dasein*'.

In a commentary on the work of Heidegger (1927 / 1962), Dreyfus (1991) considered that *dasein* is care in Heidegger's (1927 / 1962) language and the structure of care is temporality. Benner and Wrubel (1989) expanded on the work of Heidegger (1927 / 1962) and temporality. These authors consider that temporality forms the core of life development. They describe it as being anchored in the present, which has been made meaningful by past experiences and the person's anticipated future. In other words, temporality forms the connection between the past, the present and the future. In order for an individual to understand oneself, temporality is necessary, as it forms a part of the context, the context of the person's reality, the context of 'being'. This is described as follows:

“... a Heideggarian phenomenological approach proposes that the person is not a mind-body duality, but a self-interpreting being, that is, a being who is an embodied intelligence brought up in a world of meaning, who has concerns, all which provide embeddedness (connection) in a situation grasped in terms of its meanings for the self. Such a being cannot be studied objectively, because such an objective, desituated, a historical study will always miss an essential aspect – the self-interpretation, the lived meaning (Benner and Wrubel 1989: 112).

3.2.3.2 Heidegger (1927 / 1962) and The Hermeneutic Structure Of The Question.

The hermeneutic structure of the question is considered by Heidegger (1927 / 1962) to be a crucial element in hermeneutic enquiry. Heidegger (1927 / 1962) considers that questions seek out certain information by addressing themselves to something about something for some purpose. In other words, for true hermeneutic questioning to take place, the question comes from “a priori” understanding of a subject, rather than having undertaken the process of bracketing, which is refuted by Heidegger (1927 / 1962). Similar to Schleiermacher (1977, 1990), Moran (2000: 236) considers that the question may be influenced by “... more of a mis-understanding and distortion than a genuine understanding”. Furthermore, the hermeneutic question opens up new experiences so that a new understanding of ‘being’ develops (Kisiel 1985). The starting point for the question comes from possessing some understanding of ‘being’, some sort of a preconception, thoughts and experience of the phenomenon under investigation.

Heidegger (1927 / 1962) highlights the value of scrutinizing the question so that it does not conceal or distort the answer completely. However, such scrutiny needs to allow the hermeneutic questions to be flexible, broad and to allow the respondent to be able to connect to the past, present and to be projected into the future. In order to do this effectively, the notion of bracketing is refuted; instead, the development of pre-understandings is a necessary element of hermeneutic inquiry. Hermeneutic questioning within the interview is different from other types of interviewing in that there are no pre-determined questions. The questions are influenced by the researcher’s pre-understandings and fore-structures that are brought to the interview; hence the interview is open-ended and unstructured (Geanellos 1997). Such an approach to questioning necessitates the researcher, prior to commencing the research

study making explicit pre-understandings and fore-structures related to the research focus.

3.2.3.3 Heidegger (1927 / 1962) and Pre-Understandings.

As a foundation for Dasein, Heidegger (1927 / 1962) considers that the identification of pre-understandings is necessary if true 'being' is to be sought. Heidegger (1927 / 1962: 123) suggests that:

“...an interpretation is never a presuppositionless apprehending of something presented to us, rather interpretation will be founded especially upon fore-having, fore-sight and fore-conception”.

Heidegger (1927 / 1962) used the term 'preunderstanding' to describe the meaning and organisation of a culture that are already in the world before we understand and something that we cannot eliminate from our consciousness (Koch 1995). For Heidegger (1927 / 1962), this is in sharp contrast to the work of Husserl, as Husserl advocates that all pre-understandings need to be 'bracketed' prior to conducting an inquiry. Heidegger's (1927 / 1962) notion of pre-understanding, on the other hand, lends itself to the creation of data that is influenced by the researcher's pre-understandings of the phenomenon under investigation. Pre-understanding as a structure of our being in the world is composed of three elements, namely: fore-having, fore-sight and fore-conception. Fore-having is considered to be the researcher's background practices that constitute the often taken for granted influences that makes interpretation possible. Fore-sight is derived from the researcher's ability to develop a point of view regarding the phenomenon being investigated while fore-conception creates expectations as to what the researcher might expect to emerge from the interpretation (Plager 1994).

The cohesion of the researcher's pre-understandings in the research process facilitates the researcher to interact with the world in which 'being' is investigated. Heidegger (1927 / 1962) describes this interaction being facilitated through three methods, the ready-to-hand, unready-to-hand and the present-to-hand. The ready-to-hand mode of interaction with the world is that which exists for smooth activity and living. Walters (1995a: 793) describes the ready-to-hand modes of involvement as “...those that exist

in a transparent involved form in the environment". The unready-to-hand mode of engagement is the alerting to consciousness of effects and relations when a breakdown in functioning occurs. This may be in the form of human or equipment species. The present-to-hand mode of engagement occurs when the researcher becomes detached from the situation and engages in a period of reflection on the processes and outcomes of 'being' (Plager 1994).

3.2.3.4 Understanding and Interpretation: The Hermeneutics of Heidegger (1927 / 1962).

For Heidegger (1927 / 1962), understanding and interpretation are key issues that influenced his thoughts in the development of hermeneutics. His notion of existence is closely linked with the role of interpretation, while making it transparent that existence does not mean simply to be real. Palmer (1969: 131) sums up Heidegger's (1927 / 1962) notion of understanding as follows:

"For Heidegger, understanding is the power to grasp one's own possibilities for being, within the context of the lifeworld in which one exists. It is not a special capacity or gift for feeling into the situation of another person, nor is it the power to grasp the meaning of some expression of life at a deeper level. Understanding is conceived not as something to be possessed but rather as a mode or constituent element of being-in-the-world... understanding is the basis for all interpretation: it is co-original with one's existing and is present in every act of interpretation".

The above description of understanding in the context of Heidegger's (1927 / 1962) hermeneutics brings with it a meaning that is different to what the ordinary English word 'understanding' denotes. For Heidegger (1927 / 1962), understanding is a mode of "being-in-the-world", and one that is present prior to every element of being. It relates to the future and is influenced by the past and the present. Understanding occurs contextually and within historical and temporal relationships (Peden-McAlpine 2000). Furthermore, its presence enables individuals to engage in the interpretation of human activity so a decision can be made regarding the possible courses of action to take within a given situation. Understanding is a pre-requisite for interpretation. Interpretation is based on the individual's background understanding, and understanding occurs "because we are born into the world" (Koch 1995: 831).

Interpretation, according to Heidegger (1927 / 1962) is not acquiring what is understood, but rather “working out of possibilities projected in understanding” (Heidegger 1962: 148). Accordingly, interpretation does not occur without having pre-conceptions of the phenomenon, which in Heideggerian phenomenology, is an essential precondition to our understanding (Mulhall 2000). Individuals are self-interpreting beings in the context of their everyday lives; hence hermeneutic research needs to be based within the realm of the phenomenon being explored.

3.2.3.5 Heidegger (1927 / 1962) and The Hermeneutic Circle.

The hermeneutic circle originated in the work of Schleiermacher (1777, 1990) and Dilthey (1990), and was elaborated on further by Heidegger (1927 / 1962). Heidegger (1927 / 1962: 153) described the hermeneutic circle as follows:

“In the circle is hidden a positive possibility of the most primordial kind of knowing, and we genuinely grasp this possibility only when we have understood that our first, last and constant task in interpreting is never to allow our fore-having, fore-sight, and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out the fore-structures in terms of things themselves”.

Heidegger (1927 / 1962) considered the hermeneutic circle as an essential concept in engaging with the world of ‘being’. The circle provides a metaphor for the process of shifting between the whole and the parts in order to construct the essential structure of ‘being’. Heidegger (1927 / 1962: 363) advises of the necessity to “leap into the circle primordially and wholly” in order to become engaged with *dasein*. Geanellos (1998a) considers the hermeneutic circle conceptualises that there is actually no beginning to the process of understanding. In other words, pre-understandings that are brought by the researcher to the research site form part of the circle. As such, understanding continues long after the research findings are published where the readers of the report continue to formulate their own understanding of the findings. Constant interaction and shifting between the parts and the whole and the whole and the parts contribute to forming meaning and understanding of the whole, the whole meaning the phenomenon under investigation.

In summary, Heidegger's (1927 / 1962) contribution to the development of hermeneutics is most profound through *dasein* and temporality. These form the preliminary basis of understanding, from which the hermeneutic question arises. Engaging in the hermeneutic circle and expansion of the notion of 'being' highlight additional hallmarks of Heidegger's (1927 / 1962) contribution to hermeneutics. Additionally, Heidegger (1927 / 1962) laid the foundation for his work to be continued and developed further by Gadamer (1975).

3.2.4 Gadamer (1975): Understanding as the Fusion Of Horizons.

Gadamer (1975) was a pupil of Heidegger (1927 / 1962) and was inspired by the earlier work of Schleiermacher (1977, 1990) and Dilthey (1990). Draper (1997: 73) describes the work of Gadamer (1975) as one that "...recapitulates elements of the work of Schleiermacher (1977, 1990), Dilthey (1990) and others, but he was particularly influenced by Heidegger". Dissatisfied with the notion of truth being grounded in the objective knowledge of the scientific method, Gadamer (1975) considered that such an approach to truth was epistemologically inadequate in explaining all types of knowledge. This inadequacy was based on the premise that it did not take cognisance of human experiences that were necessary for true understanding (Walters 1995b; Annells 1996). Concepts that are central to the work of Gadamer (1975) include the fusion of horizons, hermeneutic circle and prejudices.

3.2.4.1 Gadamer (1975) and the Fusion of Horizons.

The fusion of horizons is a metaphor used to describe the process of understanding. Gadamer (1975: 269) describes a horizon as "...the range of vision that includes everything that can be seen from a particular standpoint". Annells (1996) describes the development of horizons as occurring through a process of understanding, with the historical past of the researcher being a major contributor to its development. Horizons are not closed entities as they are constantly developing. Human life is not attached to just one stance; life is in constant activity, constant re-creation and constant development. The development of Gadamer's (1975) metaphor of "fusion of horizons" was in response to his dissatisfaction with the ideas of Schleiermacher

(1977, 1990) and Dilthey (1990) (Hekman 1984; Ambrosio 1987; Coltman 1998; Crotty 1998). Gadamer (1975) argued that it was not possible for understanding to develop solely through stepping out of the interpreter's horizon and stepping into the horizon of the text. Like Schleiermacher (1977, 1990), the task of achieving a full understanding is an infinite process and one that the individual has to overcome by challenging the expectations of their interpretations. In an attempt to attain a true understanding, Bontekoe (1987: 16) describes this process as involving "...not a simple accumulation of disparate ideas, but a testing of them and a rejection of those that fail to harmonise into the emergent understanding". This involves merging the interpreter's historical horizon with the horizon of the present, as the horizon of the present cannot be formed without the horizon of the past (Garrett 1978). While this process may appear ideological and a straightforward activity, the task for the researcher is to demonstrate how this fusion has occurred. This is achieved in the research writing by demonstrating how the researcher participated in the co-constitution of data, depicting the expressions of the social context and then showing how the horizons of the researcher merged with the horizons of the interpreted (Hekman 1983).

3.2.4.2 Gadamer (1975) and the Hermeneutic Circle.

The hermeneutic circle was originally the insight of Schleiermacher (1977, 1990) and was further developed by Dilthey (1990) and Heidegger (1927 / 1962) in an attempt to explain the movement taking place between the part and the whole of the text while attempting to attain the art of understanding (Annells 1996). Gadamer (1975)'s understanding and development of the hermeneutic circle encompasses two significant attributes, namely, positive ontological meanings and a primordial mode of being. Positive ontological meanings indicate that the hermeneutic circle:

“...is not second best; it is not an intellectual stepsister to the methods of the natural sciences...it indicates that we are essentially beings constituted by and engaged in interpretative understanding” (Bernstein 1983: 136-137).

For Gadamer (1975, 1996), the elemental mode of being portrays individuals as reactive and alert to all forms of life. This is so that they can be shared, listened to and

be brought to the mode of understanding. What Gadamer (1975) is referring to here is the notion of prejudices that encompass the process of true understanding.

3.2.4.3 Gadamer (1975) and Prejudices.

Prejudices play a crucial part in becoming involved in the fusion of horizons and engaging the hermeneutic circle. Crotty (1998: 102) describes prejudices as "...inherited notions derived from one's culture"; this is a similar concept to Heidegger's (1927 / 1962) notion of background, pre-understandings, fore-structures and pre-conceptions. Gadamer (1975) attempted to project a positive nuance associated with 'prejudices' that were attached to it from the enlightenment. He argued that each individual is socially and historically situated and cannot be separated from the past:

"History does not belong to us, but we belong to it. Long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society and state in which we live. The focus of subjectivity is a distorting mirror. The self-awareness of the individual is only a flickering in the closed circuits of historical life. That is why the prejudices of the individual, far more than his judgements, constitute the historical reality of his being". (Gadamer 1975: 245).

In other words, Gadamer (1975) rejects the notion that to reach a finite understanding is not a matter of discarding prejudices, but instead uses prejudices to open up new possibilities of meaning continually (Kisiel 1969). Enabling prejudices, as opposed to judgements, constitute our being and rather than viewing them as negative entities. Gadamer (1996) proposes that they provide a window through which we have access to the world of understanding. Prejudices grant intelligibility to understanding and to the fusion of horizons (Bernstein 1983). Furthermore, enabling prejudices are indispensable to the process of understanding. Hekman (1986: 117) sums up the necessity of prejudices in the following passage:

"Gadamer argues that prejudice is not something that is negative or something that we should try to eliminate...we can only have access to the world through our prejudices...prejudice is the precondition of truth, not an obstacle to it".

3.2.5 Summary.

This section has provided an overview of the development of hermeneutics. The works of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975) have been described. Key aspects of the writings of these philosophers have been presented in an attempt to make transparent their application to this study. The next section supports the case for hermeneutics as a research methodology and argues that in order to remain true to hermeneutics as a research method, the researcher's pre-understandings need to be made explicit and the researcher needs to make it clear how these philosophers influenced the process of analysis.

SECTION TWO. HERMENEUTICS AND NURSING RESEARCH.

3.3 Introduction.

The aim of this section is to examine the use of hermeneutics as it is used in nursing research and to discuss the contribution of the work of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) in an attempt to demonstrate how they have influenced this study on the nature of expertise in palliative nursing practice.

3.3.1 Hermeneutic Inquiry and its Use in Nursing Research.

Nurse researchers have carried out a number of studies that have used hermeneutics as a methodological basis to guide research on various aspects of nursing practice. A review of the nursing literature indicates that hermeneutics has been used in a number of studies over the past few years. These include: ordinariness in nursing (Taylor 1991); critical thinking in nursing (Eberhart 1992); living with post partum depression (Beck 1992); caring in intensive care (Walters 1992); lived experiences of nurse students and teachers (Diekelmann 1992); nursing teachers and students (Diekelmann 1993); nearing death (Gullickson 1993); surviving incest (Kondora 1993); voices of elderly (Koch 1993); intuition (Kenny 1994); returning RN (Rather 1992, 1994); elderly long-term care (Reed 1994); family unit with HIV (Saunders 1994); older

women's stories of being strong (Moloney 1995); sexual decision-making in adolescence (Monsen, Jackson and Livingstone 1996); mental illness (Rohde 1996); quality of life (Draper 1997); practice knowledge in mental health nursing (Geanellos 1997); experiences of students (Sorrell and Redmond 1997); chronic pain (O' Loughlin 1999); recognition of patient problems (Peden-McAlpine 2000); and cross-cultural nursing experiences (Spence 2001). From the above studies, it is apparent that hermeneutics as a research methodology has been used extensively in nursing research. One of the essential processes of engaging with hermeneutics as a research methodology is that the researcher needs to engage in a process of explicating their pre-understandings "... in order to provide the phenomenon under investigation with the greatest opportunity to reveal itself" (Geanellos 1998b: 238).

While many of the above authors have utilised hermeneutics, relatively few of these authors have addressed the process in which they engaged in order to make explicit their pre-understandings and the process of self-reflection in which they engaged. For example, Diekelmann (1992, 1993), Draper (1997), and Peden-McAlpine (2000) do not make reference to the process of developing pre-understandings prior to commencing their research process. On the other hand, Taylor (1991) and Walters (1992) acknowledge the necessity of clarifying their presuppositions and pre-understandings in relation to the phenomenon under investigation. However, from their research reports, the process in which they engaged to fulfil this requirement is not clear. In an attempt to fulfil this obligation, Walters (1992) provides a list of relevant characteristics to intensive care nursing that may potentially influence his data analysis; however, the method by which these lists were derived was not clearly evident. Walters (1995c), in a later discussion on the research methodologies and hermeneutics highlights the necessity and value of undertaking this process in hermeneutic inquiries, so that the researcher's position is made clear. It may be argued that Taylor (1991) attempted to fulfil this obligation through the process of writing her impressions of interactions that she had through the course of her research data gathering regarding the phenomenon of ordinariness in nursing, but she nevertheless failed to demonstrate how these influenced her data collection and data analysis.

Despite the above criticisms of the use of hermeneutics in nursing research, hermeneutics provides an appropriate philosophical base on which to examine nursing practice from epistemological and ontological perspectives so that the interpretation of the multiple realities of the respondents can be made without being influenced by the objectivity and reductionist approach of the quantitative paradigm. The next section presents a discussion on the contributions of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) to exploring the composite of expertise in palliative nursing practice.

3.3.2 The Contribution of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) to this Study.

3.3.2.1 Introduction.

The overall purpose of this research is to examine the nature of expertise as it is revealed in the everyday practices of expert palliative care nurses working in in-patient palliative care units in hospices in the Republic of Ireland. The following section outlines the contribution of hermeneutics to the study of expertise in palliative nursing practice. Sections of the work of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) will be presented and examples of how these influenced the study will be included. Geanellos (1997) acknowledges that hermeneutic philosophy offers minimal direction on the use of hermeneutics as a research methodology. Having experienced similar problems as a result of this, I had to determine how I would accomplish the process of data collection and analysis that takes into account the philosophical foundations of the study. In order to do this, I extracted elements of the work of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) to develop a method of data collection and analysis. In the following section, I describe elements of the work of these philosophers and how these were used to guide the study.

3.2.2.2 Contribution of Schleiermacher (1977, 1990) to this study.

Hermeneutics deals with the art of understanding. The possibility of understanding and the multiplicity of competing attempts to understanding gives rise to hermeneutics from Schleiermacher's (1977, 1990) perspective. As a result, it is necessary to draw on aspects of his philosophy to generate an understanding that illuminates an interpretation of the phenomenon. In this study, the key aspects of Schleiermacher's (1977, 1990) work were drawn upon to facilitate the process of understanding leading to interpretation. These are: a) understanding consists of re-experiencing the mental processes of the author of the text; b) understanding is grasping the meaning of the parts through the whole, and understanding the whole through grasping the parts; c) understanding involves perceiving the individuality of the author as a human user of language. These three aspects are described in the work of Dawson (1966), Brandt (1968), Kimmerle (1977) and Bauman (1978) as encompassing the major tenets of Schleiermacher's (1977, 1990) work. An overview of the application of these processes is addressed and discussed in the context of this study.

Understanding consists of re-experiencing the mental processes of the author of the text.

The text in this study was composed by two authors, namely myself as researcher and secondly the respondents as co-researchers. In re-examining the mental processes of these authors, I constantly sought clarification of understandings and misunderstandings of words, phrases and actions. Clarification statements such as "can you tell me how you see your practice in this way", and "can you clarify this particular point with me" were used during the interviews with the respondents. Other questions posed to myself as I carried out the analysis were: "What is it that caused this person to view expertise in this manner", "what is causing me to view expertise in this manner", "what does this particular word mean" and "what thoughts are being expressed by this particular statement". While this was carried out during and after the interviews and observation sessions, it also involved returning to the respondents to get verification of my interpretation of what they had said. This was done at different stages of the study, either by a phone call or through making an appointment with the

respondent to clarify my interpretation and understanding. Throughout my discussions with them, I discussed my understanding of the text in order to demonstrate my mental processes in developing my interpretation. As I presented my findings in each of the research sites, it also offered me the opportunity to seek clarification of understandings and mis-understandings. While it may be argued that this process contravenes the work of Gadamer (1975, 1979), I propose that undertaking such a process helped to elucidate, what Buker (1990) refers to as knowledge of the self and knowledge of the phenomenon, the self being the “self” of the respondents and the phenomenon being that as applied within their practice. Furthermore, this process also assisted in physiological and grammatical explication, as outlined by Schleiermacher (1977, 1990), where inner unity and individuality of the phenomenon emerged (Bowie 1998). A final strategy was returning my preliminary analysis to the respondents for verification. This process fulfilled two objectives, namely utilizing the comparative and divinatory methods, which in turn laid the foundation for becoming engaged in the hermeneutic circle. The comparative and divinatory aspects of Schleiermacher’s (1977, 1990) philosophy enhance the interpreter’s understanding of the text, so that the co-creators of the text are “being together” (Bowie 1998: 30) and “a more precise determination” (Bowie 1998: 44) of the text may be reached. In the context of this study, the comparative and divinatory methods lead to the creation of the hermeneutic circle where a new understanding of the phenomenon of expertise developed.

Understanding is grasping the meaning of the parts through the whole, and understanding the whole through grasping the parts.

The above statement forms the basis for the hermeneutic circle. However, from Schleiermacher’s (1977, 1990) contribution there is the opportunity to initiate an intuitive element on the part of the researcher in creating the hermeneutic circle. An intuitive element is necessary, as Palmer (1969) points out, as there needs to be some level of knowledge of the phenomenon being investigated. Without an intuitive element, Palmer (1969: 87) contends: “...one cannot leap into the hermeneutic circle”. My intuitive thinking was challenged as the interpretation progressed and the development of this thinking was recorded in a research diary under methodological

notes, thoughts, feelings and challenges when reviewing the data that emerged from the study. Creating and gaining entry to the hermeneutic circle involved a “conjecture” or surmise as to what the data expressed. While this was tentative, it was necessary as a starting point in attempting to find out how the individual parts of the data related to each other and how they constituted the whole of interpretation. This recreative process of interpretation progressed from the conjecture phase to complete the cycle of interpretation, by including the remainder of Schleiermacher’s (1977, 1990) points highlighted above. This process resembles what Packer and Addison (1989) described as moving in the forward arc of interpretation that highlights the possibilities of interpretation. This forward movement eventually led to a return arc where a new horizon on expertise emerged. A central element that influenced the creating of the forward arc, which is described by Schleiermacher (1977, 1990) as understanding, involves perceiving the individuality of the author as a human user of language.

Understanding involves perceiving the individuality of the author as a human user of language.

According to Schleiermacher (1977, 1990), hermeneutics is concerned with the reconstruction of the author’s intended meaning. While there are no specific rules to develop this reconstruction, it challenges the researcher to avoid misunderstanding and misinterpretation. As a foundation to this process, Schleiermacher’s (1977, 1990) notion of grammatical and psychological explication provided some guidance as to how to proceed with the interpretation. Grammatical implications were brought to the forefront when I asked the following question of the data, “Do I regard this person and this speaking as occasions for the language to reveal itself? ” while psychological explications were highlighted when I asked, “Do I regard language as a means by which a person communicates his thoughts?”. While these may be two contentious questions, this process resulted in me providing me with equal consideration to both the person and the language. In some instances, this created a challenge that was based on my knowledge and rapport of the respondents. Furthermore, while the study took place in one country, cultural differences existed throughout the different research sites in relation to language and work practices. I recorded these differences and took

them into consideration when attempting to balance the grammatical and psychological explications in the analysis.

3.3.2.3 Contribution of Dilthey (1990) to this Study.

The work of Dilthey (1990) is based on the premise that the world view of individuals is grounded in life that guides actions, thoughts and feelings. Based on this premise and the challenge to develop an understanding of the phenomenon of expertise, I utilized Bontekoe's (1996: 58) structure for examining my own expressions and actions as to how they affect other people in order to develop my understanding of expertise. This is described as "seeing oneself as others do".

Seeing one's self as others do.

Dilthey's (1990) work stressed the uniqueness and particularity of human individuals as well as what they shared in common with others (Bauman 1978; Thiselton 1992). This comes about by developing an understanding of others on the basis of experience, self-understanding and through constant interaction with others (Rickman 1961). This is what Dilthey (1990) refers to when he draws parallels between the self and others by seeing one's self as others do. Within this study, this consisted of a four-part process, namely, viewing others' experiences, examining our own actions, developing a self-understanding and gaining an understanding of common human nature. The foundation for this process is based on Dilthey's (1990) notion that the interpreter's immersion in life provides an experience out of which interpretation and understanding develops. Within the context of this study, viewing others' experiences consisted of projecting myself onto the actions of the participants and viewing myself as being reflected "in the mirror of the other person's eyes" (Bontekoe 1996: 57). This focused on nursing actions that the expert nurses participated in throughout the observation process. Documenting these actions provided me with the evidence of the practices of these experts, so that I could project myself onto those actions.

The outcome of this process resulted in achieving the next stage of Bontekoe's (1996: 58) notion of developing a self-understanding, which is common nature understanding

- in this instance, a common nature understanding of the phenomenon of expertise. Furthermore, this process allows for my life as a person, nurse, and researcher to be interfaced with the lives of the respondents, a key element of understanding inherent in the work of Dilthey (1990) from Makkreel's (1975) and Lamb's (1978) perspectives. Rickman (1988) contends that through developing self-understanding within Dilthey's philosophy of meaning and understanding, a common human nature understanding is achieved. This is described as a deepening of our understanding of the phenomenon under investigation. This process occurred over the duration of data collection and analysis and will continue to develop throughout the period of writing the research report. However, a final understanding of the phenomenon will differ from one reader of the research report to another, as the nature of hermeneutic understanding involves constant correction of our assumptions about the phenomenon.

3.3.2.4 Contribution of Heidegger (1927 / 1962) to this Study

Pre-understandings and Fore-structures.

According to Heidegger (1927 / 1962), getting into the circle is a requisite for understanding. However, getting into the circle involves the setting out of fore-structures and making pre-understandings explicit. In the context of this research, I attempted to bring my fore-structures to consciousness through answering the question "How do these nurses actualise expertise in their nursing practice?". I undertook a period of reflection on my own strongly held beliefs regarding the nature of expertise in palliative nursing practice. In doing this, I was attempting to become conscious of my fore-structures. Thompson (1990: 244) describes the value of this process:

"They have the potential of showing us something about ourselves and our preferred actions and something about the object of our inquiry... they show us glimpses of ourselves, for in the act of interpretation, one must be ever conscious of one's prejudices and must examine them reflectively so that the object of investigation can speak".

While the task of generating statements regarding pre-understanding and fore-structures may appear simplistic, the value of such a process is that it creates a hermeneutically trained consciousness that submits tacit assumptions and

presuppositions to hermeneutic consciousness (Scheibler 2000). This process also fulfils the hermeneutic task of generating and creating understanding of the respondents' realities.

I undertook a reflective process prior to commencing the study. Throughout this time, I considered my most strongly held beliefs regarding the nature of expertise in palliative nursing practice. However, when writing about these beliefs, it was insufficient merely to generate these statements. It was necessary to reflect on them in depth to help me understand my beliefs and, more importantly, to understand the implications they have for palliative nursing practice. In total, ten statements were generated, from which I developed my interpretations and fore-structures. While they are presented in numerical order, each statement is of equal importance and was developed prior to undertaking the study, so that the study findings did not influence my pre-understandings regarding the nature of the phenomenon. Three of these statements are presented below, while the remainder are presented in Appendix 1.

STATEMENT ONE: The nurse creates a secure environment for the patient and family members throughout the palliative phase of care.

Interpretation.

Patients who are admitted to hospices are undergoing a transfer and shift in their living, leaving their homes, their familiar environments, it also signifies a transition in the living – dying trajectory. As the journey throughout this period of life is unknown, and has not been encountered before, it is important that the nurse is there to facilitate a smooth transition as the patient's journey is progressing, possibly from a phase of conscious awareness to the stage of unconsciousness. Together with this, family members, as part of the unit of care, are possibly experiencing a range of uncertainties that can also be traumatic for them. The imminent loss of their family member, perhaps the loss of income and loss of companionship are all possibilities that are looming on their horizon. Hence, there is an important need to create an environment that is secure, protective and yet not stifling for the patient and family. Building trust within this safe environment develops from the nurse and promotes a reciprocal

stability in the relationship through the awareness of what is going on for the patient and family members. In a sense, the secure environment helps to contain possible out of control feelings for both family and patients. Furthermore, it engenders trust and helps the patient, family and nurse to work towards the consequences of changing health status.

Fore-structure.

The nurse has an understanding of the milieu that is possibly causing turmoil, anger, doubt and perhaps hopelessness for those concerned. The previous self care capacity and bodily functions are probably being lost for the patient, possibly de-stabilising the self worth of the individual. He understands the out of control feelings that may be experienced and can put in place the structures to stabilise the feelings, worries and anxieties associated with this phase of the dying trajectory. Furthermore, he has the ability to distinguish between patient and family needs at this particular time and to channel appropriate interventions for those concerned.

STATEMENT TWO: The nurse is a friend.

Interpretation.

Many patients feel angry, deserted, helpless, disembodied and frustrated with their illness. Because of this, their acceptance of their illness is hampered to a certain degree and they cannot move on past the denial and anger stage. For some, it can result in family relationships becoming estranged to the point of the patient feeling isolated and deserted by their families, when the reality is often different. Furthermore, the fact that the person is dying in a hospice is in itself a complex challenge and can even reinforce the feeling of isolation and rejection. Frequently, there are feelings of loss associated with the process of dying that demand resilience from patients to respond to these feelings.

Fore-structure.

Sometimes false impressions can be generated from the way patients react to their illness, and the nurse in his work in caring for dying patients. The nurse appreciates the need for patients to vent their feelings of anger, rejection and isolation from others as a result of illness. There is a need to understand the different feelings and emotions that are brought to the forefront or, indeed, suppressed. The nurse fosters feelings of belongingness and inclusiveness, and makes a connection with the patient so there is no longer a sense of isolation for the patient. He also appreciates that patients are outside their normal "range" of hope at this particular time.

STATEMENT THREE: The nurse has knowledge of the health–illness, living–dying trajectory.**Interpretation.**

As patients progress through their illness, they may perceive themselves as still being in a state of health. Health is subjective for that particular individual. The living-dying trajectory is a unique pathway for each individual. The complex process of the health–illness and the living-dying trajectory represents a transition that is multi-dimensional with an array of options to deal with the transition. For some, there may be a forward and backward movement in dealing with what the illness brings with it.

Fore-structure.

The nurse is aware of what health means for the patient and can structure nursing care to empower the patients, to give them the freedom to work within their own limitations of care. Facilitating the patient and family to work on their individual strengths and limitations helps them to strengthen their ability to come to terms with their changing situations. Multiple factors influence the progression along the trajectory, together with the individual's previous concept of health and illness. He appreciates these factors and incorporates them into a plan of care in order to support the patient at this time.

3.3.2.5 Contribution of Gadamer (1975, 1989, 1996) to this Study.

Gadamer (1975, 1989, 1996) and the Fusion of Horizons.

Horizon is a way of describing context and includes everything of which one is immediately aware (Gadamer 1975; Weinsheimer 1985). Fusion involves the bringing together of different vantage points and is described by Koch (1993: 107-108) as being:

“... like a posture, or a way of conducting yourself, a willingness to open yourself to a standpoint of another so that you can let their standpoint speak to you, and let it influence you”.

The task of demonstrating the fusion of horizons is achieved by showing how the fusion of horizons occurred. As fusion is not possible without language, the focus of language is the object under investigation. In this instance, the focus of investigation is that of expertise in palliative nursing practice. In order to place the language in context as is required in Gadamer's (1975, 1989, 1996) writings, the use of observation as a data collection tool was made to translate the actions of the nurses into language. This then became complementary to the interviews where the text was created from the language of the respondent to the written word. Fusing my horizons with those of the respondents will be demonstrated in the research writings, when I show I how took part in making the data, and including rich descriptions from the respondents' interviews. Furthermore, incorporating examples of my field notes, methodological notes and extracts from my research diary will demonstrate how I have merged my horizons with the horizons of the respondents. Additionally, the horizons of the patients are also fused in the presentation of findings section of this thesis.

3.3.3 Summary.

This chapter has presented an overview of hermeneutics as the philosophical foundation to examine the composite of expertise in palliative nursing practice. The development of hermeneutics from the perspective of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) was

presented. The influence of relevant aspects of their work has been presented in order to demonstrate the contribution of these philosophies to the study. The use of hermeneutics as a philosophical basis for engaging in qualitative research has been widely acknowledged in the literature. While there appears to be an increase in its use, there is a challenge for the researcher to demonstrate the manner in which the study is influenced by hermeneutic philosophy. The consequences of this assertion by Gadamer (1975, 1989, 1996) is that in order for true interpretation to take place, a clear description of the influence of the philosophical basis for the study needs to be demonstrated, otherwise, there is a lack of transparency in the way data collection and analysis takes place. Furthermore, making the foundation and development of this philosophy is essential so that the reader is provided with a clear overview of the philosophy that guides the study. Chapter four outlines the methods used in collecting the data for the study.

CHAPTER FOUR

RESEARCH METHODS

4.1 Introduction.

This section provides an overview of the methods employed in collecting the data in this study. A number of approaches may be used to gather data in qualitative research, including interviews, focus groups, written narrative and observation (Streubert and Carpenter 1999). A multi-method design was used to gather data for this study, that of interview and observation. The combination of methods enriched the data and contributed to the credibility of the findings. Furthermore, the immersion in a period of observation helped me to experience the world of the expert palliative care nurses as they delivered nursing care in the in-patient palliative care units. Section One addresses development of the study methods while Section Two addresses the implementation of the study.

4.1.1 Research Aim.

The overall aim of this study is to explore and describe the essence of expertise in palliative care nursing practices in caring for patients who are dying and to develop a conceptual framework that depicts the practices of expert palliative care nurses as they translate their knowledge of caring for the dying into practice. The study also aims to explore patients' perspectives on their experience of receiving expert palliative nursing care.

4.1.2 Research Question.

This study is guided by the following research question: What is expertise in palliative nursing practice?

4.1.3 Research Aim, Research Question and Hermeneutics.

The design and methods used to investigate a research problem are influenced by both the research problem and the theoretical perspectives of the researcher. Inspired by the work of Benner (1984), McElroy (1990), Walters (1992), Logan and Boss (1993), Conway (1996) and King and MacLeod (2002), I attempted to make sense of the nature of expertise of palliative nursing practice, through the interpretation and understanding of these practices in caring for patients in specialist palliative care units.

Having critiqued the appropriateness of qualitative methodologies, I considered that hermeneutics provided the most appropriate methodology to answer the research question : “What is expertise in palliative nursing practice?”. The reasons for choosing hermeneutics as a philosophical basis for my study are as follows:

Ontologically, Schleiermacher’s (1977, 1990) processes of uncovering the original meanings of texts, generated by the authors through psychological and grammatical explications, allowed me to uncover any misunderstandings regarding the nature of expert practice and challenge these misunderstandings. Such a process provided the original authors with the opportunity to clarify my understandings, which otherwise may not have been accurate. As the central focus of Dilthey’s (1990) work centres on life, this mirrored the reality of life for the respondents in this study. Dilthey’s (1990) writings provided me with the foundations to explore the inner and outer worlds of the respondents. These worlds which ground the individual respondents in their reality is the reality of expertise in palliative nursing practice.

Heidegger’s (1927, 1962) work guided me through the processes of pre-reflective understandings. These understandings form the background on which all actions and understandings become intelligible to us. Heidegger’s (1927, 1962) modes of engagement were significant, particularly as they mirrored the modes of engagement within which many experts undertook their nursing practice. Additionally, they also had significance for patients as they reflected on their past, their present and their future. Gadamer’s (1975) insights into the development of the hermeneutic circle and the fusion of horizons guided me through the process of merging my thoughts, feelings and understandings of the data which emerged from interviews and observation from which a new perspective of the nature of expertise emerged. The following section provides an overview of the development of the methods employed in this study.

4.2 SECTION ONE: DEVELOPMENT OF STUDY METHODS.

4.2.1 Introduction.

This section provides an overview of the process undertaken in developing the study methods. An overview of the context of the study, the process of gaining access to the research sites, access to nurses, and access to the patients involved in the study is presented.

4.2.2 Access and Sampling of Research Sites.

4.2.2.1 Criteria for Inclusion of Sites Within the Study.

The nature of this study involves palliative care nurses working in in-patient hospice units within the Republic of Ireland and the patients receiving palliative nursing within these units. Palliative care services in Ireland consist of six in-patient units, home care services, day care services and specialist palliative care services within a number of general hospitals. As this potentially involves a large number of nurses, and due to time constraints, I made the decision to explore the nature of expertise in palliative nursing practice in in-patient units as opposed to including home care, day care services and specialist palliative care services in general hospitals. Furthermore, the geographical spread of non in-patient unit services influenced my decision to focus my study on in-patient units.

4.2.2.2 Context and Research Settings: A Description.

I undertook the selection of the research settings. The names and locations of the in-patient units were obtained from the Irish Association for Palliative Care (IAPC) (Irish Association for Palliative Care 2000). This provided me with a list of the hospice in-patient units, each hospice's catchment area, the names of the medical consultants, directors of nursing, clinical nurse managers and in some cases, the medical director of the hospice.

As there are six hospice in-patient units in the Republic of Ireland, I decided to collect data from each of these units. Two hospices were situated in the Eastern Regional Health Authority area, one in the Southern Health Board region, one in the Mid-Western Health Board region, one in the Western Health Board region and one in the North Western Health Board area. In addition to providing in-patient services, other services provided by these hospices included home care teams, day care facilities, bereavement services and educational facilities. The layout of each unit differed between sites. The following section provides an overview of the study locations.

Site One.

Site one consisted of an L-shaped unit, with the capacity for nineteen patients. The unit was divided in two for the purposes of staff allocation, team A and team B. Both sides of the unit had a nurses' office. Staff handovers and nursing and medical documentation were stored in these offices. Side A consisted of one single room and two four bedded rooms, while side B had one four bedded room and five single rooms. Television and telephone facilities were available in all of the rooms. Facilities for relatives to stay overnight were also available. The rooms were located in such a way that they all faced the garden. One nurse manager was in charge of both team A and team B. Staff consisted of registered general nurses, postgraduate and student nurses, health care assistants, pastoral care staff, social workers, catering staff, volunteers and domestic staff. Two Palliative Care registrars and one Palliative Care consultant provided medical cover for the unit.

Site Two.

Site two consisted of four single rooms, two double rooms and three open plan wards. There was a patient capacity of twenty-four in this unit. One nurse manager was in charge of the unit and patient allocation was practised in this hospice. Each ward and the rooms had a television, and there was also a day room where both patients and relatives could sit. Registered nurses, postgraduate nurses, undergraduate student nurses and health care assistants provided care to patients. A veranda provided access

to an outdoor setting. Facilities were available for relatives to stay overnight if necessary.

Site Three.

Site three consisted of an eight-bed unit, with two single rooms and a six-bed ward. Television and telephone access was provided for each of the patients. A nurses' office was located off the six-bedded ward, and a garden was visible from the ward and rooms. One nurse manager was in charge of the unit, and patient allocation was practised in the unit. Nursing staff consisted of registered general nurses, undergraduate and postgraduate nurses, health care assistants and volunteers. Pastoral care, social work and physiotherapy facilities were also available. A Palliative Care consultant provided medical cover in the unit.

Site Four.

Site four was divided into two units, each unit being similar in structure to the other. In total, there was a capacity to facilitate thirty-six patients. Each unit had its own nurse manager and there was a view of the garden from both of the units. A number of en-suite single rooms were available, together with television and telephone facilities for the patients. A day room was provided for patients and relatives. Complementary therapies, social worker services, hairdressing, occupational therapy, social worker, art therapy and pastoral care facilities were also available. Facilities for relatives to stay overnight were also provided.

Site Five.

Site five was rectangular in shape and the nursing staff were divided into two teams, team A and team B. The unit had the capacity to accommodate twenty-five patients, and one nurse manager was in charge of the unit. The rooms were single and four-bedded in structure, with en-suite, television and telephone facilities available for patients. Additional facilities provided for patients and relatives included a sitting room, tea and coffee making facilities, overnight facilities for families and a children's room. Hairdressing facilities, occupational therapy, complementary therapies and

music therapy were available for patients also. One Palliative Care Consultant and two registrars provided medical cover in the unit.

Site Six.

This site consisted of a ten-bed unit. It was comprised of a number of single rooms, and single cubicles within a four-bedded bay. The rooms all had views of a garden. Television and telephone facilities were available for patients. Staff consisted of a nurse manager, registered nurses, student nurses and postgraduate nurses. Other caregivers included health care assistants, catering and domestic staff and volunteers. A Palliative Care consultant and two registrars provided medical cover for the unit.

In each of the six units described above, staff handover was held in the nurses' office. Facilities for lifting and hydraulic hoists were provided in each of the units, while some of the units also provided a Jacuzzi for the patients. Toilet and bathroom facilities provided privacy for the patients, while the sluice rooms in each site were easily accessible to staff. Decor, heating and lighting added to the ambience of the settings, while background music was being played of a low level throughout the units. Patient call bells were in easy reach of the patients, while curtains around each bed provided privacy when needed. Scenic pictures were hanging throughout the units, and there were library facilities provided in some of the research sites. The units also had a ward clerk who worked from either the nurses' office or from a central station within the unit. Flowers and plants decorated the rooms, and volunteers attended these on a regular basis.

It became apparent to me as I carried out data collection in each of the research sites that a pleasant physical environment seemed to be a priority when setting up the hospices. Furthermore, facilities that assist in-patient care, such as electronic lifting equipment, the availability of commodes and comfortable armchairs seemed to be in ample supply.

4.2.3 Gaining Access to Research Settings.

Gaining access to the research sites involved a two-stage process, namely meeting with the Directors of Nursing, Nurse Managers and the Medical Consultants and application to the relevant Ethics Committees.

4.2.3.1 Directors of Nursing, Nurse Managers and the Medical Consultants.

Application to undertake this research study was sought from six in-patient hospice units. I sent a copy of my research proposal and a letter of application to undertake the study to the Director of Nursing, Nurse Managers and Medical Consultants in each of the hospices, outlining the nature of my study. This was followed by a request to meet with them to discuss my study. At subsequent meetings with the Directors of Nursing, Nurse Managers and Medical Consultants, I explained the nature and purpose of the study and the potential benefits for the hospice in being involved in the study. I answered any questions they had in relation to the study. Permission was granted to me to undertake the study at these meetings; however, it was subject to being approved by the relevant Ethics Committee for each individual hospice.

4.2.3.2 Research Ethics Committees.

The relevant Research Ethics Committees provided me with a pro-forma to be completed as part of the process of obtaining ethical approval to undertake the study in the research sites. Where an Ethics Committee did not exist within the hospice, a Regional Ethics Committee within the Health Board Region or the Board of Management of the hospice considered my request for ethical approval. I was invited to attend one Ethics Committee meeting to defend my proposed study and to answer questions from members of the Research Ethics Committee. Ethical approval was granted from all of the research sites.

4.2.4 Access to Nurses: Commencing the Study.

4.2.4.1 Obtaining Permission to Approach the Nurses Through the Directors Of Nursing and Nurse Managers.

At the commencement of the study, I met with the Directors of Nursing and Ward Managers in each of the research sites in an attempt to identify suitable nurses to participate in the study. A lengthy discussion ensued regarding the selection of the respondents. I felt that this was important, as the nature of the study focused on expert nurses as opposed to non-expert nurses. The nurses' duty roster was used as a database for identifying the names of the nurse and each was considered individually as to whether or not he or she met with the criteria identified by me. I was also invited by the nurse managers to attend ward meetings where potential respondents were present. This provided me with the opportunity to describe the nature of my study and answer any questions the nurses had in relation to the study. A number of nurses approached me on an individual basis to discuss details of the study. Several of them expressed their willingness to participate in the study and acknowledged the value of such a study in highlighting the essence of their nursing practice.

4.2.4.2 Selection of Nurse Participants: Inclusion Criteria.

Sampling decisions relate to the need to identify research participants who are eligible and willing to participate in the research study. Morse (1991a) considers that the principle of adequacy ought to guide the researcher in deciding the number of respondents in a qualitative research study. Appropriateness refers to "the degree to which the choice of informants and of selections 'fits' the purpose of the study as determined by the research" (Morse 1991a: 143). The use of purposive sampling was employed for the purpose of this study. Expert palliative care nurses were invited to participate in the study because they met the defining characteristics of being experts in palliative nursing practice. Through reflection on previous works addressing the nature of expertise in nursing practice, the criteria utilised for this study were guided by those originally developed by Benner, Tanner and Chesla (1992) and further developed by Tanner et al (1993). The criteria for expertise were: a) at least five years

nursing experience in the speciality, b) recognised by supervisors as being an expert nurse, c) displays advanced level of skills and knowledge in the area gained through experience in the specialty, d) is involved in ongoing education related to the speciality.

4.2.4.3 Gaining Consent of the Nurses.

I approached each nurse identified as being an expert in palliative nursing regarding their participation in the study. I invited them to participate in the study by providing them with a letter outlining the nature of the proposed study (Appendix 2). They were invited to ask questions they may have regarding the study or to raise any concerns about their participation. The main concerns focused on the observation of practice, and I explained to them that the purpose was not to form a judgment of their practice, but rather to observe the expert nursing practice in the context of palliative care. Anonymity and confidentiality of the respondents were ensured and they were informed that any records arising from the interview and observation would be stored in a locked drawer to which only the researcher had access. Each nurse participant signed a consent form indicating his or her willingness to participate in the study (Appendix 3). A total of forty nurses participated in the study. Four nurses refused to participate.

4.2.4.4 Profile of the Nurse Participants.

The participants met the criteria for participation as outlined above. These experts also reflected the literature description of experts' experience in their practice. Each participant completed a demographic profile form (Appendix 4).

4.2.4.5 Gender and Age Profile.

Thirty-eight of the participants (95%) were female, which mirrors the overall majority of female nurses working in palliative nursing practice. The majority of the nurses $n=39$ (97.5%) involved in the study were over thirty years of age, while a small number $n=2$ (5%) were aged fifty or over.

Table 4.1 Age Profile of the Nurses.

Age	25-29	30-34	35-39	40-44	45-49	≥ 50
Number of nurses and percentage	1 (2.5%)	15 (37.5%)	10 (25%)	8 (20%)	4 (10%)	2 (5%)

4.2.4.6 Years Engaged in Clinical Practice.

All of the nurses involved in the study were asked to identify the number of years they had been engaged in practice since they qualified as a Registered General Nurse.

Table 4.2 Years Engaged in Clinical Practice.

Number of years	6-10	11-15	16-20	21-24	≥ 25
Number of nurses and percentage	10 (25%)	14 (35%)	9 (22.5%)	3 (7.5%)	4 (10%)

4.2.4.7 Years Engaged in Palliative Nursing Practice.

Nurses were asked to indicate the number of years they were engaged in the speciality of palliative nursing practice. The majority of the respondents n=14 (35%) were involved in palliative nursing between 5 to 5.9 years, while n=9 (22.5%) were involved in palliative nursing practice for ten years or more.

Table 4.3 Years Engaged in Palliative Nursing Practice.

Number of years	5-5.9	6-6.9	7-7.9	8-8.9	9-9.9	≥10
Number of nurses and percentage	14 (35%)	7 (17.5%)	6 (15%)	2 (5%)	2 (5%)	9 (22.5%)

4.2.4.8. Academic Qualifications of the Nurse Participants.

The details of the academic qualifications of the nurses involved in the study are summarized in Table 4.4

Table 4.4 Academic Qualifications of the Nurse Participants.

Academic Qualification	Diploma	Graduate Diploma	Bachelors Degree	Higher Diploma	Masters Degree	PhD
Number of nurses and percentage	12 (30%)	4 (10%)	4 (10%)	18(45%)	2 (5%)	0

All of the nurses had completed at least one academic course, while a number had completed more than one programme, ranging from Certificate to Masters degree level. A number of the respondents had also completed English Nursing Board (ENB) courses, which were specific to their area of practice.

4.2.4.9 Current Studies Being Undertaken by Nurses.

A total of twenty-three nurses (57.5%) were undertaking further studies related to the specialty. The academic level and percentages are summarised in Table 4.5 below.

Table 4.5 Current Studies Being Undertaken by Nurses.

Level of study	Diploma	Graduate Diploma	Bachelors Degree	Higher Diploma	Masters Degree	PhD
Number of nurses and percentage	6 (15%)	0	12 (30%)	4 (10%)	1 (2.5%)	0

4.2.5 Access to the Patients.

4.2.5.1 Obtaining Permission to Approach the Patients Through the Directors of Nursing, Nurse Managers and Medical Consultants.

Assessing the status of the patients as to whether they were capable of participating in the study was important. The Medical Consultant, Director of Nursing and Nurse Manager were written to and an appointment was requested for me to meet with them to explain the nature and purpose of the study. In one instance, the Director of Nursing was not available to meet with me, and the Nurse Manager who was deputising for her was delegated to relay the information back to her. Permission was received from the Consultants to involve their patients in the study. The Consultants offered to meet with me on the wards on a regular basis to identify suitable patients to be involved in the study. They also invited me to attend the multidisciplinary team meetings where appropriate patients would be identified following the meetings. The Nurse Managers supported my request and offered to be available to me to discuss the suitability of patients when the data collection phase commenced.

4.2.5.2 Selection of Patient Participants: Inclusion Criteria.

Inclusion criteria for patients in this study were that they are:

a) in receipt of palliative care for ten days, b) considered to be suitable by the Medical Consultant and Nurse Manager to participate in a short conversation regarding palliative nursing, c) willing to participate in the study, d) not confused, e) over eighteen years of age.

In an attempt to identify suitable patients to be included in the study, I was invited by the Medical Consultant and the Nurse Manager to attend the multidisciplinary team meetings in a number of the sites. This provided me with the opportunity to get a sense of the overall condition and status of the patients prior to their participation in the study. It also gave me the opportunity to clarify issues regarding the patients' knowledge and understanding of their illness. In sites where I was not in attendance at the multidisciplinary team meetings, I made an appointment to meet with the Medical Consultants where I discussed the nature of the study with them and provided them with the opportunity to clarify any issues with me. All of the Medical Consultants granted permission to interview their patients. Regular meetings with them took place in the units where they identified suitable patients for inclusion in the study.

4.2.5.3 Meeting the Patients.

The Clinical Nurse Manager and the Directors of Nursing granted me permission to become part of the ward team in a supernumerary capacity prior to commencing data collection. As I attended the nursing handovers, I was familiar with the patients' names and diagnoses. Furthermore, attending handovers provided me with the opportunity to obtain baseline information about the patients. After report, I made a round of all of the patients. I checked each patient's mental and physical ability at this time to determine if they were suitable to participate in the study. If I felt that the patient's condition had deteriorated, research issues were not discussed with them. I engaged in general conversation with them and their families when present.

4.2.5.4 Gaining Consent and Sampling of the Patients.

All of the patients were at different stages of their illness trajectory and as a result of this, the number of potential respondents was limited. When potential respondents were identified, I approached them and invited them to participate in the study. I provided them with a letter of invitation to participate in the study which provided them with an outlining the nature of the study (Appendix 5). I answered any queries they had in relation to their participation in the study. On two occasions, the patients died within twenty-four hours of being approached to participate in the study. Twelve patients refused to participate in the study. They voluntarily indicated that they felt either too tired, or they felt they did not have much to add to the study or their families preferred that they did not take part. Any questions regarding the nature of the study were answered, and on one occasion, a family member requested further information regarding the nature and purpose of the study. When agreement to participate was given, the patient signed a consent form (Appendix 6). A number of the respondents expressed their delight at being involved in the study so that they could share their experiences with others. One recipient identified that it made him feel good to give something back to nursing as he had got so much from the staff in the hospice throughout his illness. In all, eleven patients participated in the study. A brief profile of the patients is presented.

4.2.5.5 Profile of the Patient Participants.

Prior to commencing the study, I anticipated that it may be difficult to include an equal number of patient respondents from each of the six sites, due to the nature of their illnesses. As the study progressed, it emerged that patients from three sites were either too ill to participate or they refused to be involved in the study. In total, eleven patients from three sites were included in the study. A detailed profile of those patients who participated in the study is provided in Appendix 7. An overview of their gender, diagnosis, reason for admission and the number of days after the interview when the patient died or was discharged is provided in Table 6.

Table 4.6 Profile of Patient Participants.

Gender	Age	Diagnosis	Reason for admission	Discharge or Died
Female	60	Breast Cancer. Bone Secondaries.	Respite Care.	Discharged 3 days following interview.
Male	66	Tracheo Oesophageal Cancer.	Terminal Care.	Died 3 days following interview.
Male	63	Oesophageal Cancer.	Terminal Care.	Died 3 days following interview.
Female	84	Dukes C Bowel Cancer.	Symptom Control.	Discharged 2 days following interview.
Female	61	Bronchial Cancer Spinal Metastases.	Symptom Control.	Died one day following interview.
Male	77	Prostatic Cancer.	Terminal Care.	Died 5 days following interview.
Male	63	Lung Cancer.	Terminal Care.	Died 4 days following interview.
Male	70	Prostatic Cancer.	Terminal Care.	Died 2 days following interview.
Female	70	Breast Cancer. Spinal Secondaries.	Symptom Control.	Discharged 4 days following interview.
Female	59	Breast Cancer.	Symptom Control.	Died 1 day following interview.
Male	43	Liver Cancer.	Symptom Control.	Discharged two days following interview.

4.3. SECTION TWO: IMPLEMENTING THE STUDY.

4.3.1 Introduction.

The use of interviewing as a means of data collection in qualitative research has received much discussion in the nursing and research literature (Carson 1986; Mischler 1986; Drew 1989; Seidman 1991; Fontana and Frey 1994; Stuhlmiller and Thorsen 1997). These authors provide a discussion on issues related to interviewing, such as ethical issues, methods of analysis and relationship with the respondents. Despite the plethora of literature regarding the nature and type of interviews in qualitative research, there is little information regarding the influence of the

philosophical approach to the study on the data interviewing process. As hermeneutic interviewing strives to uncover meaning, the researcher strives to discover assumptions upon which the respondent's views are based (Honey 1987), hence, the interview process demands an analytical process that can illuminate the phenomenon under investigation. In an attempt to maintain this approach, I undertook a period of preparation prior to the data gathering process. An overview of the preparation for interviewing and the interview process will be described in an attempt to demonstrate the transparency of the interview as a data collection method.

4.3.2. Preparation for Interviewing.

4.3.2.1 Pilot Study.

The pilot stage of the study involved two nurses and two patients who agreed to participate in this phase of the study. I considered that these interviews were influential in developing my skills for the main study. Minor changes were made to my interviewing technique. On listening to the audiotapes of the pilot interviews, I became aware that I interjected too quickly in two cases, which may have resulted in valuable information being lost. Furthermore, the quality of the recordings indicated to me that I needed to ensure the volume control was increased to its maximum level for the remainder of the interviews.

4.3.2.2 Reflection.

Reflection is a central aspect of undertaking hermeneutic research. The writings of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) influenced my reflective process. Specific elements of their writings, as referred to in Section 3.2.2. guided this process. The reflection continued throughout the complete phase of data collection and analysis, and has continued to influence the final presentation of the research findings. As the data collection continued, my understanding of the nature of expertise was reshaped as I challenged my own thoughts regarding the nature of expert palliative nursing practice. Becoming immersed in the psychological and grammatical explication, listening and recording

the language that depicted the inner and outer forms of life that I was exposed to throughout the data collection period, engaging in the hermeneutic circle, fusing my horizons with the horizons of the respondents and developing insights in to the nature of dasein and temporality of the data that I collected helped create new insights in to the nature of expertise in palliative nursing practice.

Prior to undertaking each interview, I reviewed and re-read the previous interview that I had undertaken in the context of the above philosophical influences. I also re-read my pre-understandings and fore-structures that I had developed prior to commencing the study. This helped me to clarify my own thoughts, feelings and beliefs regarding the nature of expertise in palliative nursing practice. I maintained a diary throughout the interviewing process where I documented my thoughts, feelings and methodological decisions, the manner in which interviews challenged me, my thoughts regarding the analysis of the interviews and the nature of the relationship I developed with the respondents.

4.3.2.3 Equipment.

Prior to each interview, I carried out a check on the mini-disc, ensuring the microphone was in working order and that the batteries were charged. Additional batteries and blank mini-discs were available in case they were required. An advantage of using a minidisk to record interviews is the facility to create a mark on the disc as the recording is taking place. In order to capture the non-verbal actions of the respondents, I developed a coding system to record these. A sample of the use of the coding system is presented in Appendix 8, however, the complete non-verbal actions are included in the transcripts. The coding system was pilot tested on three respondents and minor adjustments were made. The value of using the coding system to capture non-verbal actions of the respondents is that it helped to form a complete understanding of what was happening, helped me to enter the mindset of the respondents and to capture the distinctive elements of the respondents, all of which are aspects of hermeneutic investigations (Bontekoe 1987; Mueller-Vollmer 1985; Bowie 1998).

4.3.3 Interview Process.

4.3.3.1 Timing of the Interviews.

Interviews took place at different times in each of the sites. This was dictated by patient dependency and the availability of the respondents to participate in the interviews. A number of interviews took place in the early afternoons, usually towards the end of the morning shift when there was an overlap of staff. Other interviews took place in the evenings or in some cases, a suitable time was arranged while the respondent was on night duty.

4.3.3.2 Nurses' Interviews.

Interviews commenced in January 2001 and were completed in April 2002. They usually took place in the early afternoons or at the end of a shift when staff were available to participate in the interview process. Interviews were also conducted with a number of the respondents while they were on night shift.

4.3.3.3 Patient Interviews.

Patient interviews commenced in January 2001 and were completed in March 2002. The interviews took place in their bedrooms, in a sitting room or in a library attached to the unit. As interviews took place immediately following a period of observation of practice, I wore a white tunic and navy trousers, which was the uniform I wore while collecting data and engaging in practice in a supernumerary status.

4.3.3.4 The Nature of Questions: Staff and Patients.

The opening question for staff was:

“I’m interested in your experience of being an expert palliative care nurse. Maybe you would start by telling me what this is like for you”.

The opening question for patients was:

“I’m interested in your experience of receiving expert palliative nursing care. Maybe you could start by telling me how this has been for you”?

These questions were used to commence the interview and to maintain the focus on expertise in palliative care. They were kept intentionally broad so that they allowed the respondents to evoke natural responses rather than having the respondent fit responses to preconceived categories or interpretations. This, according to Sorrell and Redmond (1995) allows further questions to be stemmed from the respondents' answer to the opening question. As the data gathering process evolved, I anticipated that additional or different questions might be asked. Samarel (1992), Sorrell and Redmond (1995) and Koch (1996) suggest that encouraging the respondents to engage in conversation in which they describe their stories as they have experienced them is important in getting to know the actual lived, day-to-day perspective. The broad nature of questions allowed the respondents to respond by describing a vivid picture of their experiences. On some occasions, the patients commenced their conversations by relaying stories regarding the nature and onset of their illness. As they became engaged in this conversation, they began to elicit their experience of receiving expert palliative nursing care. Such an approach also helped in making the respondents feel relaxed as they relayed the story of their experiences.

In an attempt to maintain "iterative interactions between the investigator and respondent" (Lincoln 1992: 380), I attempted to pose questions that would elicit a clear understanding of the stories as they were contextually situated in the world of the expert nurse and the patients. My interest in the phenomenon of expert nursing practice from the perspective of expert nurses and patients guided my probes and questions throughout the interviews. Sorrell and Redmond (1995: 1121) describe "recapitulation probes ... and silent probes" as being useful when conducting interviews. Furthermore, silent probes provided me with the opportunity to reflect on what had been said during the interview. Recapitulation probes took the participants back to the beginning of the story and allowed a more detailed description to be presented. The silent probe was useful in capturing feelings of the respondent that were not captured in words. The silent probe was used on a number of occasions, particularly with the patients when memories and feelings regarding their illness were too painful for them to discuss.

4.3.3.5 Location of Nurses' Interviews.

Where possible, a quiet room in each of the units was used to record the staff interviews. If this was not available, a vacant room away from the unit was used. Prior to commencing the interviews, I asked the respondents if they had any questions about the study. Several of them acknowledged their satisfaction in being considered to participate in the study, while others acknowledged the contribution of the study to palliative nursing. Minimal disruption to the interviews took place, and where it occurred was usually in response to the needs of patients. These interruptions were brief, and interviews usually recommenced within five minutes. While these interruptions disrupted the trail of thought of the respondents, it also allowed the respondents to concentrate fully on the remainder of the interview, knowing that the needs of their patients had been met.

The interviews were conducted face to face with all of the respondents. The presence of a recorder and microphone was an initial distraction for some of the respondents. I made the decision to use a mini disc recorder for the remainder of the interviews as it was less conspicuous and it had a highly sensitive microphone. This allowed the microphone to be placed out of sight of the respondents throughout the interviews. Once the respondents began telling their stories, they became absorbed in remembering their experiences and explaining the nature of their practice or experiences of receiving expert palliative nursing care to me.

4.3.3.6 Location of Patient Interviews.

The majority of patient interviews were conducted in their rooms. Where patients shared rooms, the interviews were conducted in a private room off the main ward area. Prior to commencing the interviews, I asked the respondents if they had any questions about the study. Several patients acknowledged their satisfaction in being considered to participate in the study, and expressed their gratitude in being able to contribute something to the hospice. Four of the patients requested that their voices be deleted once the interviews were transcribed. I felt that this was an unusual request. However, on further discussion with the recipients of palliative care, one respondent indicated to

me that he did not wish his voice to live on after his death, while the other indicated that he had a “bad experience” of being recorded in the past. The remaining two patients did not offer any reason for their request. Their request to have their voices deleted was fulfilled after transcribing the interviews.

4.4. Observation.

4.4.1. Introduction.

Field research consists of :

“... a systematic study, primarily through long-term interactions and observations, of everyday life. The goal of field research is to understand daily life from the perspectives of those in the setting or social group being studied” (Bailey 1996: 2).

A strength of this approach to data collection is that it provides the opportunity for developing a deeper and richer understanding of human behaviour than is possible with more rigid rigorous procedures (Grbich 1999; Polit and Hungler 1999). Morse and Field (1995) describe four observation methods of collection data. These are complete participation, participant-as-observer, complete observer and observer-as-participant. For the purpose of this study, I considered that complete participation was not an option due to ethical considerations. Participant-as-observer was also rejected, as this would have involved negotiating a work role within the research sites. Such an approach would have hindered the data collection process and would not have facilitated me in gathering the range of data that I sought. Complete observer was also dismissed as in this role as “the researcher is passive, having no direct social interaction in the setting” (Morse and Field 1995: 109). I felt it would be impossible to have no direct social interaction with the respondents or the patients of palliative care. I decided to undertake an observer-as-participant role for the purpose of data collection, which is also described by Adler and Adler (1994) as peripheral member researcher. This method allowed me to be completely overt in my observation of nursing practice. Furthermore, it allowed me to be “in-the-world” of the respondents so that I could continue to challenge my pre-understandings and my fore-structures. This involvement helped me in co-creating the text as co-researcher throughout the

study, which according to Thompson (1990) reveals the phenomenon under investigation, in this instance, the phenomenon of expertise in palliative nursing practice. It also helped me to complete the circle of practice, namely staff talking about their practice, and then me witnessing the delivery of patient care by these nurses.

4.4.2 Observation and Hermeneutic Research.

Risser (1997: 389) in a review of the work of Gadamer (1975, 1989, 1996), acknowledges that the centrality to hermeneutics is that of understanding the voice, and that voice contributes to creating the text for interpretation. However, he broadens the focus of the voice in saying that a voice is created in a "living language". The focus of this living language is one that is created within a given interaction with man, the creator of the voice. He supports the notion that voice is a breath and is situated within a space. Acknowledging the difficulty in interpreting and understanding the voice in the out of context situation, and as a sole means of understanding, there is a breach of continuity of meaning and understanding. He proposes that including the context of the situation where the voice is centred maintains this continuity and adds to the understanding and interpretive process. Supporting this, Sokolowski (1997), in an overview of Gadamer's (1975) theory of hermeneutics challenges the deconstruction and reconstruction of life events, particularly when interpretation and understanding emerges from one source. He proposes the true identity and understanding is manifest in various forms, which includes more than voice, as described by Risser (1997) above, when he suggests that:

"Various sorts of objects prescribe various manifolds of appearance. The identity needs the manifold to be and to appear, but the identity never becomes simply one member of the manifold of appearances" (Sokolowski 1997: 229).

The above quote supports the notion of including the various manifolds within which the reality of life events takes place in order to achieve a true understanding. In keeping with the above views, I made the decision to include observation as a means of data collection, so that the composition of expertise would be illuminated in more

than one form, namely, through the voices of expert nurses and patients receiving palliative nursing care. I argue that the need to interpret nurses' actions within the various forms of the practice of expert palliative care nurses makes observation of practice of paramount importance in its contribution to illuminating the phenomenon of expertise. Furthermore, it allows for the various manifolds and living language of the phenomenon to be included in the realm of interpretation and understanding.

Young (1983) explored the hermeneutical significance of Dilthey's (1990) theory of world-views and acknowledged the centrality which life had in Dilthey's (1990) writings. Similar views were proposed by Tuttle (1969) and these authors describe life to be composed of a whole, a unity that is difficult to view in isolation. Each element of life, Young (1983) argues, is interpreted within the context of inseparable elements from which it is formed. The inseparable elements consist of the location of action and thoughts, where living and being are taking place and being created. Combined, these form the basis for unity in interpretation and understanding. Taking these viewpoints, as palliative nursing practice is delivered within the context of life and living, utilising observation as a means for creating the text from which to interpret the phenomenon of expertise is in keeping with the writings of Dilthey (1990), Young (1983) and Tuttle (1969).

Having considered the writings of the above authors and with my understanding of the writings of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996), the inclusion of observation as a means of data collection within this study appeared to generate valuable insights into the nature of expertise in palliative nursing practice while also keeping with the philosophical basis of hermeneutics.

4.4.3. Preparation For Observation.

4.4.3.1 Relationships.

The presence of the researcher as observer is one of the problems associated with an observer-as-participant method of data collection (Angrosino and Mays de Perez 2000). In preparation for undertaking the observation sessions, a minimum of five shifts in each site were used to develop a trusting relationship with the staff and patients. Throughout this time, I mingled with both the staff and patients in order to enhance relationships with them and to reduce the risk of reactivity to having a researcher present in the hospice (Addison 1992; Mason 1996; Polit and Hungler 1999). Furthermore, it also helped to reduce the risk of causing a distraction to nursing practice.

4.4.3.2 Pilot Study.

I also used this opportunity to undertake a pilot study as to how best to record the field notes and observations. At the end of each session, I reviewed the recorded field notes, looking for description as opposed to feelings and subjective interjections throughout the recorded notes. Throughout the preparatory phase of data collection, a number of issues emerged for me to consider. These included what to observe and record, how to record, when to record and where to record the observations. Singleton and Straits (1999) advise that researchers need to address these issues prior to commencing observations in order to enhance the structure, process and outcome of observation as a means of data collection.

4.4.3.3 Reactivity and Observation.

While the "...social role of the observer determines what she or he is likely to see" (Polit and Hungler 1999: 367), there is the possibility that reactivity may occur due to the presence of the researcher in the field. In an attempt to minimize this occurrence, I maintained minimum interaction with the staff members and patients during the observation periods. This allowed me to concentrate on the nursing actions and to record field notes during the events. A further strategy employed was to inform the

nurses that the observation was solely to note nursing activities and not to make a judgment of practice. This was also highlighted to the nurses at information sessions held with them prior to commencing the study, however, it was important to reinforce this at the commencement of each observation period. As I was familiar with some of the research sites, having been associated with them in the capacity of co-ordinator of palliative nursing education, I considered that this would help lessen the possibility of reactivity to my presence as a researcher. While Field and Morse (1985: 77) are resolute that collecting data in a site where the researcher is known will “prevent the collection of valid, reliable and meaningful data”, I did not accept this perspective. Darbyshire (1994b: 194) supports this view and considers that Field and Morse’s (1985) argument is:

“...based upon the premise that there exists an objective reality or external truth which the researcher is there to discover and which can best be achieved by maintaining objective distance”.

4.4.3.4 Observation Process.

I adopted the observer-as-participant role throughout the study. As I had previously engaged in clinical practice, my work experience helped me in adopting this role for the purpose of this study. From that experience, I realised that undertaking the role of participant-as-observer would have hampered the data collection and recording of observations, particularly my ability to record field notes on the spot. I dressed in a white tunic top and navy trousers, which is the most common form of male nurse’s uniform. Dressing in this manner allowed me greater access to view the actions of the nurses. My name badge stated ‘researcher’ as opposed to ‘nurse researcher’ as I felt that identifying myself as a nurse as well could infer a willingness to participate in nursing practice (Mazer 1993). A total of 297 hours were spent undertaking observation. The breakdown of these hours is presented in Appendix 9.

4.4.3.5 Focus of Observation.

The layout and structure of three of the research sites were not familiar to me. I needed to become familiar with the layout of the units. As there were six different sites, it was necessary to create a sketch of each unit, so that when reading the observation notes, I

could refer back to the actual location of events as recorded in the field notes. On my first visit to each site, I drew a diagram of the research location. This took a very brief period and this diagram later helped to jog my memory about events that took place during the observation periods. Furthermore it furnished me with a “textual overview” of where the world of the palliative care nurses was actually taking place. The layout included the location of the wards, individual rooms, nurses’ station / handover area, sluice room, linen cupboard, dining room, patient sitting area, lounges, library and any other rooms that were in the unit.

Similar to Woodward (2000), I was conscious of not intruding on intimate care throughout the observation process, and this was kept to a minimum. Throughout the observation period, I made a deliberate attempt to avoid participating in hands-on care, and maintained the role of a passive observer. This was explained to the expert nurses and they were in agreement with this.

The field notes contained records of observations and conversations with staff members and patients. This ranged from handover, meeting with patients, admitting and discharging patients, family meetings, multidisciplinary meetings, being present when patients were dying, removal of bodies to the mortuary, and accompanying patients to day care or the library. The range of activities observed was also influenced by the time of day the observations took place.

4.4.3.6 Process of Recording Observation Notes.

Initially the observation notes were purposely unstructured in order to allow me to expand my “tacit knowledge and develop a sense of what is seminal or salient” (Lincoln and Guba 1985: 275). At this stage, the notes contained information as to the room number the nurses entered, how many patients were in the rooms, the first and subsequent actions in which the nurses participated, to whom they spoke, how long they stayed in patients’ rooms, where they went when they left patients’ rooms and with whom they may have conversed. Conversations I had with staff as we moved from room to room were also written down.

Whenever possible, I attempted to write down what was said by the nurses verbatim. This was done in an effort to capture the respondent's words and expressions, however, this proved to be difficult in some instances. It was challenging to write notes and to engage in conversation. Often times, I had to ask the respondents to slow down or repeat what they had said, which overall affected the flow and rate of conversations with the respondents.

On reviewing the field notes, I structured them according to verbatim notes and summarised statements (Mazer 1993). This was the first form of applying some order to the notes. Verbatim accounts captured the respondents' words and phrases and I strove to record these as much as possible. However, that carried the disadvantage of interrupting the flow of conversation and eye contact with the respondents was broken. Summarised accounts helped me to synthesise a series of events into a succinct description. Summarised accounts were completed as soon as possible after the observation session ended. On occasions, I was able to write summarised accounts immediately after the verbatim accounts, when recall was at its highest. An example of verbatim and summarised notes are presented below and are taken from the data collected during an observation session. Both accounts depict the same observed activity.

Verbatim Account.

O= Observation. S05/5: Respondent. KC: Kevin Connaire.

O: Frank [pseudonym used] is lying on the bed and facing the wall. He is tearful and has his arms over his abdomen. He has his head held down and his eyes are closed. His breakfast is on his bed table and he has not eaten it. It's now 9.45am.

S05/5: He is very upset this morning. He didn't sleep well last night. I think he's in more than visceral pain you know, I know it's more than that.

O: S05/5 sits down beside him and asks him how he is. Frank doesn't answer. Says after a few seconds he wants to be alone. S05/5 says, "Ok, when you need me call me". Leaves room and puts hands in the air. Out on corridor.

S05/5: I know I need to get in there and do more. But there's such a block, he blocks us all out, he won't let me get in there and help him to sort it all out.

KC: Sort it out?

S05/5: Yeah, there's so much he has to deal with yet and he hasn't done it. Time is running out, going fast and I'm afraid I won't be able to get in there.

KC: Get in there?

S05/5: Yep, I'm just waiting for the barriers to be let down, then I'll know more where he's at.

O: Walking down corridor into treatment room.

S05/5: This is coming for a long time. He's here 4 days, and it started the day he came in. He's blocking me out and the rest of us.

O: Makes stop sign with both hands and shrugs shoulders.

S05/5: There's not a lot I can do just now.

Summarised Account.

Was with S05/5 this a.m. Looking after 5 patients. Frank in a lot of pain. Didn't say much and didn't eat breakfast. S05/5 was aware of his pain, but wasn't able to do much about it. She tried to talk to him to sort it out, but he didn't want to talk at this time. She told me she needed to get to the root of it, because she felt there was a lot she could do about it.

4.4.3.7 Providing a Framework for Managing Field Notes.

As the process of recording verbatim and summarised notes continued, the volume of notes from my observation sessions mounted. My challenge was to arrange these accounts into a structure that could be interpreted hermeneutically. I used a modified framework by Miles and Huberman (1994) that allowed me to capture an array of information that provided a structure for my field notes. On completion of the day's observation, the framework was used as a guide to writing up the field notes. The verbatim and summarised accounts helped me in compiling the contact summary sheets. This framework also heightened my awareness regarding my technique of recording field notes and as the study progressed, my method of recording became more refined. Using this framework also helped me in maintaining some consistency in my observation pattern, yet allowing a degree of flexibility in collecting the data. I avoided applying my own label or category to the events that I observed; however, I

was constantly aware of my pre-suppositions, prejudices and fore-structures as I collected and recorded the field notes. I was also conscious of not incorporating any personal reactions into the field notes as this may have distorted the events that were taking place. A field diary was commenced and used as a means of recording my feelings, ideas and impressions as to what was going on in the field. An example of a Contact Summary Sheet is presented in Appendix 10.

4.4.3.8 Location of Note Recording.

Notes were recorded in several areas, including the ward, single rooms, corridors, nurses' station and staff canteen, and this varied throughout the course of the study. The main factor that influenced the location of note taking was the context of the event being observed. It was not always appropriate to record notes at the time events were taking place, for example, when a patient was dying or when a nurse was dealing with upset family members. However, I attempted to write the notes as soon after the event as possible so as to reduce the risk of poor recall.

4.4.3.9 Timing of Observations.

Observation sessions took place in the mornings, afternoons and during the night shift. Timing of the observations was dictated by the availability of the nurse and the researcher to undertake the observation. An explanation of the observation procedure was provided to the respondents and they were informed that their practice was observed for a period of time. No respondent refused to participate in the observation period. The observation periods lasted up to four hours, however, on two occasions these were cut short due to the death of patients being cared for by the nurses being observed. The duration of observation varied, lasting from twenty minutes to four hours per person at any one time.

4.4.3.10 Closure of Observations.

On completing the observation sessions with each of the staff, I thanked them for their participation. I asked them if they had any questions regarding the observations. Several of the respondents inquired if I was satisfied with what I had seen and if I had

achieved the goal of my observation. Others expressed their gratitude for being included in the study. None of the respondents voiced concerns that it was a stressful or threatening experience for them.

4.4.3.11 Diary.

Hammersley and Atkinson (1983) support the use of a diary in qualitative research in order to capture the researcher's feelings throughout the research study. Commencing a diary is paramount in the early stages of the research process, so that clarity regarding the nature of the research problem and research question may be achieved. The research diary is a part of the process of analysis. Furthermore, Denzin (1980) considers that the use of a diary helps to keep a record of any changes that occur in the researcher. The diary contained an account of changes that were occurring as the data collection and analysis took place. It also contained accounts of how I felt regarding the changes that were taking place in the patients, who were generally getting weaker, and how this impacted on me. Other issues included challenges that I faced throughout the study and how I addressed these. Furthermore, I considered the diary helped me to challenge any biases I may have developed as the study progressed. An example of a diary excerpt is presented in Appendix 11. The excerpt presented in this appendix is one of a number recorded throughout the data collection which helped me to explore feelings outside of the normal data collection. It also brought back to reality that I am a researcher, yet I also have a life outside of this study. This separation of self from the data provided a meaningful and rich picture of the reality of expertise in palliative nursing. The above mentioned excerpt from the diary reinforces the reality of expert palliative nursing that was confirmed for me as I sat observing practice in the distance.

4.5 Ethical Considerations.

4.5.1 Introduction.

This section addresses the ethical considerations pertinent to this study. An overview of ethics and research is presented. This is followed by a discussion on the ethical issues involved in this study, namely, defining the terms vulnerable, vulnerable

patients and research, time and research, anonymity and confidentiality of staff and patients, obtaining informed consent, sensitivity and storage of information.

4.5.2 Ethics and Research.

Ethical implications for the researcher and the respondents cannot always be foreseen in qualitative research (Seymour and Ingleton 1999). The protection of research participants is of paramount importance in any type of research. Although the research process may create tension between the aims of the research and the rights of the respondents to maintain privacy, this can be reduced through the application of appropriate ethical principles (Orb, Eisenhauer and Wynaden 2001). Within the Irish context, these ethical principles are addressed by An Bord Altranais's Code for Professional Conduct for each Nurse and Midwife (An Bord Altranais 2000) as follows:

“In taking part in research, the principles of confidentiality and the provision of appropriate information to enable an informed judgment to be made by the patient must be safeguarded. The nurse has an obligation to ascertain that the research is sanctioned by the appropriate body and to ensure that the rights of the patient are protected at all times. The nurse should be aware of ethical policies and procedures in his/her area of practice”.

It is the responsibility of the researcher to ensure that his or her study is ethically rigorous. However, while codes for ethical procedures are available, issues may emerge throughout the study that may not be foreseen prior to conducting research. The researcher needs to maintain a high level of reflexivity in order to become aware of possible ethical issues that may emerge as the study progresses.

4.5.3 Ethical Principles Applied in this Study.

The goal of palliative care is to relieve suffering and to improve the quality of life for dying patients and their families. In an effort to deliver effective care and evidence-based practice, it is necessary for studies to be undertaken involving this group of patients. Despite this, there appears to be uncertainty as to the ethical limits of conducting research that involves dying patients (Annas 1998). While general ethical principles of conducting research can be applied to patients who are dying, it appears

that this population is considered to be a vulnerable group. Casarett and Karlawish (2000) challenge the notion that special guidelines need to be formulated when conducting research on patients who are dying. However, such a proposal raises the question as to what constitutes a “vulnerable” group?

4.5.3.1 Defining “Vulnerable”.

When involving patients as co-researchers, irrespective of their health status, researchers need to be aware of their ethical responsibility towards the respondents and to justify the inclusion of patients in research (Randall and Downie 1996). This is necessary, as the researcher may be asking them to evaluate the care they receive, reflect on issues related to their health and illness, or to explore painful issues related to life events. It is necessary to make them aware of the consequences of their involvement in research studies. Patients who are receiving palliative care are considered to be a vulnerable group, particularly when becoming involved in research. Grisso and Applebaum (1998) deem that patients are vulnerable when they lack decision-making abilities or when they do not make choices voluntarily.

4.5.3.2 Vulnerable Patients and Research.

The issue of involving vulnerable groups in research has gained considerable discussion in the literature (Raudonis 1992; de Raeye 1994; James and Plazer 1999; Seymour and Ingleton 1999; Casarett and Karlawish 2000). Dying patients are considered to be a vulnerable group (Roy and MacDonald 1998; Ferrell and Grant 2001). Despite this consensus, there appears to be polarity regarding the protection and involvement of this group in research studies. Raudonis (1992) argues the notion that dying patients should not be involved in research. This absolutist view considers that all research that involves humans treats people as a means to a research end. An alternative view presented by Mount et al (1995) and Bruera (1994) considers that all individuals, even those who are dying, should be allowed to make the choice for themselves. Kellehear (1989: 65) further supports the inclusion of the dying in research and supports his argument:

“Without questioning the dying about their social experiences as they see it and as they interpret it, we are confined to speculation and the opinion of

caretakers. Without information about what may or may not be typical, individual dying persons may feel that their own needs or experiences are deviant, eccentric or neurotic. Without systematic talks with the dying, we may not reliably determine what are their problems and what are our problems...without this sort of work, the dying have no idea how others like them die, and they want to know”.

These viewpoints present plausible arguments for and against the involvement of dying people in research. I considered that the former approach removed patient choice in engaging in research. On the other hand, the alternative view was considered to be more appropriate, as it provided the patients with the right to choose or decline to participate in the research study. Copp (1997: 5), however, warns that such an approach places responsibility on the researcher to:

“... constantly evaluate the patient’s condition and whether he/she still wishes to participate”.

Taking into consideration the views of the above authors in the context of the present study, I considered Mount et al’s (1995), Bruera’s (1994) and Kellehear’s (1989) approach to be reasonable in including patients in this study. My view was that patients had the right to make the choice themselves to participate in the study. However, as the study progressed, a further issue emerged that created an ethical issue for me. This is the issue of time and research.

4.5.3.3 Time and Research.

Throughout my fieldwork, it became apparent to me that many patients died in the hospices. I felt that the time leading up to their deaths was a precious time for patients, and felt that they may be pre-occupied with poignant issues such as family affairs or knowledge of impending death. Taking cognisance of the issue of time, this created a dilemma for me. I was aware that many of the patients might die in a relatively short time after the interview. I wondered if they spent time recovering after the interview, a time that could otherwise have been spent with their families. I questioned if the patients felt there was what Dean and McClement (2002: 376) call “relational vulnerability” when they consented to participate in the study. Relational vulnerability is described as that which stems from interaction with caregivers and patients. I

considered that their time would be well spent talking about their experiences of receiving care from expert palliative care nurses, as it would contribute to the quality of care for patients in palliative care settings. Furthermore, I was influenced by the work of Rier (2000) who considers that the voice of the critically ill is missing from research, resulting in the loss of valuable insight into caring from this group. I made an effort to maintain both balance and complexity throughout the interviews. As the interviews progressed, the issue of taking up patient's time subsided when it became apparent that the interviews lasted from twenty to thirty minutes maximum.

4.5.3.4 Anonymity and Confidentiality: Staff and Patients.

Anonymity and confidentiality are problematic in qualitative research (Darbyshire 1994b; Holloway and Wheeler 1996; Polit and Hungler 1999; Boman and Jevne 2000). In order to maintain anonymity, a code number was allotted to each of the respondent's transcripts. I am the only person who can link the interview transcript and the observation data to each respondent. The names of the research sites are not included in the research report. Whenever the research site was named in the interviews, pseudonyms were substituted in order to preserve the anonymity of the site. Confidentiality in research, according to Kvale (1996: 114) "...implies that private data identifying the subjects will not be reported". Owing to the small sample sizes, the rich descriptions provided by the respondents that are presented in the research report make the principles of confidentiality difficult to uphold. In an attempt to maintain confidentiality, any information provided by the respondents that they did not wish to disclose to others or in the research report was withheld. In an attempt to assure anonymity and confidentiality to the respondents, they were invited to sign a consent form prior to participating in the research study.

4.5.3.5 Informed Consent.

Obtaining informed consent is a complicated issue and one that is open to much debate (Behi 1995; Smith 1997, 1998). While Beaver, Luker and Woods (1999) emphasize the importance of obtaining informed consent when involving terminally ill patients in research, the degree and content of consent is open to scrutiny. As patient

status may change throughout the course of a research study, altered cognitive function may result in difficulties in explaining what the respondent is actually consenting to. Furthermore, Lawton (2001) highlights the problem of consent when aspects of the study evolve into something different than that to which patients and staff originally gave their consent.

With these issues in mind, I attempted to ensure that informed consent was obtained from the respondents. A two-fold approach was used in this study. I first attempted to establish the competence of the patient prior to interview through verbal interaction with them. I established this during my period of supernumerary status prior to commencing interviews. Secondly, I continued to verify and re-verify with the patients at different stages throughout the interviews their agreement to continue. Consent was obtained in writing from the respondents before the interview and observation. Prior to obtaining the consent, an explanation of the research study was given to the respondents and any questions that the respondents had were answered. While this did not present with any difficulty in relation to the interviews, it presented me with a dilemma in relation to the observation of nursing practice. I felt an obligation to inform the patients that I was present in the role of an observer of the nurse caring for them. Each time a nurse who was being observed approached a patient to carry out nursing care, I explained my role as researcher to the patient in a language that I believed they understood. There were occasions when I wondered if the patient actually understood what it was that I was doing. However, I felt I had made a reasonable effort to explain to the patient and obtain their permission to undertake the observation.

4.5.3.6 Obtaining Consent: Consent Form.

Each participant was asked to sign a consent form. The form was composed of two parts, namely that of disclosure and authorisation.

4.5.3.7 Disclosure.

The following information was disclosed:

(a) the purpose of the research study, (b) nature of participation, (c) who was conducting the research, (d) benefits and risks, (e) degree of anonymity, (f) confidentiality of the data, (g) person to contact if the participant had any concerns or questions regarding the nature of the study.

4.5.3.8 Authorisation.

The participants signed the consent form stating that:

(a) they understood the information provided to them, (b) they were willing to participate, (c) they granted permission for the information generated from the study to be made available through publications. A number of the participants sought clarification regarding the purpose of the study and the nature of my role when gathering observation data. These were explained to the respondents.

4.5.3.9 Sensitivity.

This research study is generally free of ethical problems, however, the issue of sensitivity, as emphasized by Costello (2001), regarding the subject of palliative care when talking to patients was highlighted to me as the study progressed. The most sensitive aspect of the interviews that I considered was the subject of approaching death. I made the decision that in the event of this occurring, respondents would be given the opportunity to terminate the interview if they felt uncomfortable talking about their impending deaths. Reflecting on the nature of negative emotions that may arise throughout the interviews with the patients, I felt that emotions such as crying and sadness are not equated with harm. The expression of emotions is often regarded as beneficial to the respondent as opposed to being harmful to them (Aranda 1995). Two respondents became tearful during the course of the interview. The first respondent to demonstrate any element of tearfulness explained that since her diagnosis, she frequently cried when she thought of what was ahead of her. Another respondent wept openly when talking about a trip to the hospice garden accompanied by a nurse. He indicated that such a trip "brought him back to his happier days at

home” and he wept while telling me this story. In both instances, the recordings were discontinued for a period of time and recommenced when the patients indicated a readiness to talk again. The patients were given the option to stop the interview, but both declined this offer. On completion of the interview, I offered them a debriefing session. Both accepted and expressed that they had overcome their emotional responses following this intervention. I also offered the patients to tell their nurse and medical consultant about their feelings, however this was declined. The respondents were also given the opportunity to withdraw from the study, but neither accepted this offer.

Reflecting on the above incidents, I felt that as patients had cried, it may be interpreted that I had inflicted harm on the patients, and I felt responsible for upsetting them. While I considered that I had resolved the issue following the interviews, I felt I needed to follow up on this issue in order to ensure that I had not caused any harm to the patients. On a follow-up visit two days later, the patients indicated that they had felt the better for having had a cry and being able to express their feelings. Such an expression of feeling indicated to me that the interview had acted as a possible catharsis, which Hutchinson, Wilson and Wilson (1994) suggest is a benefit of participating in qualitative research.

4.5.3.10 Storage of Information.

Due to the number of respondents and the nature of observation data collected throughout the course of the study, a large volume of notes and transcripts were generated. Initially, the interviews were recorded on a mini-disc. I then transcribed these and produced a hard copy of each transcript. A total of three folders of transcripts were generated from the interviews. These were stored in a locked filing cabinet in my study to which I am the only person with access. The mini-discs are also stored in a locked filing cabinet in my study. All information, including any reference to the respondent's name, place of work, colleagues' or patients' names who may have been referred to throughout the course of the interviews have been deleted and replaced by a pseudonym or a code number.

4.5.3.11 Summary.

This chapter has presented an overview of the methods employed in collecting the data. A description of the research sites and the approach used to gain access to these sites and to the respondents was addressed. An overview of the structure and process of the interviews and observation was presented, together with a discussion on the ethical issues pertinent to this study. The following chapter provides an overview of the data analysis process that was undertaken in this study.

4.6 Conclusion.

Researchers are presented with multiple challenges in conducting research in the palliative care setting. These include the justification of involving patients as they live with their dying. However, excluding the patient who is dying and their family in research studies has implications for the ongoing development of knowledge regarding their needs and their experiences. Addressing these challenges and engaging in palliative care research not only recognises the value of palliative care research but also gives a voice to this vulnerable group of people. Engaging in data collection methods as discussed in this chapter has the potential to illuminate individuals' understanding of their dying process and provides carers with a new horizon through which quality patient centred care may be delivered.

CHAPTER FIVE

DATA ANALYSIS

5.1 Introduction.

The overall purpose of this study was to examine the composite of expertise as it is revealed in the every day nursing practices of expert palliative care nurses. The hermeneutics of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) provided the philosophical foundation for creating and analysing the data. While hermeneutics influenced the analysis of data, the framework advocated by Koch (1993) that was adapted from Colazzi's (1978) framework, guided the process of analysis. There was constant interaction between each of the steps described below. This chapter provides an overview of the method and approach used to analyse the data in order to illuminate the essence of expertise in palliative nursing practice from the horizons of the nurse respondents, patients and the researcher. A diagrammatic representation of the processes in which I engaged is presented in collecting and analysing the data is presented in Appendix 12.

5.2 Influence of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) on Analysis.

Data analysis was influenced by my understanding and interpretation of the writings of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996). As referred to in Section 3.2.2., it is necessary to demonstrate the influence these philosophers have on the data analysis in order to demonstrate transparency of method and methodology. As I read the interview transcripts and observation notes, I asked questions of the data that arose from my understanding of reading the philosophers' work. These questions are presented below according to each of the philosophers' works and their application to one interview is presented in Appendix 13.

5.2.1 Influence of Schleiermacher (1977, 1990) on Analysis.

I generated the following questions that were derived from my understanding of Schleiermacher's (1977, 1990) writings.

5.2.1.1 Understanding Consists of Re-Experiencing the Mental Processes of the Author of the Text.

What is it that caused this person to view expertise in this manner?

What is causing me to view expertise in this manner?

What does this particular word mean?

What thoughts are being expressed by this statement?

5.2.1.2 Understanding is Grasping the Meaning of the Parts Through the Whole, and Understanding the Whole Through the Parts.

What is being said in this instance, what understandings have I now from what this person has said?

What is this sentence saying to me in relation to the totality of the interview?

What are these actions from my observation notes telling me about the whole of the person's practice?

What is each sentence telling me when it is viewed in the context of my observations?

5.2.1.3 Understanding Involves Perceiving the Individuality of the Author as a Human User of Language.

How best can I apply language to what I am seeing in the context of this observation?

What are the unique elements of my understanding of this person's interview and practice that go to create the whole of the experience?

What circumstances surround the individuality of this person in their practice that have created this text?

Does what the author is saying have meaning and understanding for me as a person, a nurse and a researcher?

5.2.2 Influence of Dilthey (1990) on Analysis.

How does my life interface with the lives of the nurses and the patients?

How can I express what I am seeing into words that can adequately capture the true reality of the nurse and patient situations?

As the nurse cares for each individual patient and family member, are there any expressions that are so complex that they may even be contradictory, and if so, what is their meaning?

5.2.3 Influence of Heidegger (1927 / 1962) on Analysis.

I brought my pre-understandings and fore-structures to the text so that they enriched the data analysis for me.

These consisted of the following statements:

The nurse creates a secure environment for the patient and family members throughout the palliative care phase of care.

The nurse is a companion.

The nurse has knowledge of the health-illness, living-dying trajectory.

The nurse believes in palliative nursing practice.

The nurse responds to crisis in the family and individual.

The nurse combines knowledge of the patient's physical, psychological, social and spiritual needs with appropriate interpersonal skills when caring for patients and families.

The nurse is authentically present to patients and families.

The nurse is competent and caring in undertaking nursing interventions.

The nurse has unknowingness about the patient and family.

The nurse promotes advocacy and empowerment for the patient.

5.2.4 Influence of Gadamer (1975, 1989, 1996) on Analysis.

From my past experience as a nurse, what am I bringing with me to this creation of data: my experience of caring for patients in palliative care settings and my knowledge of how nurses care for patients in palliative care settings.

Having cared for a family member requiring palliative care since this study commenced, what understanding of the expert palliative care nurse's role is

being influenced by my own personal experiences of caring in a similar situation?

Being a researcher in a palliative care setting, how is this present horizon influencing my interpretation and understanding of the data I am collecting?

5.3. Description of the Approach to Analysis Used in this Study.

The process undertaken in conducting the analysis is outlined below. As I collected the data and transformed it into text, I printed the set of questions outlined above and as I read the transcripts, these questions guided my thoughts and facilitated me to confront the data so as to develop an understanding of the composite of expertise in palliative nursing practice. While there are no specific guidelines to undertake hermeneutic analysis recommended by the above philosophers, I was guided by the work of Koch's (1993) adaptation of Colazzi's (1978) framework for analysis to manage the data as it emerged. An overview of this framework is presented in the following section

5.4. Framework For Analysis.

The framework used for the analysis was that from Koch (1993) that was an adapted version of Colazzi's (1978) framework. While Colazzi advocates returning to the participants to validate the findings, in Koch's (1993) case that was not possible, as many of them had died at that stage. Similar events occurred in the context of this study, hence the appropriateness of utilising this framework.

5.4.1 Guiding Principles of Analysis.

The following section presents an overview of the guiding principles of analysis used in this study.

5.4.1.1 Step 1. Protocols / Descriptions.

“Read through the entire subject's description for a sense of the whole... in order to acquire a feeling for them, making sense of them” (Koch 1993: 224).

Prior to commencing the above process, my first task was to transform the data I collected into a manageable entity. This is what Huberman and Miles (1998: 180) refer to as “data reduction”. Data reduction involved transforming the audiotapes into the written word through the process of transcription. When transcription was complete, the interviews and field notes were printed and bound in a folder for ease of access. The data consisted of interview transcripts and field notes from six research sites. In order to facilitate ease of access to the transcripts and field notes from the different research sites, each set of data associated with the individual sites were colour coded. This involved printing all notes and transcripts on different colours for each of the research sites. Each set of data were then stored in a ring-bound folder. Interviews and contact summary sheets were read on a number of occasions in order to get a sense of the content. Throughout this process, I became familiar with the text and the context in which the data were generated.

5.4.1.2 Step 2: Extract Significant Statements.

“Extract significant statements that directly pertain to the investigated topic”.
(Koch 1993: 225).

Selecting significant statements commenced when the first interview was complete. Statements were considered to have significance when they allowed “some things to show up as a relatively important or relatively unimportant” (Benner and Wrubel 1989: 412). As the phenomenon of expertise in palliative nursing is the focus of this study, I asked of the data “What is it that these nurses are doing that makes them an expert nurse that is different from the way non-expert palliative care nurses deliver care to palliative care patients”? Significant statements were also centred around the questions I posed of the data as identified in Sections 5.2.1 - 5.2.4. This was in an attempt to remain true to the hermeneutic analysis and to remain in the hermeneutic circle. For example, one significant statement was: “**We are here for the patient and family**”. This is presented below.

+Nurse 1: “Maybe it’s a part of the knowledge that we don’t have the answers, but that **we are here for the family**, because I think it’s a lonely journey at the end of the day, it’s a very lonely journey for the person who is dying and one they can only do, and nobody else can do it for us or come with us, but it

maybe just bridges that gap across the loneliness for that person just for that bit of time. In the terminal phase, a lot of about being there might be for the family rather than for the patient as the patient slips further into unconsciousness or reduced consciousness”.+

A number of the respondents throughout the study identified being there as being a key part of their role. Another respondent also described her role as an expert palliative care nurse as one of being there as follows:

+Nurse 28. “Yeah, **being there with both the patients and the families**, is so important. And to me, it’s how we are with them too. It’s so often not what we say while we’re there, it’s not the saying, it’s just us being there as a person. And there’s time when my being there is what makes the journey for the relatives and the patient maybe that bit easier, maybe it’s just they know I’m there for them. After all, it’s a road that they haven’t travelled before, neither have we, not with this particular person, so in a way, it’s a privilege for us to be there with them. And I think it’s what we bring with us that’s important. It’s the totality of our being there, yeah, that’s it”.+

A respondent from another site describes similar sentiments of her role as an expert palliative care nurse in being there for the family.

+Nurse 33: “You’re working with the family in getting to know them. Sometimes it’s not what you do, sometimes it’s the way you do it and **the way you are with them**, it’s the relationship that you build up and the little things, the little things that make the difference. It’s listening to their families and what their families say about them”. +

As well as the respondents describing their role as an expert palliative care nurse as involving family care, I had noted this in my observation notes. This is evident from the following excerpt from my field notes.

+Nurse 33 is caring for four patients this afternoon: two men and two women. She went to introduce herself to each of them. They all have relatives visiting them. Nurse 33 introduces herself to relatives. Checks if patients are in pain or need anything to make them more comfortable. Takes Ita [pseudonym used] for walk down corridor. Sits in lounge with Ita’s husband. Pulls up chair opposite him. Husband tearful. Nurse Two holds his hand and pulls chair nearer to him. Talking to him for twenty-five minutes. Tells me Ita’s husband needs a lot of support from staff, as he feels isolated from her since she came into hospice. Wants to be more involved in her care. Nurse 33 goes to Ita’s nursing notes and gets out care plan. Updates care-plan to include him in her care. Makes the suggestions on the care plan as to how this can be done. Nurse 33 says there needs to be more done for him so he is part of her life and caring while she’s here in the hospice. Talks about arranging a family meeting, and

looks in diary to see when is the soonest time this can be arranged. Goes into Ita's room to see if he is ok, and to talk to them about arranging a family meeting.+

The above exemplars demonstrate a blending of data sources that I used in the selection of the significant statement "We are here for patient and the family". Additional significant statements are presented in Appendix 14.

5.4.1.3 Step 3: Analyse Each Transcript Separately.

"Continue extracting significant statements from each interview"
(Koch 1993: 232).

The process described above was undertaken for each interview. This involved searching for significant statements in each of the interviews that resembled those identified in earlier transcripts as well as significant statements that were unique to each individual interview. An initial overview of the manner in which data were organised into clusters is demonstrated in the segments of interview data included in the above extracts. A total of one hundred and eighty significant statements emerged from the data.

5.4.1.4 Step 4: Develop clusters.

"Compare the whole data set, grouping together significant statements into clusters that represent commonalities of experience. The analysis continues by developing these clusters" (Koch 1993: 234).

Significant statements were clustered together in order to identify commonalities amongst the data. A total of fourteen clusters or categories emerged from the data. The amount of data within each cluster varied from one sentence to five sentences.

5.4.1.5 Step 5: Develop themes.

"The strong clusters were integrated into five themes" (Koch 1993: 234).

In total, the fourteen clusters from one hundred and eighty significant statements were developed from the interview data and these were then clustered into five themes. The themes and categories that emerged from the process of analysis are presented in Appendix 15.

5.4.1.6 Step 6: Create exemplars.

“Transcripts were re-examined to select exemplars of significant statements to illustrate clusters and themes” (Koch 1993: 237).

Each theme will be presented by providing exemplars that are excerpts from nurses’ and patient interviews, together with data from my field notes recorded during observation of practice. The findings of this study indicate that the essence of expertise in palliative nursing practice from a nurses’ perspective is composed of five themes and fourteen clusters.

It was not sufficient to “create” the themes and clusters. It was necessary to take these a step further and ask what is all this saying to me, what is my overall interpretation and understanding of what is going on here. To answer this question, I continued to “peel back” the layers of understanding in order to reach one that brought all of the nurses’ and patients’ stories together and to finalise a statement to elucidate the composite of expertise in palliative nursing practice from the horizons of the respondents and me as researcher. A final statement emerged for me to make explicit the composite of expert practice as being one that nurses foster an optimal functional self in patients and families in their living in dying.

5.5 Managing the Data.

As there was a considerable amount of data generated from the study, I decided to use computer software to assist in managing the data. Within the context of this study, this software package acted as a means of data storage and retrieval as it allowed me to remain close to the data and emergent categories and themes, as considered by Morse (1991b). The following section provides an overview of the use of the Non Numerical Unstructured Data Indexing Searching and Theorizing (NUD*IST) software to facilitate the storage and retrieval of data in this study.

5.5.1 Use of NUD*IST Software in This Study to Facilitate Data Analysis.

This involved processing the data obtained from each interview. The NUD*IST software was used to facilitate data management and retrieval throughout the study.

Initially I transcribed all interviews verbatim using Microsoft Word Processing package. Each interview and piece of observation data was given a 'filename' that corresponded to the codename given to each respondent. For importing data into NUD*IST, interview files are considered as 'raw files'. A document header, which corresponded to the respondent's codename, was then given to each raw file. Once the raw file was imported into NUD*IST, each transcript was read and re-read for expressions of each respondent's essences of expertise in palliative nursing practice and deposited in a "free node". A "free node" contains the name of a concept or an idea about the data that is being analysed. Each transcript was coded line by line. The number of lines varied between interviews, as did the number of free nodes that were created. On completion of the analysis, I had created a total of one hundred and fifty free nodes. These nodes provided me with a guide to generating significant statements as described in Section 5.4.1.3.

Names applied to the free nodes include: "cues", "facilitating", "humaneness", "loss", "memories", "openness", "planning and anticipation", "reminiscing", "translating" and "sharing". A list of the free nodes is presented in Appendix 16. These "free nodes" were used to form the basis of extracting the significant statements from each interview. A sample of the contents of two free nodes is presented in Appendix 17.

As each transcript was read in its entirety, I asked the questions identified in Section 5.2. of the data in order to remain true to hermeneutics as a methodology. This process occurred a number of times, and after completing each series of questions, further questions were generated. This process continued until such time as I reached a clear understanding of the nature of the expertise as it was illuminated by the data. However, a final understanding will never be reached, as a transformation continues to occur as each person reads my analysis.

5.5.1.1 Generating Significant Statements and Clusters.

As each interview was read and re-read a number of occasions, I began to merge significant statements in order to generate clusters from the data. As this process

undertaken with each interview, a file name was given to a number of significant statements that were similar. This formed the basis of developing clusters or categories from the process of analysis. The categories were then merged to form five themes.

5.5.1.2 Creating Memos.

Each free node was given a title to identify my ideas about the particular data contained in that node. The NUD*IST system allowed me to add a number of memos to each of the free nodes. These memos consisted of my ideas about the data, reflections about the data, answers to the questions I posed of the data and information from my field-notes and observation sessions.

5.6 Establishing Trustworthiness and Rigor in the Study.

Much discussion and debate has been levelled at the lack of validity and reliability in qualitative research findings (Hinds, Scandrett-Hibdeb and McAuley 1990; Porter 1993; Beck 1994; Hogston 1995). The criterion used in this study was that as proposed by Lincoln and Guba (1985: 290). These authors suggest that the researcher poses four questions regarding the trustworthiness of a qualitative study. These are:

1. Truth-Value: How can one establish confidence in the "truth" of the findings of a particular inquiry for the subjects (respondents) with which and the context in which the inquiry was carried out?
2. Applicability: How can one determine the extent to which the findings of a particular inquiry have applicability in other contexts with other subjects (respondents)?
3. Consistency: How can one determine whether the findings of an inquiry would be repeated if the inquiry were replicated with the same (or similar) subjects (respondents) in the same (or similar) context?
4. Neutrality: How can one establish the degree to which the findings of an inquiry are determined by the subjects (respondents) and conditions of the inquiry and not by the biases, motivations, interests, or perspectives of the inquirer?

I used the above guidelines in an attempt to maintain rigor throughout the study and data collection. Lincoln and Guba (1985) make a number of suggestions in order to

maintain trustworthiness in the study. The application of the above guidelines will be discussed in an attempt to demonstrate my efforts to maintain rigor throughout the study.

5.6.1 Truth-Value.

There are three criteria that are recommended by Lincoln and Guba (1985) to maintain truth-value. These include: prolonged engagement, persistent observation and member checking.

5.6.1.1 Prolonged engagement.

The aim of prolonged engagement with the researcher and research sites is to promote the development of trust between the researcher and the respondents. It requires spending sufficient time to learn about the culture of the organisation and observe for distortions within the site and the researcher (Lincoln and Guba 1985). It also allows the researcher to detect and take into consideration any distortions that may have influenced the data. Prolonged engagement has the added advantage of developing trust by reducing the threat to respondents posed by the presence of the researcher which could influence the truth-value of the research findings (Sandelowski 1986).

I was involved in prolonged engagement in each of the research sites throughout the study, spending a total of two hundred and ninety seven hours in observation of practice. Throughout that time, I was able to establish knowledge of the culture of the environment. While the total number of hours spent in each site was greater than the hours spent undertaking observation, part of that time was spent at reflection, note taking and getting to know the staff and patients in each of the units. I spent a total of sixteen months collecting data between the six sites.

The time spent in each unit varied and overlapped. The overall length of time spent on each unit depended on a number of factors. These included the availability of expert nurses on duty; this was the main deciding factor, as it affected the opportunity to undertake observation sessions and interviews. Furthermore, the availability of

suitable patients of palliative care being present in the unit affected my engagement periods in the site. It was apparent in some sites that the turnover of patients was greater than in others. In some sites, patients were rarely discharged, and the majority of them died shortly after admission. In other sites, there was a more rapid turnover of patients, resulting in a number of them not meeting the inclusion criteria for the study. Accompanying this, a number of patients also declined the invitation to participate in the study.

The number of hours spent in each of the units per day also varied. This ranged from three hours to a full day shift or night shift of twelve hours duration. During this time, I became known to the nurses and patients and developed a rapport with them. Being invited to attend handovers and multidisciplinary team meetings also seemed to enhance my relationship with staff in the units. The long periods in the in-patient units gave me ample opportunity to test information that I gained through observations and interviews with the nurse respondents through analysis of my field notes and interview data.

5.6.1.2 Persistent Observation.

Lincoln and Guba (1985: 304) consider the aim of persistent observation as being to:

“...identify those situations that are most relevant to the problem or issue being pursued and focusing on them in detail”.

In order to do this, I applied ‘tentative labelling’ to issues and events observed during the observation periods. These were recorded in my field notes and stored in the NUD*IST package for ease of access; it also allowed me to link them to individual interviews. In an attempt to condense a large volume of field notes recorded during the observation periods, I scrutinised the findings in order to identify the salient and atypical findings that may have significance to the phenomenon of expertise. Tentative labelling continued throughout the observation collection process in order to capture the real life experiences of expert palliative care nurses. On completion of the process of tentative labelling, I utilised the framework by Miles and Huberman (1994: 52-53) to:

“... capture thoughtful impressions and reflections... and makes them available for further reflection and analysis not only by the field-worker but also by others”.

This consisted of using a “contact summary sheet”, and this formed the basis of condensing a large volume of observation data into a more manageable structure.

According to Miles and Huberman (1994: 52) the data in a contact summary sheet:

“... are essentially phrases or sentences that the field-worker considers to be an answer to the form’s questions after the complete write up of the contact has been reviewed”.

Initially, the contact summary sheets after each observation consisted of four pages; however, I found that I was including data that needed refinement. Such a process of refinement facilitated me in addressing the key issues that emerged from the observation period.

5.6.1.3 Member Checking.

Meadows and Morse (2001) support the notion of member checking as a means of ensuring truth-value of research findings. However, these authors caution against the reliance of “lay validity” of the research findings as such a process may detract from the research findings (Meadows and Morse 2001: 196). I engaged in the process of member checking during and at the end of interviews in order to clarify any ambiguities that may have arisen in the process of the interview; Lincoln and Guba (1985) state that this is a major way of demonstrating truth-value of the findings. A copy of my analysis of the study findings was sent to each of the nurse respondents in order for them “...to provide an assessment of the overall adequacy in addition to confirming individual data points” (Lincoln and Guba 1985: 314). Respondents were invited to review the findings and the following questions suggested by Holloway and Wheeler (1996: 166) and Begley (1997) were posed:

1. Do you recognise your experiences as an expert palliative care nurse in the above descriptions?
2. Do they have meaning for you?
3. Does it have meaning for expertise? For nursing?

4. What aspects of your experience, if any, have I omitted?
5. What aspects of your experience have I exaggerated?

Sandelowski (1993) discusses the value of returning to members who have participated in the research study and argues that people seek their own viewpoint as opposed to the consensus of opinion. She suggests that the study findings ought to be presented to groups of individuals in similar contextual situations. In keeping with Sandelowski's (1993) recommendations, the findings of this study have been presented to audiences in Ireland, the United Kingdom, Australia and New Zealand. The findings within each of the settings created much discussion and were found to be credible.

Furthermore, Munhall (1994: 189) refers to assessing affirmation of participants as one of the criteria for establishing rigor in qualitative research. Affirmation is confirmed through observing "nods" of agreement when participants hear your interpretation or read your interpretation. During my presentations of the research findings at the six research sites where the participants were present, all of those present began to "nod" as they heard the findings and reflected on the full meaning for them of the study findings. Member checking with the patients did not occur as all of the respondents died within a short period of participating in the study.

Each participant was sent a copy of my analysis of the data. A total of thirty-two nurse participants (80%) returned comments to me regarding my analysis. Overall, the participants generally agreed with my analysis. For some of these participants, the findings had a greater meaning and significance for them than for others. The responses of all those that returned their comments to me are presented in Appendix 18.

5.6.2 Applicability.

Applicability in qualitative studies mirrors the criterion of external validity, the degree to which the study findings may be generalized (Sandelowski 1986). Generalisability is reflected by the process of transferability, that is, the extent to which findings from the study may be transferred to other similar settings or groups (Polit and Hungler 1999). According to Leininger (1994: 106) transferability:

“...refers to whether particular findings ...can be transferred to another similar context...and still preserve the particularized meanings, interpretations, and inferences for the completed study”.

The criterion of transferability in qualitative research is maintained through the provision of a clear explanation of the experiences being studied in their natural settings. This will be carried out by providing thick descriptions of practice and through salient quotes from the respondents, while remaining sensitive to the protection of confidentiality.

5.6.3 Consistency.

Lincoln and Guba (1985: 298-299) advocate the use of dependability as a criterion for reliability in qualitative research. Through the process of replication, a quantitative study is deemed to be reliable where:

“...two or more repetitions of essentially similar inquiry processes under essentially similar conditions yield essentially similar findings, the reliability of the inquiry is indisputably established”.

In an attempt to demonstrate dependability throughout this study, I used a decision trail so that there is a clear description of the method, analysis and findings in order that these are clearly auditable to those who read the research report. The inclusion of raw data, data reduction and analysis techniques, data reconstruction synthesis and process notes will meet the criterion of dependability. These are interspersed throughout my presentation of findings.

5.6.4 Neutrality.

Neutrality refers to the determination of the findings from the respondents as opposed to the biases of the researcher. The concern of ensuring neutrality rests with the characteristics of the data as opposed to the characteristics of the researcher. However, in qualitative research there is no detached, objective position from which human beings can be studied, as we are all human beings. The challenge to the hermeneutic researcher is to ensure the integrity of the text as being representative of the interpreted phenomenon. Guba and Lincoln (1985) consider that neutrality is established when auditability, truth-value, and applicability are evident. The frequent use of exemplars from the nurses' interviews in the research report demonstrates neutrality within the analysis and research process. Brink (1991) also encourages the use of triangulation in which multiple methods are used, in an attempt to increase the rigor of qualitative research. In this case, both observation and interview methods were used in an attempt to articulate the composite of expert palliative nursing practice.

5.6.5 Conclusion.

This chapter has presented an account of the approach taken to undertake data analysis. The philosophies of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996) were used to guide the process of analysis. I generated a number of questions from their writings in an attempt to remain true to their philosophies. These questions were posed of the respondents' interview data and observation data in order to analyse the data hermeneutically. NUD*IST data management package was used to facilitate management of the data, so that all data were easily accessible. Lincoln and Guba's (1985) criterion was used to maintain trustworthiness of the data. The next chapter presents a section of the findings relating to the nurses' and patients' data that makes explicit the essence of expertise in palliative nursing practice.

SECTION THREE

**PRESENTATION OF FINDINGS
and
DISCUSSION**

CHAPTER SIX

PRESENTATION OF FINDINGS THEME ONE AND THEME TWO

6.1 Introduction.

The spoken information and field notes obtained throughout the course of data collection provided the text for interpretation. In total, forty nurses were interviewed regarding the nature of their expertise in palliative nursing practice. A total of 297 hours of observation of nursing practice was also undertaken in order to illuminate the essence of expertise as expert palliative care nurses practise it. The process of data analysis was described in chapter five. Findings from the study will be presented in the next three chapters.

Analysis of the findings of the study indicates that the composite of expert practice is composed of five themes. These are: “presencing”, “journeying”, “preparing for death”, “comforting in dying” and “family caring”. Each theme is comprised of a number of categories. These will be presented in an attempt to make explicit the composite of expertise practised by expert palliative care nurses in in-patient hospice units in the Republic of Ireland. Part of the findings from the study, encompassing the first two themes, will be presented in this chapter.

6.2 Interpretive Decision-Making.

A text may have multiple interpretations; it is often necessary for interpreters to make choices about challenging interpretations. In the final analysis, interpretive decisions are accounted for by the meanings developed from the text. While the interpretations presented here are my interpretations, I acknowledge that readers of this thesis may apply an alternative interpretation to the excerpts presented. Decisions made regarding my choices of interpretation were influenced by my pre-understandings and fore-structures, together with the writings of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1979, 1989, 1996).

THEME ONE: PRESENCING.

6.3 “Presencing”: An Interpretation.

“Presencing” refers to openness, an awareness to be inspired by other people; in this instance, the nurse, patients and patients’ families. It embraces a sense of understanding that comes from the nurses’ internal frame of reference that has developed through knowledge and experience in delivering palliative care nursing. Presencing permits the uniqueness of the individual to cultivate a reciprocal relationship between the nurse, patient and patient’s family. This facilitates the creation of a multidimensional form of presencing, one that contributes to an interactive process between the nurse, the patient and the patient’s family. While nurses are physically present to those for whom they are caring, presencing extends beyond a physical state. It encompasses both a tangible and intangible interdependence in interactions that varies in intensity, duration and aspirations. It is influenced by the degree to which the nurse, patient and family members are established within themselves, and the extent to which they are present to themselves, whether in a state of health or ill-health. Mutual conditioning interplays in the presencing relationship where the patient, the nurse and the family are equal providers to the presencing process.

Presencing manifested itself in a number of ways in this study. Presencing as an element of expertise in palliative nursing practice came into my horizon as being comprised of “listening”, “silence”, “touch” and “being there and being with the patient”. My interpretation of presencing, together with interview and observation data, will be presented in an attempt to elucidate the theme “presencing”.

6.3.1 CATEGORY 1: LISTENING.

6.3.1.1 “Listening” as Presencing: An Interpretation

“Listening” refers to the genuineness of the nurse in engaging with patients. It involves actively capturing the variety of meanings from patients’ verbal and non-

verbal actions, in an attempt to read between the lines to hear what is said beneath and beyond the actual words and actions. Capturing meanings forms a central aspect of listening, so that nursing actions are initiated within the nurse-patient mode of presencing. It leads to a response that helps patients and families to achieve a purposeful outcome from their verbal and non-verbal mode of engagement.

6.3.1.2 “Listening” as Presencing: Findings.

Listening was used by several of the respondents as a means of presencing. Nurse respondents sought content themes as they engaged in conversations with patients. This was done in order to make sense of what was being said by the patient. This is evident from the following excerpt:

+Nurse 18: “I listen, I let them talk, and as they’re talking, it’s as if what they’re saying is just going round in my head [outside interference]. I try to process it all, you know, and this needs to be done quickly, sometimes I get it, sometimes I don’t... Yeah, I try then to clarify what it is they’re actually saying ... I need this time to make sure I can understand what it is they are talking about ... It’s getting what they’re saying and understanding it that makes the difference for me in how I listen to them”.+

The above excerpt suggests that the degree of presencing influenced the extent to which the effectiveness of listening was enacted. However, from my observations, it was not always possible for nurses to remain present through listening and physical presence to patients. This was due to the necessity to attend to caring for other patients. This is evident from the observation notes below:

+She (Nurse 18) sat with Mike [pseudonym used] and held his hand. She had the curtains pulled and as he talked, she sat in silence first and let him say what he had to say. When he finished, she paraphrased what he said. He nodded in agreement and then as she spoke again, she was called away. She left Mike and said she would return in a few minutes. She came back a short time later.+

The focus of listening emerged as being more than a mere two-way interaction of receiving and perceiving a message. It encompassed innumerable thoughts, feelings, and emotions from nurses and patients. The excerpt below highlights how one expert attempted to interpret what a patient was saying, merely by listening to what he had to say. Taking the time to be present through listening, in this instance, provided the opportunity for the nurse to capture the meaning of what was being said.

+Nurse 4: “And I think a lot of it is about being patient and trying in some way to understand what is actually happening [motions with hands], and hearing what’s being said [emphasis], even though they are going over and over the same ground. Sometimes ... the image that comes to me is one of a spiral, they go round and they go around, and the odd time you hear, Oh God, I’m going down the same avenue again. ‘T is about being patient’”.+

The tangible elements from the above excerpt are captured in my field notes as follows:

+The curtains were drawn in room five, we went in together. Nurse 4 stood at the end of the bed initially, and then pulled up a chair and sat at the level of John’s [pseudonym used] head. She said nothing initially and then John started telling Nurse 4 how he felt so awful, how there was no relief from the pain, the worry about what was to come, and how he was going to cope with it. He described his feelings of fear and anxieties as being ones that were getting bigger and bigger. Nurse 4 sat listening, nodding to what he was saying and, all the time, she had her hand on his shoulder. She nodded in acknowledgement to what he was saying; she sat and listened to him voicing his concerns. +

Feelings from patients regarding the listening process emerged as affirmation that they were being listened to and being heard. The centrality of hearing what was being said provided patients with security that they were not isolated in their thought processes. Isolation infers more than physical remoteness and separation. For some patient respondents, the nature of their illness lent itself to the possibility of being separated and secluded from communicating with staff and fellow patients. Nurses took cognisance of this possibility, as is suggested from the following excerpt from patient respondent 2, as he grappled with the difficulty in speaking as a result of his illness:

+Patient 2: “Sometimes I feel life is just going so fast, and all kinds of different thoughts come into my mind. And then I start talking to the nurse and I can get all mixed up. ‘T is hard to put law and order on what I’m thinking at times, you know, but I know [emphasis] when I’m talking to her, she knows what I mean, she understands me, even with the way I am with the cancer. Talking is an effort, but worth it when she understands me. I’m not made feel alone then”.+

Being present and listening, for one expert nurse, was sufficient to help a patient to experience an enhanced feeling after telling his story to the nurse. The nurse did not have to offer a solution or advice; all that was required was to sit and listen to him. In the extract below, the nurse highlighted the patient’s use of energy in attempting to

conquer the issue that was on his mind, however, due to her listening and presence, he was able to move on from the issue that was causing him concern.

+Nurse 8: “He was putting a lot [emphasis] of energy into trying to be on top and from once he spoke about it, he felt well. You know, he got it out, he shared it and he actually himself felt better and said that he felt better after being able to say what he had to say, I just sat there and heard or received what he was saying”.+

The extract above provides an insight into the feelings and emotions that patients experience as they are trying to verbalise their feelings and move on from a particular point in their illness. In the context of the above patient, he was feeling disappointed that he had not achieved all that he wanted to in life. He had several long-term and short-term goals that he had not achieved. As a result of this, he felt he was a failure in life. These thoughts were blocking him from seeing his life as having a meaning, a value and a purpose. However, when Nurse 8 sat and listened without offering him any advice, his self-concept improved. He verbalised this and acknowledged that he could now see some positive aspects about his life and the achievements he had made. Without the nurse’s presence and listening, this would not have occurred.

Numerous patient respondents commented on the impact of nurses’ awareness of patients’ difficulties in dealing with their current situations. The following extract provides an insight into how one patient respondent felt about the impact of her illness on her, and described the value of nurses’ response to her current situation when she said:

+Patient 5: “It can be a lonely world when you’re at the stage I’m at. It so good when you know you can have a nurse come to you and help you [pause] come to terms with what’s happening to you. It can be like a death sentence, but I have no choice but to get on with it. The nurse knows this and I think she tries to help me with it. It can be just sitting down and listening to what I have to say, that’s what I want a lot of the time, and I get it from them her without having to ask for it”.+

Providing support to patients as they progressed through their illness encompassed numerous modes of engagement and actions. On occasions, support was overt while at other times, it was present in a covert manner. Overt support strategies included engaging in care activities, such as washing, walking and assistance with feeding.

Covert support took the form of being present to patients without providing physical assistance with activities. One such activity was listening. While nurses were often faced with numerous questions from patients regarding their illness, support was provided without having the solutions to the questions patients asked them. This is evident as one nurse respondent reported:

+Nurse 32: "I think sometimes it's supporting, sometimes I think it's just being there listening, but it's actively listening [emphasis] to what the patient is saying, because a lot of the time we can't answer their questions as in: how long have I got?, what does this mean?, what does that mean for me?, my suffering ... we can't answer those questions but we can be there [emphasis] and I suppose maybe the reply, well, what do you feel [emphasis] does it mean to you".+

Listening provided a forum for responding appropriately to patients' concerns throughout different stages of their illness. For some nurses, the admission assessment provided a basis to build a relationship with a patient, and as one nurse identified, the relationship depended on what she heard and how she interpreted the patient. It appeared as if the transition from home to hospice marks a significant event in the life of the patient. The nurse interpreted this as being a time when what the patient needs is a person to be with them, to be present to them, as described below:

+Nurse 31: "Sometimes when a patient comes in and especially if it's a first for them, 't is as almost they're closing the door on the outside world ... They've left their home world behind, and some know they won't be heading back out to that again... But for me, this is where I try my hardest [emphasis] to be with them... Yes, and as I'm admitting them then, [frowning] that's when I listen really hard [emphasis] to them and try to hear their concerns, their world, their lives".+

The above extract signifies the nurse's concern for patients as they are being admitted. The extent of this concern is dependent on the degree to which the nurse is present with the patient; present in the sense of being able to hear what is being said, and interpreting this within the individual context. The above extract suggests that the foundation for creating a presence is heightened when the expert nurse admits the patient and from that point forward, a relationship begins to develop. From a patient's perspective, the value of such an assessment as a basis for forming a sense of

belonging, of worth and creating a secure environment for patients is evident from the excerpt from patient 9:

+Patient 9: "I'll always remember the day I came in, last Monday it was. 'T was the sad day for me. I felt this was it; the end was coming. I'd soon be dead. As soon as I came in though, the nurse that admitted me explained it all to me ... what the day was like, the food, what to expect... I felt safe straight away ... I'm so happy here now..." +

As palliative care encompasses caring for family members, listening provided the basis for one respondent to be present to the patient and family. The focus of this presencing was that of attempting to obtain a sense of the wider dimensions of the patient's family life and previous psychosocial issues. In this manner, listening provided support for them. Furthermore, it provided the nurse with valuable information in which to plan appropriate nursing interventions and individualised nursing care.

+Nurse 8: "I think like, how do you sense, I think by listening to them (patient and family) you find out more, an awful lot. You don't have to ask them questions really. Let them talk [motions with hands] and between them you can sense what's going on and you begin to realise that there's an awful lot of old issues from years back and I feel in palliative care you can't solve those, you know. You can give support when you listen".[silence] +

Listening as presencing involved one expert nurse being a facilitator for a relative who was having difficulties in dealing with past family issues. Being a facilitator in this instance entailed being there to listen to her, without providing any solutions to her problems or concerns.

+Nurse 10: "Yeah, mmm, yes, what I did was, I suppose first of all through listening I heard a lot. [reflecting]. You know, I was actually a facilitator and this for the individual concerned, the relative, was, it was her way of dealing with the situation like. She had said to me, 'All I want is someone to listen to me, I don't want you to do anything about it, I don't want you to mmm, feel you to, you know, correct any of this for me, I don't want help. The help I want is that you listen to me'. So she identified her needs first and she wanted me there as a listener. Now part of me inside, you know from my professional end of thinking, this person needs help. But listening to her boundaries around that situation, she decided who she needed help from, or if she'd take any help. So I felt, all I could do really was to offer her what was available, I was there and I listened". +

The need to be present for a family member in the above situation highlighted that there was no solution sought. It seemed as if the family member had attempted on a number of occasions to be heard, to be heard by the patient, the doctor, the social worker and the nurses. However, even though she was talking and voicing her concerns, these were not being heard. She did not want a solution; all she wanted to do was to be listened to. In this case, the expert nurse listened to her. The listening process and the interaction between the nurse and family member were intangible, and it opened a network within which the relative was being heard. This was all that was needed. The nurse's presence in the form of listening was the opening the relative needed to deal with her problem.

In summary, listening within the context of expert palliative care nursing has numerous interpretations. It provides nurses with the opportunity to extract content themes from patients and families as they engage in conversations and interactions with them. The complexity of the listening process challenges nurse respondents to interpret what is being said in context specific situations while at the same time taking cognisance of each patient situation. Providing support through listening to patient and family members portrays the centrality of presencing through different stages of patients' illnesses. Listening provides the tools for witnessing reality, for acting as intermediaries and as a means of facilitation with patients and families. It also achieves a level of understanding between the nurse and patients that promotes affirmation of knowledge and of understanding, while generating a new sense of self in the form of narration.

6.3.2 CATEGORY 2: SILENCE.

6.3.2.1 "Silence" as Presencing: An Interpretation.

"Silence" refers to the nurse's ability to be present within the calmness and stillness of himself / herself and to be open to what the patient situation brings to the interaction. It is an inner and outer presence and openness without the verbal sense to accompany the situation. Silence speaks within the realms of the interaction in which it is present and encompasses the ambience of emotive thoughts and feelings. The removal of

speech provides a forum for self-contact with feelings, emotions and sub-conscious moments of life's processes. It is an affirmation that there is no need to tell, to inform, to judge. It is being with your own self through inward and outward listening.

6.3.2.2 "Silence" as Presencing: Findings.

Silence, as a means of presencing, formed an important component of the essence of expertise. It was used as a single entity and in combination with other components of presencing. A number of respondents indicated that silence indicated to patients their presence to patients. One respondent described her use of silence as follows:

+Nurse 39: "There's times and I don't have to say anything, it's not always about what I say. [emphasis] Sometimes it's about what I don't say you know. It's not as if I have to try and fill the silence that's filling the room or the ward, sometimes it's about just being comfortable with letting the silence fill the spaces. Patients have said to me, it's, it's a healthy silence that can often get them over what it is they're trying to get through you know".+

Silence, as described in the above excerpt, creates an atmosphere where tangible and intangible events occur. The tangible presence of silence generates a peacefulness that allows the patient to open up to the nurses or to remain silent and be with the moment. It allows a time of processing thoughts and feelings and while the expert nurses gauged the intensity of silence, they respected the need for its use within the nurse-patient interaction. This is evident from my field notes below:

+Judith [pseudonym used] didn't sleep last night. She had no physical pain and yet she said to the staff nurse on nights she had a lot of inner pain. Nurse 39 was caring for Judith and I was with her for the morning shift. We went in to her room and her curtains were open. Her radio was not playing and there was silence. Nurse 39 sat down beside Judith who was looking out the window at the garden. Judith continued to gaze out the window and breathed quietly. I sat down also. We sat there for ten minutes. No words were spoken. Nurse 39 and I stood up to leave. Judith turned towards us and said, "Thanks for being with me and leaving me in my moment. I feel better for it knowing that you were there for me".+

When I asked the above respondent her reasons for sitting in silence with Judith, she indicated that she did not want to break Judith's connection with her own thought. Nurse 39 considered that being silent signalled her concern for Judith. It appears from

the above extract and the interaction with Judith that the nurse was reading and interpreting the silence. It helped the patient to connect to her own feelings, to acquire a sense of meaning of what was going on for her. Nurse 39 said, "I just know her, I know this is what it means for her". Another respondent used silence as a tool for being present to patients as they experience spiritual pain. This is evident from the following extract:

+Nurse 5: "Sometimes I find that silence, and I, I know this might be hard too, but silence can be a powerful tool [emphasis] to help someone to open up to you and talk about the pain, and I mean the spiritual pain they could be having. It's almost as if it kind of soothes the pain, you know, softens the severity of it without having to talk about it. That in itself is enough sometimes to let the patient know you care and you're there for them".+

While spiritual pain has a variety of meanings, the use of silence as a means of addressing it does not infer that the staff member is ignoring its presence. Rather, silence in this instance, in an intangible way, allowed the patient to know that the pain was being acknowledged; as described above, "it ... soothes the pain". The expert acknowledges that this approach to addressing spiritual pain would not be effective for all patients, and she makes that judgement in individual cases.

Silence was a skill used for being present to a total stranger. While staff cared for patients, the degree to which they knew the patients varied. In some cases, depending on how long the patients had been in the unit, staff considered that they did not know the patient very well. Despite this, staff used silence as a means of being present to them, as this nurse describes:

+Nurse 4: "The silence, I suppose, it depends on how comfortable I am with a silence in my own level, [speaks slowly] in order to be able to sit in silence with someone, a total stranger who is grappling for life. Mmm, it's not about filling the time, it's, it's about trying to ascertain if the individual patient is comfortable with, with the encounter as such. It's very hard to describe the silence; it's just something you know. It's the atmosphere, it's the environment, and it's the relationship with the individual. It's about being in touch with my own powerlessness within the arena of care."+

Silence, as described by the expert in the above excerpt appears to have a focus. It involves assessing the patient and the extent to which the patient is comfortable with

the silence encounter. A number of respondents described silence as an element of the total patient interaction, as encompassing the environment, the relationship and the individual's own powerlessness. It appears that using silence when powerlessness exists either allows the powerlessness to subside or alternatively, acknowledges that the staff member is comfortable with being powerless within the situation.

Silence as a form of presencing was considered by patients as being an important aspect of their being in the hospice. In part, the use of silence was dictated by the severity of patients' illnesses, however, silence was frequently seen as an opportunity for patients to speak about multiple issues.

+Patient 8: "I like to talk, but I like to say nothing as well, when that suits me. To me, sitting with the nurse in a quiet few minutes can help me a lot. It's hard to explain it ... but saying nothing can be also saying a lot". +

When I asked Patient 8 to explain what he meant when he said the above he continued:

+Patient 8: "There's a kind of peace in not having to be talking all the time. Do you know, like, [laughs], silence in itself can speak loads [pause]. It can let the nurses know how I am, and they're never far wrong in what they take from me not talking. Another thing is you're not forced to be doing the talking all the time. [pause] A nurse could come in here and sit on the bed or that chair and we just sit here, having nothing to say. And like, we don't feel we have to talk, no, we can just sit here". +

While the above excerpt highlights the value of silence from a patient's perspective, it also promotes a sensation of security and companionship. While the dying process brings with it several unknown factors, the use of silence for one respondent provided her the assurance that she was not alone in facing her illness. Silence formed an important component of this presencing as one respondent commented:

+Patient 9: "I'm not alone in this at all, I know I'm not. And 'tis knowing they're there for me, that's what carries me along, that's what's getting me through all of this, you know, without them, I don't think I could go on as I am, they just bring me along and a big part of it is the way they get it across without saying it. Like, they can be here with you, they're in and out and when they sit with you without talking, that's often when you can get a lot from them". +

The comments from patient 9 above suggest that the use of silence is not considered in a threatening manner, but rather as a means of support. The patient's awareness of silence as a means of maintaining contact and interpreting this contact in such a manner conveys the power that is inherent within a silent interaction.

In summary, silence was used by a number of respondents as a means of presence for patients. The focus of silence was one that inferred the nurses' presences to patients throughout their illness. It provided the arena that allowed patients to speak if they wished and in doing so, it inferred a degree of control for patients. It created opportunities to develop and enhance the nurse-patient relationship through recognising patients' concerns while creating the atmosphere for patients to generate contact with their feelings, emotions and concerns.

6.3.3 CATEGORY 3: TOUCH.

6.3.3.1 "Touch as Presencing": An Interpretation.

Touch refers to a sensitive attachment and a connection with a person. It is an instrument to indicate understanding, togetherness and unity. Touch provides a medium through which a form of protection is offered, a protection from often unknown sources. It is an action performed with feelings, wholeness and in congruence with thoughts, emotions and behaviours. It generates a connection that varies in duration and intensity while bridging the life world of the person performing the touch with the person being touched. Touch infers sincerity and a willingness to be present within a safe environment.

6.3.3.2 "Touch as Presencing": Findings.

Touch as a means of being present with patients emerged as a common attribute of expertise. While all of the experts used touch with patients, it appeared to have a different focus as part of the nurse-patient interaction. A number of nurse respondents considered touch to be a means of creating a bond with patients and their families. Touch is considered in the context of practice as being more than instrumental touch,

but also as a protector and a form of inclusion for the patient. This is evident from Nurse 12 in the context of her nursing practice as she described the use of touch as an element of her expertise.

+Nurse 12: "I use touch all of the time. I think it is very important, because patients very often are touched if they have to be moved, or if something physical has to be done to them. So to go and touch someone, it breaks the social isolation straight away. So very often there's a ward round going on, I'll stay behind and put a supporting arm around them afterwards. It just lets them know that I'm there for them".+

The following extract from my field notes confirms that this respondent acted as she indicated above:

+Field Notes: With Nurse 12 this morning. Doctors' ward round started at 10.30 a.m. Went on ward round. Visited her five patients. Doctor sat with Lucy [pseudonym used] and discussed her illness with her. Lucy was tearful. Team moved on to next patient. Nurse 12 stayed behind and sat with Lucy for five minutes. Pulled curtain around her. Sat silently with her. Put her arm around her and stayed for about three minutes, until patient was all right.+

It appears that, in the above instance, touch was used as a form of protection for the patient. It also inferred that the nurse was present to her so the patient would not be alone to deal with whatever issues were discussed during the ward round. It demonstrated a high degree of sensitivity on the part of the nurse towards the patient and how she may be feeling after talking with the consultant regarding her illness.

One respondent considered that touch as a presence provided a sense of space for the patient. The purpose of space was to allow the patient's problem to be released into an open arena - a wider space so that it could be then dealt with. As one respondent said:

+Nurse 30: "The barriers [makes inverted commas] can be there, and they are there a lot of the time. It's as if I want to get through to them, and when the talking isn't getting me through, well I use touch quite a lot... it's not just a pat on the shoulder, it's deeper than that. And I like to use it as if it's helping them to leave go of some of their fears, some worry they might have ... and by using touch on them, I think it helps them to open up more".+

Touch, as described by the expert above, appears to act as a type of release for the patient. This release can be considered to be a form of assurance, an assertion that the nurse is trying in some way to understand what is going on for the patient and to

overcome some barriers to this process. It provides a sense of sharing, a sharing of the patient's pain and perhaps the patient's worries and anxieties. Patient data supports the above nurse respondent's statement:

+Patient 1: "I love touch. It helps me loads. I can feel relief and secure when the nurse touches me. It's a special time when she sits and we touch ... I value these times ... I feel less pain and more at ease in myself".+

Touch, as a means of presencing, seems to create a sense of timelessness for some patients. Timelessness as described by one respondent, indicates how her use of touch with one patient helped him to feel more content within himself. When approached by the respondent, who used touch to connect with him, it was viewed as being timeless, as is evident from the excerpt below.

+Nurse 17: "I remember last week, I was on nights and Frank [pseudonym used] wasn't able to sleep ... I went down to him, and got him to tell me what it was that was bothering him. There were several things on his mind and as he told me about them, I just held his hand. At first, it was a gentle touch, but the way we connected began to deepen, [moving towards me] it was as if our connection just freed him from what it was on his mind. When he was finished talking, I continued to hold his hand in that way for about half an hour. When he opened his eyes he felt hours had passed. He felt I had held his hand all night. For him, the touch was timeless". [silence]+

It appears that what emerged from the touch with the patient as described above is that he experienced a shift in consciousness from his pain and concerns to one of contentment. It is also possible that the nurse's touch provided him with some freedom from his worries and anxieties. Data obtained from the patient referred to above (patient 11) supports the nurse respondents

+Patient 11: "I feel comfortable with being held and touched. At my stage, I know my time is limited and time can be long. I find it hard to sleep sometimes. The night nurse knows this ... she can read it in me. So she comes down and sits beside the bed and holds my hand. We don't speak; just hold hands. It's enough to make me feel safe, gets rid of the worries I have [pause] ... I value this ... that time just flies ...".+

Touch appears to form a type of attachment that goes beyond the social interaction of touch. However, it appears that creating this attachment is dependent on the extent of the nurse-patient relationship together with the nurse's skill in creating the bond

through touch. There seems to be no “universal” form of attachment through the process of touch, as was evident from the excerpt below:

+Nurse 22. “It’s, it’s giving myself in a way that maybe gives the message to the patient or to the family that yes, I understand, I care, I’m here to listen and support you, you know what I mean. It’s a kind of hard to describe in a way, [pause]‘cause the intensity of the touch and the presence, well, it differs from one to another. But having the awareness that it is important and doing something about it - that makes the difference, the big difference”.+

From my interpretation, three key issues emerged in the above extract, namely, “giving”, “support” and “intensity”. “Giving” conjures the notion of presenting, and in the excerpt above, the giving that appears to have taken place is more than the use of touch. It consists of a wholeness and genuineness on the part of the nurse to give the feeling of presence, a feeling of understanding of the patient’s situation and letting the patient know that she is there for him. “Support” implies there is sustenance in the way the nurse is present to the patient. This sustenance is in the form of the nurse’s presence and the manner in which she connects with the patient. Finally, “intensity” infers the force, the greatness and the strength with which the act of touching is enacted to convey the appropriate message to the patient.

One respondent described using touch as an instrument for creating openness between herself and the patients. This openness consisted of a reciprocal interaction, that of an openness between the patient and the nurse, and the nurse and the patient. The lack of openness infers a sense of control within the person, which in the context of patients receiving palliative nursing may exclude the nurse from being a partner in the patient’s care. A respondent in the following excerpt aptly describes this:

+Nurse 20: “I think, yeah, it’s about being open, [rocking] being in the arena of care ... it’s the touch and when I say touch it’s almost as if it’s inviting them to accept my presence that I’m there for them and with them, to be open. And there’s times you know that the touch speaks loudly to me in the sense that it mmm, it bridges me to them and vice versa.[motions with hands]We open to each other”.+

Admission to the hospice and the onset of the dying process seemed to generate fear within a number of patients. The presence of such fear can result in patients feeling isolated as they are progressing through their illness. It can cause a feeling of

exclusion from interacting with others and focusing on living. One nurse described how she uses touch as a means of presencing with patients who present with this fear as follows:

+Nurse 12: "I know for so many patients I've looked after, well, there's sometimes an obvious fear of what might be going on for them. And having said that, the fear is so awful, so intense, it's like a stumbling block for them. ... it stops them even trying to think what it is that's not letting them even see what the whole picture is. [makes inverted commas] ... and then I use the touch to just let them know, no, you are not totally alone, you've someone here that can offer some small help, and mmm, this might be tiny, but yes, it's important".+

Fear, as a component of the dying process, was not uncommon among the patient respondents. This manifested itself at various stages throughout their time spent in the hospice. The manner in which patients dealt with this differed. For some patients, it was addressed through silence, for others through speaking about it. One respondent commented on how she felt the use of touch helped her to deal with her feelings while in the hospice as follows:

+Patient 3: "It's lonely sometimes here. You might be in your room and not feeling able to get up and go down to the dayroom. Then you have time to think and it can be lonely. But when they see you like that, they come and talk ... [breathless]. That helps, it gets me going again. [pause]... they might hold your hand and ... that makes me feel good again". +

The above excerpt supports the value of touch as a means of presencing to patients as part of the practice of the nurse respondents in this study. While the degree of touch varies in duration and intensity, findings indicate that it creates a bond between the nurses and patients and in doing so, provides a source of security, protection and friendship for patients.

In summary, touch was used by a number of the respondents as an attribute of their expertise in palliative nursing practice. The focus of their touch was to act as a protector for the patient, to create a sense of calmness, to create an openness between the patient and the nurse and finally to reduce isolation during their illness.

6.3.4 CATEGORY 4: “BEING THERE” AND “BEING WITH”.

6.3.4.1 “Being There” and “Being With” as Presencing: An Interpretation.

“Being there” refers to the ability of the nurses to make themselves available to the patient and family in order to provide them with their presence. It presents opportunities to support the patient and family in dealing with situations as they arise. The quality and extent of “being there” is governed by the persona of the nurse and the patient and their ability to connect with the process and product of this presence. “Being with” refers to the nurse’s ability to be present with the patient and family so that a therapeutic engagement is created. It is a presence that that involves more than a “bodily presence”; it incorporates an intangible element that fosters feelings of security and support for patients and families. The degree of therapeutic engagement varies in accordance with the stage of illness in which the patient is present and the ability of the nurse to attach and engage with the patient and family members.

6.3.4.2 “Being There” and “Being With” as Presencing: Findings.

A number of respondents spoke about “being there and “being with” patients and families as a component of their expertise. The process of “being there” and “being with” presented itself in a number of ways. It was more than just being there from a physical perspective: it involved being there in a complete totality of presence. This process required meeting in time and space so that the nurse and patient experienced an absolute presence. The quality of the time shared through “being with” and “being there” was critical in achieving a complete presence. While complete presence may be an ideal towards which to strive, the degree of completeness was governed by the nurses’ and patients’ willingness to share the moments of the interactions as they took place. These moments presented themselves at different stages throughout the nurse-patient interactions. “Being with” and “being there” were characterised by intensity, vigour and possibilities.

“Being with” the patient was considered to be a lifeline to the patient to hold on to living, to hold on to being a human being as death approaches. It seemed as if the bond

lent itself to creating a transformative process, from one of focusing on dying to focusing on living. This is evident in the following excerpt:

+Nurse 36: "I think as a palliative care nurse ... I think being with patients as they live and as they're dying is important. And it's not just enough to be there physically, 't is creating the bond with them as they live, [moving towards me] as in, have life while they're here. I can give them a kind of 'wisdom' about life, [emphasis] you know, reliving memories and that and mmm, then it kind of gives them a new lease of life and mmm, it's as if they, as if they're reliving it all again and it changes them, brings them back to memories; that's precious to them and indeed, sometimes it can bring up sad feelings too".+

From the above excerpt, the focus of the nurse's presence is "being with" patients at this phase of life. The "bond" may be seen as a support for the patient and the nurse's presence in "being with" patients during this phase of their illness lends itself to creating an attachment, mutuality and sharing. The affiliative dimension of the nurse's presence to patients' past experience and present affective state appears to create a link with the patients' past experience and their present health status. As identified by the respondent above, "... 't is creating a bond with them... can give them a wisdom about life".

"Being there" and "being with" patients did not mean nurses needed a solution to the many questions of "the what", "the why" and "the how" of what was ongoing for them. The nurse's presence for the patient was, "being there" as a support for him, and shouldering him through the array of emotions that he was experiencing at this particular time of this illness. One respondent described "being there" for one particular patient as follows:

+Nurse 4: "Recently a man with a tumour in the floor of his mouth and tongue ... he was extremely anxious, and all that was going on for him, he began to just spill out all that was going on for him. And that he was losing control [nods head] and he was even losing the feet from under him 'cause he hadn't got the energy to walk ... and in between the actual conversation, I was trying to find out what the underlying feeling was. But in between times, I wasn't thinking of the next question. I wasn't thinking of what I should do, or what should I say. I had no answer, all I could do was just be there, be there for him"+. [moving away from me]

“Being there” for this particular patient involved an ongoing assessment to read beyond the patient’s actions and what he was saying. His affective state was a part focus of the expert’s attention, with its possible link to role performance, self-affirmation and loss of self-function. However, it is evident from the above excerpt, the nurse’s intervention was primarily one of being present with the patient and assessing his affective state in order to instigate appropriate nursing actions. Data from my field notes highlighted the nurse’s response to this patient:

+Field Notes: Nurse 4 sat with Laurence [pseudonym used] in his room. She held his hand and listened to what he had to say. She allowed him to talk without interrupting him. She paraphrased what he had said and helped him to transform what he had said into her words without losing its meaning. The focus of what he was saying was made clear and towards the end she pulled his ideas and feelings together. Then she confirmed with him that these were the issues that were of concern to him. Three issues emerged and between them, both Nurse 4 and Laurence worked out a strategy to deal with these issues.+

“Being with” patients, for one respondent, appears to express values regarding the nurse-patient relationship; presence emerged as the nurse having compassion for patients.

+Nurse 20: “You’re letting yourself feel other people’s emotions, there are some patients that you’re very fond of, that you gel with, that you feel their pain, you’d love to take away some of their suffering if only you could, you feel hopeless, they’re hopeless and they’re broken hearted, and it hits you, and it hits you hard”.+

The above excerpt highlights the existence of inner harmony in this expert nurse, one that allowed her to feel the emotions of the patients she was caring for. While it was not possible to take away the patient’s suffering, the nurse’s sensitivity of the patient’s situation heightened her awareness of the possible feelings, pain and suffering that patients encounter throughout the dying trajectory. This awareness forms the basis for implementing appropriate nursing interventions.

Possessing sensitivity for patients’ suffering and feeling did not go unnoticed. While there were occasions when the severity of patients’ illness was such that interventions were limited, there were enhanced instances when patients were aware of nurses’ feelings towards their sufferings. This is evident from the following excerpt:

+Patient 5: "I know some of the nurses feel for my pain, they don't have to say it, I just know it. I know they are genuine and feel for me".+

Another respondent articulated similar sentiments when she expressed her helplessness in what she was able to do for the patients. She described her presence as one where she journeys and walks with patients as follows:

+Nurse 8: "Mmm, [pause] for me, I would sum it up really as a mmm, a very short sentence, it's being with the patient, being there for the patient and walking with them with open hands really, because mmm, at that stage, I'd be doing the usual nursing care, but it's not the important thing. OK, it's being there, walking with them, in one sense, I feel very vulnerable myself, because I feel that, you know, there is very little I can really say or do, I'm just there ... I'm a presence. I'd sum it up like that". [silence]+

For another nurse, the "being there" was a source of receiving as opposed to giving, a reciprocal relationship of give and take, the giving of self and the taking of information. It comprised of learning about the situation at hand for the patient; it was a presence that built on the past and formed the basis for the future, a "being there" that valued the "here and now" of what the situation presented to the nurse.

+Nurse 2: "So it's about the now, and in some way, you know for me, you know the client can teach you a lot and you know it's about the value of the now. [reflecting] Sometimes in terms of, maybe our expertise flows from being so present in the present, it flows from the present, you achieve a focused expertise".+

From one patient respondent's perspective, "being with" provided security for the patient. This security came from knowing that the nurse had the capability to address whatever issue the patient presented with. This is evident from the following excerpt:

+Patient 1: "I know she is there for me. She is with me in all of this. I know I can call them at any time and nothing is too much to ask. I know she will do all she can to get me over whatever is happening for me. It's a great security for me".+

In summary, "being there" and "being with" provided patients with an environment where caring centred on the needs that emerged at different stages of their illness. "Being there" and "being with" enhanced the value of the "now" for patients, and strove to meet their needs and address their situations as they arose. Patients acknowledged the value of the interactions that depicted these two processes, which emerged as being different between patients. "Being there" and "being with" were not

isolated elements of nursing practice, they were enacted in conjunction with a variety of the other forms of presencing already presented.

6.4 THEME TWO: JOURNEYING.

6.4.1 Introduction.

“Journeying” emerged as a theme from my data analysis. Data indicates that several patients progressed through a three-stage journey, namely: “returning to the past”, “living in the present” and “looking towards the future”. The duality of journeying within living and dying is one that presents multiple challenges to both patients and their carers. As each journey is unique and personal, there is a limit to the extent in which carers can accompany patients throughout this journeying process. A time emerges when care staff can no longer continue in the patients’ journeying process. Within the context of this study, therapeutic interventions by expert nursing staff facilitated the process whereby patients could revisit past life experiences and explore their relevance to their current situations. The nature of the therapeutic interventions varied, however, they were encompassed within the nurse-patient relationship. These themes will be explored and relevant interview and field note excerpts presented to support my interpretation.

6.4.2 “Journeying”: An Interpretation.

“Journeying” involves a movement, a transformative process where there is an ongoing “to and fro” movement. The symbolic nature of the duality of the living and dying process involves a stage of transition from a state of conscious awareness to a stage of unconsciousness and death. There is a starting point, a portion of the journey that is current, and a finishing point. Journeying challenges the individual to travel with openness in order to address the trials and challenges that living brings with it. As life’s journey is being undertaken, there is an ongoing interchange within the patient; one of revisiting past events, one that grounds them in the present, and the other that anticipates the future. There is no uniformity in the duration spent in each section of the journeying process; this is unique to each patient situation.

6.4.3 CATEGORY 1: RETURNING TO THE PAST.

6.4.3.1 “Returning to the Past” as Journeying: An Interpretation.

“Returning to the past” refers to revisiting past experiences, thoughts and emotions. This journey provides time to stay with moments passed, to dwell and contemplate on them and to value them. It provides the opportunity and challenge to recapture past moments and events so that closure can be brought to unfinished life events. It also allows time to develop an appreciation for what has passed, reflect on life’s events, and create the basis for living in the present.

6.4.3.2 “Returning to the Past” as Journeying: Findings.

A central theme that emerged from the interviews was that of “place” or “present location”; in other words, where the patient was located within their journeying process as a focus point for commencing their journey. It appeared that this formed the basis on which nursing care was centred, a starting point from which the nurse respondents could plan appropriate nursing care. Discovering where the patient was located in their journeying process formed the foundation to facilitate the journeying process. This is evident from the following excerpt:

+Nurse 7: “... when a patient and a family come in, initially, everyone’s trying [emphasis] to discover where people are at, where the family are at, and where the patient is. And within the first few days to the first week, you have a picture of as to whether this family need a lot of input, [speaks slowly] and the patient is going to need a lot of input, at all levels. So putting the pieces of the jigsaw together from the staff nurses, the doctors, from the social workers...you’re discovering where people are at”.+

The above excerpt suggests that the admission assessment formed the centrality from which patient care issues emerged. Additionally, it infers a sense of urgency to find the patient within this journey so that appropriate support may be provided. The above respondent described the process of discovery as “... putting the pieces of the jigsaw together”, suggesting that the discovery process presented many challenges. Those did not always occur in a once off event, but rather involved numerous interactions, conversations and attempts, in order to create “a picture” at the end of the assessment. It appears that this “picture” was one that was unique to each patient situation.

Creating the picture was also dependent on the nurses' ability to discover where the patient was located within their journeying process; this required them to possess openness in their interpretation of what patients were saying to them. Furthermore, it demanded a capacity to tune into the course of patients' individual journeys in order to understand these personal journeying processes. Like creating a jigsaw puzzle, where the pieces are interlinked to each other, the process of discovering the journey was one that involved seeing the evolution of the complete picture, from its early stages of creation to its present form. This lent itself to providing care that was personal, unique and significant to patients. One respondent described this when she said:

+Nurse 22 "You can be there, it's the story when they tell you, that's right, but that makes your caring for them after that so much more enriched, because you know where they've come from and you know what experiences have coloured their lives and what gave meaning to their lives, so it does help you have a, ... a different quality to your caring because of that".+

She went on to describe the quality of that caring as follows:

+Nurse 22: "It's like, how would you explain it? [looking down towards ground] It's like when you are climbing a hill [motions with hands] and you get to the top of the hill and you see the view, you know that feeling that, maybe it was the struggle to get there; but you get up and say: "oh yeah, it was well worth it, this is it, yes", [emphasis] and you get glimpses of that at times. And other times you might climb the hill and you might never get the glimpse. You might see nothing. But it's a not giving up with the trying and to keep at it. I think that's where we let people down when we get disheartened and we stop trying. I think that's when people must feel the most abandoned but it's awful hard to do that for every single person that you meet".+ [frowning]

While the above excerpt takes cognisance of the struggle and the ambivalence associated with the journeying process, some respondents acknowledged the difficulty in locating patients in their journey at all. This appears to be linked to patients' willingness to allow nurses the opportunity to engage with them as they attempt to locate patients in their journey. Data suggests that the majority of patients on admission returned to the past and recommenced their trajectory at an earlier point of their illness. This was evident from the nursing admission assessment where patients' histories of illness were discussed. A number of nurses indicated that there seemed to be a tendency to remain with the past at a time when their illness was at a less

advanced stage. For others, there was a tendency to return to the past at several stages during their admission to the hospice; unresolved issues were addressed and joyous occasions were also revisited. However, patients' abilities to engage in this process appeared to be governed by their willingness to open to the awareness of their current situations. Not all patients cared for in the research sites participated in this process. One respondent described her encounter with a patient who was reluctant to allow her to engage with her as part of locating her in her journey. She described this as follows:

+Nurse 32: "Every day you go in and you sit and you're sitting with her, is there anything you can do?; no; would you like me to do anything?; no; would you like me to sit with you for a while?; no; and that's very hard [emphasis]..." +

In contrast however, one patient respondent described the impact of her admission to the hospice and the care provided by a number of expert nurses had on her as follows:

+Patient 4: "The past... 't was as if it didn't matter. 'T was gone, and for me, all the happy times went with it, like the friends and neighbours calling in, [pause] 't was as if it was all a blur or a dream, and when I think of it, it all went around the time I got the word I wasn't going to get better, [breathless] that I had the cancer back again. Yeah, that's when it all went. And it wasn't until I came here and 't was as if the whole past was brought back to me again. It was all rekindled and yeah, then I could appreciate the good times I had. She [the nurse] just brought it all back to me". +

The above extract highlights the importance of the past for Patient 4, a past that she felt she had lost when she was given the diagnosis that her cancer had returned. When asked to tell me how she was brought back to her past, she elaborated:

+Patient 4: "T was the day after I came in and she sat down there (pointing to the chair) and she asked me to tell her about how I was managing at home. Now for me, I kinda had that out of my head, 'cause I thought it would upset me like. But she made me realise as I was talking I had a very valuable past, a very valuable past indeed [pause]... Well, it done me so much good, [breathless], I felt I relived the last few years of my life again, all through talking to her, do you know? That was better than any medicine she could have given me". + [laughs]

Helping patients to return to their past appeared to be a process of enlightenment, of challenge and also appreciation of the value of life. While the process of returning to the past was considered to be painful for some patients, it was also a time of joy and

fulfilment for others. Additionally, it seemed to provide the freedom and the authority to move on in their living. The nurse respondents demonstrated an awareness of the value of facilitating and participating in such a process. This is evident from the following:

+Nurse 40: "It's as if when reality dawns the past lights up, the good times, tasks completed, chores unfinished, the regrets, yes, it's almost like a fence that keeps them in the past. Maybe it's just reality [emphasis], maybe it's just life. But with that, it gives them a chance to go back to it, to bring it to the present, to stay with it for a while; after all, it has been a part of their life ... I read between the lines and know when to talk to them about where they are in the past ... but it's not everyone that will let you bring them back or bring them forward".+ [speaks slowly]

The above extract indicates the nurse's awareness of a "past self", an entire self that remained in the past and had not moved on. The focus of "the self" in the above situation seemed to be on the individual's role in society, the achievements and the regrets of life. This expert read the signals, looked for the cues that the patient was giving and interpreted them in the light of her knowledge of the patient.

A number of respondents remembered the names and incidents associated with patients who were in their care and had since died. For some of these, the nurses, too, had returned to the past, returned to the memories of caring for patients throughout their illnesses. For this expert, her description of being with a patient as she returned to the past describes how she (the nurse) attempted to address the past so as to bring her (the patient) to the present.

+Nurse 33: "I remember Mary [pseudonym used] so well [emphasis]. Yeah, it was about three months ago, and it was like her past was her anchor, and yet, she had a life that she lived to the full. But there was the sadness about her ... and on nights, we talked, maybe for two or three hours about it and I asked her if she would like to do a collage. I said to her it might be good for her to think of her life in that way. We worked on it for my nights on. And when I came back the following week, it wasn't finished; [reflecting] there was a space, a blank space in the middle. [motions with hands] I couldn't help feeling that she was stalling ... why she was stalling, I didn't know. [speaks slowly] We finished it on Friday evening after tea. She died on Saturday morning. She was moving from her past to the present".+ [reflecting]

The above excerpt suggests that there was a need to move on from the past and to live in the present for this patient. The respondent seemed to be aware of this need within the patient and attempted a number of strategies to help the patient to move on from living in the past. She understood from her interaction with the patient and her interpretation of a number of conversations that she had with her that the patient was grounded in the past and was unable to move forward in her living. When I asked the nurse respondent how she knew, she replied:

+Nurse 33: "I've seen it in a lot of patients before, they want to get on with living and it's the way you read the signals, the tone of voice, [pause] what's not said, a kind of behaviour [emphasis] that tells you she's stuck. There's no bag of rules that tells you this, you just know it. I've seen it in different ways so often, it all adds up".+

While the respondent in the above extract described her actions in facilitating a patient to return to the past through the use of a collage, Patient 6 described the impact of a return visit to his home; a returning to his past generated the opportunity for him to die happy as a result of this visit. He described this to me as follows:

+Patient 6: "I'm lying here thinking. I know I'm going to die, and I know that [emphasis] well. But my wish was to get out home even for one more look at the place. I see how they're [the nurses] all so busy. But anyway, Nurse 9 organised the minibus to bring me out yesterday, so I got another last look at the place before I go. She knew it would mean a lot to me, we hadn't talked about it, I'm forever grateful to her; I'll never forget it for her. I'll die happy now". +

Data from my field notes supplemented the actions that took place to organise the visit home for Patient 6.

Notes entry: +Nurse 9 is looking after Patient 6 and three other patients. They are all high dependency patients today. At report she discussed the notion of arranging for Patient 6 to go out home for a home visit. The shift co-ordinator considered this would not be possible, because of his immobility and the difficulty in getting a wheelchair into his house. Nurse 9 said that she was not satisfied with this; it wasn't reason enough for him not to go out. She proposed to arrange for a volunteer to go with Patient 6 to bring him in the mini-bus and to get a care assistant to go with him for two hours. Within half an hour it was all arranged. She said she would tell Patient 6 later, as she knew he would be thrilled to get to out, to go back to where he had spent so many years of his life. +

One respondent considered that powerlessness in patients' current status seemed to heighten the need to return to the past as a means of overcoming their perceived and actual change of health status. It appeared as if patients' perceptions of meaningful control measures over their lives and progressive illness status were limited. However, returning to their past provided the opportunity to improve their self-perception regarding their function and purpose in life. This is evident from the following excerpt:

+Nurse 1: "Some patients are so helpless. [emphasis] It's as if they lose all their views and belief in themselves from once they know they're coming in here, probably to die. 'T is as if when they're no longer a part of living ... there's no point in going on. So when I read those signals, I do my best to try and put emphasis on the good, [emphasis] the good in their present, in their past, and concentrate for a while on that with them". +

One patient respondent described how his views of his shortcomings in life were overcome through his interaction with one of the nurse respondents. While the process they engaged in to address these shortcomings consisted of talking and listening, the outcome of the interaction provided the opportunity of the patient to revisit his feelings and move on from them. This is evident in the following excerpt:

+Patient 11: "I was always a hard worker, [pause] I always tried to be honest and do good. But coming up to the time I got sick, I had this awful guilt [emphasis] I should be doing more, I could be better and that stayed with me. It often came between me and my sleep. [pause] I talked about it to her [nurse] a good few times. Going over it all, it's better now, I'm not thinking like that any more. 'T isn't bothering me now, I'm gone on from it". +

It appears that the nurse interpreted this patient situation as one where she made time for the patient and responded to what was beneath that which was being said. It inferred a supportive nurse-patient relation that focused on positive self-worth; this allowed the patient to overcome his sense of powerlessness and lowered self-perception.

For some patients, returning to the past reawakened unpleasant memories. While nurses were aware of this possibility, a number of them felt that the benefits of revisiting the past outweighed the possible sadness that it may cause. They interpreted

the patient's current situation and sensed that exploring past experiences would create a therapeutic opportunity for the patient to deal with unresolved issues. This is evident from the following extract:

+Nurse 17: "It's like therapy, but it can be painful. The past can bring up a lot of things, and some might not be so nice. But all in all, the end result lights up a new way of seeing things for the patient. It's often finishing unfinished business and until that's done, they can't move on. And it could be a personal issue, a family issue, or money. It really could be anything".+ [swaying in chair]

In summary, returning to the past was a course of action that was facilitated by expert nurses as they engaged in caring for patients. The process involved making an assessment of the patient's need to undertake this activity and in doing so, it assisted them in moving on in their illness, dealing with unresolved issues in the past or it was a link between the patient's past and their present.

6.4.4 CATEGORY 2: LIVING IN THE PRESENT.

6.4.4.1 "Living in the Present" as Journeying: An Interpretation.

"Living in the present" refers to the ability to be aware of current activities, thoughts, feelings and emotions and to savour the moment for whatever it brings to the situation. It is an acceptance of the persons' "being"; a contentment or a searching for meaning in each individual situation. While this awareness is overt for some individuals, the covert elements of the situation influence the process of living in the present for individual patients. Living in the present presents the reality of the situation for patients. This reality may not always be one of relief from pain, loss, anxiety or ill health. Rather, it highlights the reality of many patients' situations, which invariably means acknowledging a deterioration in their condition and adapting their activities to adjust to their changing situations. On the other hand, living in the present can provide a sense of security for the patient where they can stay with the situation and not move on to the immediate future.

6.4.4.2 “Living in the Present” as Journeying: Findings.

For some, living in the present was a time of acknowledging their awareness of the full picture of their reality. Some respondents felt patients differed in the way they addressed the present. For some patients, it was a stalling point, for others it was a time of movement. The following excerpt highlights how a respondent interpreted the process of living in the present and the actions she took to facilitate this in the patient:

+Nurse 14: “The pain, the anger, the frustrations, [emphasis] the joy, all the emotions swell up yeah, and there’s sometimes a lot more too. It shows us really how things are. I describe it like for some it’s like as if the light is green and they can move on, for some it’s red and stays on red for a long time. And I see that as if the patient is saying, no, I’m not ready, I’m staying with the fear, anger, joy, contentment, staying with life. I don’t force them to move on, I let them stay with it”.+

When asked to describe the signals that this respondent saw as indicating that the patient was living in the present, she commented:

+ Nurse 14: “There’s different ones for different people. There’s no list [emphasis] of them, I just know. I sense it from the patient that this is what it is for them. That’s all I can do, ... there’s no recipe or list. I’ve got to know what is the right way to do it”.+

The process of living in the present presented some difficulties to patients. This was in part influenced by the degree of pain patients experienced, their acceptance of their illness, the onset and duration of their illness and the extent to which patients were supported in dealing with their current situations. The reality of what was happening to patients frequently came to light when they were admitted to the hospice for continuing care and management. While some of the respondents expressed concerns about being admitted to the hospice, others realised the value of this admission to them. The excerpt below supports the nurses’ actions in helping patients live in the present.

+Patient 11: “I was in shock when I came in here first. Like, you know, I know a hospice is where people come to die, that’s what we grew up with and suddenly here am I in the hospice. But after getting over the first shock of it all, well, I couldn’t do it on my own. I was made feel that it wasn’t the end. There was more to it than just dying. They made me value my life, and mmm, you know, let dying be a piece of it. I realised it wasn’t going to go away”.+

The above excerpt highlights this respondent's perception of the nature of support he received from the nurses in helping deal with his situation. While he acknowledged he was dying, nursing actions highlighted the value of his life and his current state of living.

A number of patient respondents seemed to have an awareness that their medical condition was one that was not improving. While acknowledging this however, they valued the actions of the nurse respondents as a means of helping them to live in the present. One respondent described this as follows:

+Patient 2: "There's times and 't is hard to talk about it [dying], and that might be just [emphasis] for me. But when she comes and it might just be when she's washing me or helping me to cut up the dinner, she might bring up the subject, maybe asking how am I, and before I know where we are, there I am talking about what's going on, like, what's happening to me. I don't know how to put it, but 't is like she just knows the right time to talk to me about it".+

He continued to highlight that making the reality of the present known was not carried out in such a way to generate hope that the person would be cured. Another respondent supported this when she said:

+Patient 4: "I know I won't get cured of this [illness], there's no hope of that unless there's a miracle cure, but she gives me a bit of hope all the same. Now, 'tis not the hope that I'll be cured, she gives me the hope that things will be easier to face, I know there's no cure ... I usually feel so much better after we've talked and then I know the true story for me".+

General hospitals acted as referral centres for patients to be admitted to the hospices in all of the research sites. While there were palliative care teams in a number of these hospitals, many of patients required ongoing palliative care management and as a result were transferred to in-patient palliative care units. While this transfer to a hospice may signify a progression in the disease process, it appears that it also allowed patients to receive more time from nursing staff in caring for them. One respondent described how this transition from hospital to hospice care was a time for patients to live in the present, an event that had a greater significance other than that of a progression of their illness.

+Nurse 22: "Some patients are relieved to be here. When they're transferred from the general hospitals, they know the difference [emphasis] in the time we give them that they don't get in the general hospitals, and you can understand that. [pause] They sometimes see it as a new time in their life for them and the way they settle in here, some of them say they want to stay at that".+

While there appeared to be a desire to live in the present for some patients, it also presented anxiety for some patients in the sense of the symptoms they experienced. On the other hand, despite the presence of symptoms, some lived every moment of the present to the full where they valued life, valued the moment. This is evident from the following:

+Nurse 28: "Mmm, I see I suppose for a lot of patients they have a lot of living to be getting on with. [makes inverted commas] You know, I think to live in the moment is at times a bit frightening for some patients, like, you know, the pain, the nausea, and whatever, and you might have someone who lives every second to the full, treasures every moment of it. In a sense like, too, 't is not as if there's denial about their illness, no, 't is just the way they are. It's just them".+

For a number of patients in the hospices, the severity of their illnesses dictated the extent to which they engaged in activities during the day. While these were optional, for those who took part in them found them useful in creating a focus to their day. Instead of sitting by their beds and being inactive, participating in activities created a sense of worth to their living. It seemed as if participating in activities added a new dimension to their lives. This is evident from respondent Patient 10:

+Patient 10: "I used to be waiting for it to happen. I'd lie on in bed and wonder if it would happen today. Then I came in here and there's always something being done. Like, you know, the breakfast, then they'll talk to you, the bath or shower, then there might be music put on. And before you know it, half the day would be gone... they might arrange some music tapes, some painting, you know, even I've started knitting again since I came in. So instead of waiting for it to happen, I'm kept busy now during the day".+

Data from my notes highlights the manner in which two expert nurses arranged a relaxation session for four patients in the afternoon.

+Notes entry: Attended report this afternoon. Nurse 3 and Nurse 4 expressed that they wanted to set up activities for patients who were well enough. They suggested reflexology or showing a film in the day room. Eventually they

decided to organise a relaxation session in the day room. Got music, bean bags and arranged for four patients to take part in it.+

One expert talked about some patient situations where the journeying appeared to be stagnant, there was no movement and in a sense, it was where there was a remaining in the present without being with the present. She described how she interprets this as follows:

+Nurse 7: “I suppose the biggest thing I’d be calling on within myself would be the need to see if this is a totally foreign journey for the patient or that they’ve had a sense of a spiritual journey prior to their sickness, but in their sickness, have been ... thrown off their journey or off track, so it’s the need to see where the patient is actually coming from, from overall in their whole, in their overall life’s journey. [outside interference] Because if it, if it’s somebody who’s never really given much thought to, mmm, that kind of spiritual journey, or their own inner journey and that they’ve always been, I suppose, functioned, at a superficial level in life, then my approach would be very different. ‘T would be more, say, trying to see do they see a meaning in life just beyond the superficial side of things. So it’s trying to make an assessment on the overall journey of the patient really’.+

Living in the present as described in the excerpt above indicates a practice of finding meaning in life at a particular part of their illness. While the respondent acknowledges that not all patients may have reflected much on their journey, it seems an integral component of the work of expert nurses to assess the journeying process of the patients in their care and to locate the patients within that journey. However, as is evident from the excerpts presented, this process involves knowledge of self, and utilising a range of skills that provide the nurse with the opportunity to gauge the location of the person within their personal journey.

In summary, expert palliative nurses considered it was an important part of their role to be aware of patients living in the present so that they could modify their nursing actions according to this stage of their journeying process. It required that the nurses possessed the knowledge and the skills to be in a position to become aware of this phase of patients’ journeys. The role of the expert palliative care nurses in facilitating the living in the present encompassed a range of skills that assisted patients in their care to continue with living in the present and to move towards the future.

6.4.5 Category 3: LOOKING TO THE FUTURE.

6.4.5.1 “Looking Towards the Future” as Journeying: An Interpretation.

“Looking towards the future” refers to the ability to look beyond the here and now, to view the future as one that encompasses every moment of living. The duality of living and dying challenges the individual to move onwards and take in hand the reality of life. It includes a vision of possible challenges and rewards that the process of living might bring with it. Furthermore, the inevitability of death is acknowledged within the individual, but there is still a focus in living as well as an awareness of dying.

6.4.5.2 “Looking Towards the Future” as Journeying: Findings.

A final aspect of journeying that appeared to encompass the nature of expert nursing practice was caring for patients as they journeyed towards the future. In general, the future for patients receiving palliative care inevitably meant death. Nurses considered that their role in dealing with the onset of the future provided them with many challenges. However, they viewed their role as exploring the future through a number of lenses so that value was placed on considering the future with patients. Being aware of patients’ visions of the future and their journey meant that the nurse respondents could attempt to instigate appropriate nursing interventions to help patients in this part of their journeying. The respondents acknowledged that patients had a variety of ways of looking towards the future; this invariably meant the expert nurses needed to tailor their nursing interventions according to their interpretation of the patients’ actions and feelings. One nurse described how she interpreted the process of moving to the future, using an example of a case where the patient’s inner struggle manifested itself in physical symptoms of pain. These symptoms were relieved when the patient was able to move to the future. She said:

+Nurse 7: “I suppose, in relation to the moving on ... you can actually see [emphasis] a patient who required a lot of break through analgesia, and this actually seems to lessen, [emphasis] even though you haven’t actually increased their maintenance dose, ... you can actually end up reducing [emphasis] analgesia. That for me is one indication in seeing where the patient is a kind of coming more at home with themselves, coming I suppose to terms with their inevitable death. That can be one way of seeing. Another way can

be, that they appear to be, happier within themselves, more at peace [emphasis] within themselves, and you can sometimes see that. And indeed, sometimes a patient will say that to you, too”.+.

The future was not always something that patients looked forward to, as many of them knew the inevitability of their death. While many deaths occurred in each of the research sites, staff invariably made the effort to reduce the impact of a death in the unit on other patients by being open with them and discussing it with them. For some patients it brought tears, particularly if they had developed a rapport with the person who had died. For others, the death of a patient heightened their awareness of their own future. Despite this, many patients appreciated it when nursing staff spoke to them about the occurrence of a death on the ward; it appeared to help patients prepare for their own death as opposed to ignoring the fact that death was approaching:

+ Patient 3: “I’m not looking forward to what might happen. No, I see so many others dying, and I’m afraid it might be like that for me, too. But I know they will do all they can to make it easy for me”. +.

Journeying prompted a number of patients to express their fears and their anger as they moved towards the future; it was important for the experts to recognise that these feelings and emotions were related to the process of journeying. Without this interpretation, there was a possibility that the focus of care may have been inappropriate for patients at that particular time in their illness. It was also necessary for nurses to be aware of patients’ covert awareness of the future so they could deal with that as effectively as the overt indicators of the awareness of the future in patients.

+Patient 8: “I found it so hard to accept. [pause] All I could do was ask why me?, I was so angry. I still am at times; I think it will never fully go away. But it’s a bit easier since I came in here; I’m getting on with it. They help me with it, I couldn’t face that truth that I’ll soon be dead; I couldn’t face it without them [nurses]”.+.

When I asked Patient 8 to share with me what it was the nurses did to help him face the fact that he was dying he said:

+Patient 8: “I sat here and she talked to me. We talked about different things. We even talked about my life. Yesterday we just sat here [pause] and talked about nature out in the garden. I came to realise I have a life, [breathless] and the future is very much a part of me. But I couldn’t see that until yesterday. We

spoke about what tomorrow and the rest of the week might bring for me. [pause] I realised I had a future”.+

The above extract highlights the importance of involving patients in their life, not only for the present but also for their future. While the above interview was carried out on a Thursday and the weekend was just two days away, this was significant in the life of this particular patient. The nurse’s prompt of helping to plan for two days ahead made him appreciate that he had a future, he had a life.

On the other hand, while the future for the patients in the hospice was not long-term, many patients indicated they valued each day, even though it brought pain for some patients; for others, it provided them with a purpose to live, a focus for their living. Patient 5 highlighted how she now had a sense of the future, a future she felt she did not have prior to coming into the hospice when she said:

+Patient 5: “There was no future for me, I came in here to die. But they’ve changed all that, there’s a focus in my life again ... yeah I’m here to live and die. And I have a lot of living to do yet before I die”.+

A number of the experts considered that, for some patients, looking towards the future was a process that needed some acknowledgement, some intervention to help them to move along in their journey. However, without the nurses recognising that the patient needed intervention, it was possible that patients may remain grounded in the present. It was the recognition of “grounding” in the present that was essential for nurses to recognise so that the patient could possibly be facilitated in moving on. One nurse described this movement as a “paradigm shift”, as is evident in the following excerpt:

+Nurse 10: “Sometimes following maybe a certain amount of counselling, people might feel very safe when they come to the hospice and they may feel they can talk about certain issues or whatever. And sometimes it's not until a certain resolution [emphasis] has come that the living with dying begins, because sometimes people will arrive at a point when, maybe they're still in denial but that doesn't necessarily mean that they will always stay in denial too. [reflecting] Do you know, that through some of the processes, through the expose, through the encounter, through whatever medium, something may happen, you know and you see this shift, this paradigm shift, as they call it, do you know, and I have witnessed that in people as well”.+

Being aware of this paradigm shift inevitably influenced how the expert nurses actually dealt with patients' current situations. It indicated a movement, a progression in the journeying process for patients. However, this journeying was not always considered to be "forward" as in looking towards the future. In some cases, it indicated a return once again to some part of their past for a brief period of time before the "moving forward" process began. One respondent described this returning to the past before looking to the future, as follows:

+Nurse 24: "They're going forward for a while and then there's like a turn around, and they go no further. Maybe they even go back a bit to the past, [emphasis] try to deal with it and then move on again. I read the signs in them, and then I help them to move on again".+

One respondent described looking towards the future as consisting of a two-fold future, one the short-term, the other long-term. She described how she tunes into the journeying situation as follows:

+Nurse 36: "Oh when they talk about what's ahead of them, it's like as if there's two futures: the short day to day one and then there's the longer term one. They just know the long term is very long, but for some there's the peace though, the living in dying future that some, some really live in dying and ... they try to [pause] it. It's that peace that's hard to describe that you see in them, then you know they've thought of the future, and you work around that".+

The above excerpt suggests that the expert nurse had the skills to read the signals from patients that indicated they had given some consideration to their future. When I asked the above respondent how she knew when patients had given consideration to the future, she replied:

+Nurse 36: "Some will have very obvious signs, like, they're not talking, there's a sadness about them that wasn't there before. Others will say it straight out, and then that's the opening for me to talk to them about it. Some will close off very fast, others, well, you gauge when enough is enough".+

One respondent described how she has the awareness that there may be a change in some patients when it comes to addressing and acknowledging the future. She is conscious of the possible moving on from the present to the future and what it means for the patient in terms of dealing with their symptoms.

+Nurse 23: "I know like, the future, it's funny; [laughs] for a lot it's as though they nearly blot it out. It's as if it's a sore point, no, it's not an issue they might want to talk about, and then suddenly 't is as if it becomes an issue, yes, there is a future, and I've seen where there's almost a turn about in them when it comes to talking about it. And this is where I come in at times, it's where I might carry them along for a while, just to get them over the low points of where they're at, getting them to move along".+

The above account indicates that while the future may not be one that patients wish to acknowledge or to confront, the expert nurse has the ability to identify those particular times and to provide appropriate interventions to help the patient move from their current position.

In summary, looking towards the future is a period of potential emotional turmoil for patients, especially as the inevitability of death becomes apparent. Moving forward may not be possible without first moving back to the past and acknowledging what has already gone beforehand. Expert palliative care nurses have the ability to read the signs and cues with which they are presented, so that they can identify if the patient is moving on or is grounded in the present or in the past. While there may not always be overt signs that patients are grounded in the present, being aware of the covert signals from patients can result in facilitating the journeying process more effectively.

6.5 Conclusion.

This chapter has presented two themes that describe the essence of expertise in palliative care nursing practice. These themes are "presencing" and "journeying". Presencing consisted of "silence", "touch", "listening", "being there" and "being with". These practices were undertaken in conjunction with each other while specifically focusing on individual patients' needs. The theme "journeying" was comprised of three sub-themes, namely, "returning to the past", "living in the present" and "looking towards the future". The practices that depicted the themes outlined above were carried out within the context of the personhood of the patients they were caring for. The extent to which each element of these practices was undertaken varied across the living-dying trajectory and was dependent on patients' needs. The next

chapter presents the themes “preparing for death” and “comforting in dying” as aspects of the essence of expertise in palliative nursing practice.

CHAPTER SEVEN

PRESENTATION OF FINDINGS THEME THREE AND THEME FOUR

THEME THREE: PREPARING FOR DEATH.

7.1 Introduction.

Dying is an intensely emotional event that results in an array of physical, psychological, social, cultural and spiritual responses from patients. There are physical losses related to bodily functions, and social isolation resulting in feelings of rejection and reduced self worth. At the same time, there is uncertainty about how death will present itself, which invariably results in patients being reluctant to confront the reality of their situations. Patients regularly cling to the possibility that death will not occur in the immediate or short-term future while others appear to deny the approach of death completely. Alternatively, patients may view death as a form of release from their suffering.

The roles of the expert nurses involved in this study encompassed presencing and journeying as described in the previous chapter. These nursing interventions were based on the necessity to provide quality care to patients as their illness progressed. As the aim of palliative care is to affirm life and regard dying as a normal process, preparing patients for death formed a key aspect of the expert nurses' role. From my analysis of data, "preparing for death" and "comforting in dying" emerged as themes that were revealed in the everyday practices of expert palliative care nurses. The categories that compose the theme "preparing for death" are: "confronting the reality of dying" and "preparing for the inevitability of death". The categories that compose the theme "comforting in dying" are "physical caring as comforting in dying", "symptom control as comforting in dying" and "spiritual care as comforting in dying". As it forms a central part of the nurses' caring role, preparing the patient for death was one that encompassed an array of knowledge, skills, attitudes and competencies. Furthermore it was also influenced by the relationship that nurses developed with patients as they cared for them.

This chapter is presented in two sections. Section one presents the theme "preparing for death" while section two presents the theme "comforting in dying". Appropriate

excerpts from nurses' and patients' interviews and field notes will be presented to support my findings.

7.2 THEME THREE: PREPARING FOR DEATH.

This section explores the theme "preparing for death" as an attribute of expertise. As caring for the dying is a nursing role in palliative care, the nurses' supportive role at this particular time is one that eases patients' transition from life to death. Throughout this time, the major focus of the nurse's role is one that takes cognisance of patients' physical, psychological, social, cultural and spiritual needs. Furthermore, it requires nurses to possess a wide range of knowledge and skills to deal with issues that may arise for patients at this particular time. From the analysis of data, the categories that comprised the theme "preparing for death" were "confronting the reality of dying" and "preparing for the inevitability of death".

7.3. "Preparing For Death": An Interpretation.

"Preparing for death" refers to the nurses' ability to provide information and support to patients throughout the dying trajectory. It involves a process of communicating with dying patients in an understanding manner that demonstrates a sense of closeness and confidence to patients and caters for individual responses to dying. It involves nursing interventions that support patients physically, psychologically, socially, culturally and religiously as they approach death. The process of preparation for death is one that requires both cognitive and affective skills to address the challenges that emerge at this time. There is a need for openness in interpreting the signals that patients present that infer they are engaging with this process.

7.3.1 CATEGORY 1: CONFRONTING THE REALITY OF DYING.

7.3.1.1 “Confronting the Reality of Dying” as Preparation for Death: An Interpretation.

“Confronting the reality of dying” refers to the nurses’ ability to help patients to come to terms with their current situation and instigate appropriate interventions throughout this process. It involves helping the patient to find meaning in the reality of their situations and to instigate appropriate interventions to deal with their living with dying. The search for meaning is ongoing and while complete meaning may never be attained, the nurse strives to help patients confront the true reality of their situation. While patients may struggle with the reality of confronting their situations, nursing interventions support patients throughout this struggle in order to assist them in dealing with their situation.

7.3.1.2 “Confronting the Reality of Dying” as Preparing for Death: Findings.

For many patients, confronting the reality of their situation is difficult. It appears from the findings of this study that this process is influenced by patients’ self-awareness, the nurses’ knowledge of the patients and the ability of the nurse to read and interpret the signals patients present to them. A number of expert nurses were aware of the value to patients of confronting the reality of their situation. This awareness grew as their relationship with patients developed, and especially where nurses possessed insight into patients’ thoughts and feelings. It was similar to “surveillance” by the nurses, where they searched for evidence as to the value of helping patients to confront the reality of their situation. This is evident from the following excerpt by one expert nurse:

+Nurse 1: “You get to know the ones [patients] you can help to come to terms with what’s going on. You’re connected to them [emphasis] at a deeper level. You know they want to know the real story, and so often, it’s hearing that call for help, to confirm for them that they’re not going to get better. While getting to know them might be challenging, they get to trust you and they have confidence in you”.+

When I asked the above respondent to describe the connection with the patient, she responded:

+Nurse 1: "It's hard to put words on it. It's one I'd put eight on out of a scale of one to ten. You know, it's deep, it's precious, it's special. Words can't describe it, you just know you've got it with them".+

It appears for the above respondent that preparation for death was influenced by the relationship that had developed with patients, particularly the degree of trust and confidence patients had in the respondent. It was not unusual for respondents to encounter patients who ignored the reality of their situation. Such situations may be considered to be ones in which patients were in denial about their condition. One expert described how patients for whom she cared had not confronted their reality, despite the physical evidence, as she said:

+Nurse 12: "Yeah, well, I mean the 'physical self' [makes inverted commas] I suppose in terms of my patients, it's something they cannot really control, because the cancer is eroding their body. It's just in terms, patients know they are weaker and can deny them, deny that so completely, you know... and in their heads they picture themselves as being well, you know, and being able to do things that are beyond them and they expect more than they are".+

Another respondent in a different site expressed similar views as she described how patients were in denial at various stages of their illness, as follows:

+Nurse 40: "Some patients when they come in, they seem to close their eyes to their illness, to their dying. Some come in for pain management, others come in for terminal care ... A lot of times, it's as if it doesn't exist for them, [pause] their illness. Sometimes it stays like that, for others, it seems to come and go".+

While nurses in the above excerpts acknowledged the role of denial in patients coping with their illness, they interpreted the extent to which patients wanted information regarding their illness. This interpretation came from my field notes when I attended staff handover in one research site as Nurse 40 discussed her views regarding a patient in her care.

+Field Notes: Handover: Nurse 40 talked at length about Mary [pseudonym used] not wanting information or wanting to know anything about her illness. Nurse 40 expressed concern that she felt Mary wanted to ask questions, but she felt Mary was stalling. She felt Mary wanted to know, wanted to look at what's ahead of her. Nurse 40 considered from Mary's body language and from speaking with her that she was reluctant to ask. Nurse 40 interpreted the cues from Mary that she wanted to some information, but didn't want to get the complete story regarding the likely progression of her illness.+

Experts gauged the scope and depth of this awareness so as not to create hopelessness and immobilization in the patients. This required the nurses to balance the extent of information regarding what the patients wanted to know versus what was necessary for them to know. The skill of balancing the degree of information those experts provided to patients in helping them to confront reality was one they developed over a period of time.

+Nurse 22: "I know so many of them want to face reality, face the facts, face life and face death. I can read it in them. I've seen it so often before. My role is... I go with them, I read the signals, interpret them, act on them and I'm guided by them. As I'm going along, I balance the amount [emphasis] of information I give them. I know when enough is enough. I've seen it over the years".+

The above excerpt indicates that there is a need to read and interpret the cues that patients give and to work within the parameters given by patients. Experts read the signals as to when it was appropriate to work with patients in confronting the reality of their situations. Data indicates that the respondents gauged when enough was enough by reading the signals from patients that this point had been reached. Patients were aware of nurses' ability to provide appropriate information at the appropriate times as the following patient data highlights:

+Patient 6: "They know how much of all of this I can take. Sometimes I'm ready to take more than others ... I have to be in the form for it ... and they know when the time is right".+

Another patient supported this by saying:

+Patient 10: "They never yet broke me with what they tell me. They know how much I can take at one time ... they can read me".+

While balancing the amount of information nurses provided to patients to assist them in confronting the reality of the situation, there was an ongoing assessment as to patients' responses to this information. This involved vigilance in observing reactions of the patients as they came to realise the reality of their situation. Detailed staff handovers and regular team meetings provided a forum for nurses to share their views and assess patients' progress during their stay in the hospices.

Seeing the reality of the situation can pose a problem for patients, and this influenced how the nurses approached patients and dealt with their current situations. However, bringing the reality to the forefront for patients can have the effect of shattering or diminishing any hope the patients had regarding their life, and their illness. To avoid this, the nurses staged the process of confronting reality. The staging process was one that demanded connecting to the patient and one where there was an understanding of the patient as a person.

+Nurse 14: “There can be such a stark reality; after all, death so often is not far off. And you know, there’s often the times the reality is staring them [patients] in the face and while I might see it, it’s not heard, not seen, not taken on board by them [patients] ... In my practice, I try to present the reality as it is to them. So it’s giving the message in stages ... It’s a matter of capturing the moment [emphasis] and then beginning to feed them the reality in bits, not all together”.+

Another expert described how she uses a staging process when helping patients confront the reality of their situations as follows:

+Nurse 11: “Pacing the information is important. [moving towards me] I like to think of giving it in layers, and in amounts that I know they can take. And it might happen I’d give it to them as I’m taking them for a walk, or sitting with them at their bedside or in the library. It’s like putting pieces of a jigsaw together, building it bit by bit. And I do it at their pace, so they can only take small bits at a time. I build from where they’re at and sometimes, that can be very limited from where they are”.+

The above excerpt highlights the ability of the expert nurse to create the awareness when patients are not confronting the reality of their situation, while at the same time avoiding the possibility of diminishing patients’ hope. Furthermore, the experts were in a position to provide information in stages that were appropriate for each patient and use patient-appropriate strategies to highlight the nature of their reality. However, there needs to be a degree of desire in the patient to become somewhat aware of their situation, as described by this respondent:

+Nurse 12: “I mean, it’s very hard and if you have somebody...who has expectations beyond the reality, it’s very hard to chip away at their hope. I mean, it is a denial with them, [motions with hands] if that’s the case... however much you dress it up you give them the information, you drop cues and if they want to pick it up you need to explore it with them a little bit. Very often they’ll come around to the fact that yes, I am dying”.+

One respondent described how his desire to know the reality of his situation was met by the expert nurses that cared of him. This is evident from the following excerpt:

+Patient 3: "I'm the kind that likes to know. I was always like that, and 't is no different now. I like to be told straight out what's going on. That way, I won't be in for surprises. And she does that here".+

The layout of the research sites, as described in chapter four, consisted of single rooms, double rooms, four-bedded rooms and open wards. Invariably, patients died in each of these areas. It was not possible for staff to conceal the deaths of patients from other patients in the wards. According to a number of the respondents, seeing other patients die in the room or ward frequently acted as a catalyst for patients to talk about their own reality. However, the experts attempted to avoid using this strategy to highlight the reality of other patient situations. Often times, the experts spent time with the other patients and talked about the death of fellow patients in an attempt to acknowledge that death had occurred. Furthermore, as many of the patients had developed a rapport with each other, staff considered it essential to address this loss with the other patients, so as to acknowledge the loss that occurred and to allow other patients to talk about the event and its impact on them. This is evident from the following excerpts:

+Nurse 17: "You've seen yourself; we have the big ward and the smaller rooms. Now, even in the last week, four patients died, and it had an effect on the others in the ward. What I do is talk to the others, if I can when they see relatives upset in the ward, like, they know there's something going on. And I talk to them about it. It's not breaking any confidentiality or anything. It's just, it's respect, and it's a part of living. And sometimes it gives the other patients a chance to open up and talk about their own deaths too". +

Another respondent commented:

+Nurse 40: "Seeing other patients die, like in the bays, I make a point of talking to the others [patients] about it. It doesn't take long to talk about. I look on it too as one way of helping patients open up; it's hard for them, because it's putting the reality of their situation in front of them. [outside interference] And I take it from there, if they don't want to talk about it, that's ok, but they usually do". +

Data from my field notes highlighted the openness that existed in a number of the research sites.

+Field Notes: Two patients died today. The staff were expecting their deaths. Two nurses involved in this study were present. They made no attempt to conceal the deaths from other patients. As the patients were dying, they spoke to the other patients in the ward and afterwards told them that death had occurred. Then they sat with the patients for a while and answered questions the patients had about the death.

The above extract highlights the nurse respondents' approach to addressing the occurrence of death when other patients witness it. While it may not be desirable for all deaths to be witnessed by other patients, findings from this study highlight the positive aspects of such practice, as is evident from the following patient respondents:

+Patient 5: "I'm here now since Tuesday and today is only Sunday ... and four have come and gone since then ... they were very sick, [breathless] worse than I was. And I saw them getting worse ... and they died so peacefully. [tearful] [pause] It made me sad ... I hope it's like that for me when my turn comes ... I'll be more prepared now".+

Another patient in a different research site commented:

Patient 11: "I used to be frightened about dying. Now, since I came in, I've seen a good lot die ... I'm not as frightened now".+

In summary, confronting the reality of the onset of death with patients was an element of the practice of the expert palliative care nurses in this study. Developing a connection with patients and having an insight into their thoughts and feelings provided the foundation for helping patients to confront the reality of their situation. Experts attempted to avoid patients becoming hopeless and becoming immobile in confronting their realities by balancing the degree of information they provided to patients. Such interventions helped patients to maintain their independence and functioning to a point that staff felt was appropriate for individual patients. Furthermore, nurses were aware of the necessity of not diminishing patients' hope throughout this process. Creating an awareness of patients' realities provided the foundation for patients to prepare for the inevitability of death. This category is presented next, in the context of the practices of the respondents in this study.

7.3.2 CATEGORY 2: PREPARING FOR THE INEVITABILITY OF DEATH.

7.3.2.1 “Preparing for the Inevitability of Death” as Preparation for Death: An Interpretation.

“Preparing for the inevitability of death” refers to the nurses’ ability to be open to patients’ needs as they progress nearer the dying stage of their illness. It involves more than physical activities, it involves dealing with the symptoms, the pain, nausea and vomiting as they occur and trying to allay these symptoms as much as possible. It is a time for being present with and for patients; a time for relief of suffering and distress, and maintaining dignity; it is a time of reflection and in some small way making a patient’s transition and approach to death easier.

7.3.2.2 “Preparing for the Inevitability of Death”: Findings.

The death of patients in palliative care units was an event that regularly occurred. Preparing for that inevitability is part of the work of the palliative care nurses involved in this study. However, this preparation appears to be a unique and individual process for each patient that requires an array of skills by nurses to help confront and deal with the inevitability of death. Expert nurses acknowledged that for some patients, preparation commenced prior to being admitted to the hospice, while for others, preparation was ongoing up to their time of death.

+Nurse 40: “When some patients come in, they’re already resigned to the fact they’re dying. They know the reason they’re here. Even patients that come in for respite, I often read it in them ... it’s in what they say, and sometimes in what they don’t say; [emphasis] you know they’re preparing for death ... I try to get them to start preparing ... getting them to think about their life, what they would like to do, if there is anything else they need to try and fulfil. And it could be simple things, like, visiting someone, maybe just giving themselves some special time with their families, it just differs”.+

The above excerpt indicates that forward planning may in some small way make a difference to patients’ lives before they die. It appears however, that nurses need to gauge the extent of preparation that has taken place in patients while in the hospice. This skill appears to be one that had developed over time and one that was constantly being refined as the experts dealt with a variety of patients. Furthermore, the extent of

preparation was individual for each patient. One expert commented on this as she explained how her skills in reading the signals developed.

+Nurse 1: “When I started in palliative nursing first, I couldn’t see what it was in patients that gave me the signs they were getting ready for death. Now, many years later, it just comes naturally to me. [stood up] Dealing with different patients all the time, seeing how others deal with them and read the signs, that’s how I’ve picked up on it over the years. Also, now I’m older myself, I’ve got more feelings now, different feelings, and all of that helps when I’m dealing with people in here”.+

Another respondent commented:

+Nurse 33: “I would see it more that I had to reach a certain area myself as a person and as a nurse before I felt that maybe...in my first two years of practice as a palliative care nurse, me personally, I didn’t get to those areas with patients at all, but as the years passed, I felt I did and I did have to build up a relationship with the patient but equally, even quite early on in the relationship, I felt more able, [pause] more comfortable myself probably, even being able to go into that area with them so I think it was more change in me”.+

While many of the experts developed skills in preparing patients for the inevitable, the range of skills needed to be adjusted according to the individual needs of patients and according to the location of the patient in the dying trajectory.

+Nurse 23: “It depends, there are sort of two case scenarios; there are the patients that you can be completely open with, who will know, who will have been told it’s two weeks to six weeks, or whatever, so your approach to those patients is completely different...for other people, you just do the physical things, the pain relief, the turning, the checking the pressure areas...it depends very much on the patient”.+

Many patients who were admitted to the hospice knew they would probably die while they were there. Despite this, there were some who blocked out the inevitability of their death and did not prepare for it. Some needed assistance to help them in that process and one respondent described how she prepared patients for the inevitable.

+Nurse 17: “When patients realise that they’re in the hospice, some of them know what’s ahead for them, but even though they do, I can work with them to prepare them. I think I can make some small difference in what I do to help them through what it is they’re going through. [reflecting] I think as a palliative care nurse, it’s essential I help the patient to prepare for death, and I

do this through maybe reflection with them, music maybe, maybe meditation and reading, maybe even silence. There's no script for it, I just do it".+

Not only did experts prepare patients for the inevitability of death, they also prepared them for possible symptoms of their illness that may develop, including nausea, vomiting and pain, so they could continue with living in their dying. Many experts commented on their role in preparing patients that these events may occur and alerting them to these possibilities. Furthermore, where possible, they identified for the patients strategies that may avert some of these symptoms. One respondent identified how she attempted to prepare patients for the onset of these symptoms as follows:

+Nurse 30: "Sometimes when patients see other patients being sick or losing weight, not sleeping and generally unwell, they often ask will it be like that for them. All I can do is in some way prepare them for that possibility ... so I make sure I prepare them in some small way for that possibility. It might be simply telling them that there is medicine to help them, I will make every effort to get in before they get the pain or nausea or whatever".+

Helping them to prepare for dying seemed to be influenced by the extent of the relationship that staff developed with patients. Because a number of patients died within a short time following admission, staff were limited in some instances in the extent they could prepare patients for death. On the other hand, some patients had numerous admissions to the hospice and as a result, developed a rapport with the respondents. This gave respondents the opportunity to provide an extended input into their preparation. While this achieved a degree of acceptance of death in patients, one respondent described times when it became apparent that the preparation had been complete and the patients had accepted the inevitability of death. One expert describes this as follows:

+Nurse 25: "I think it can be so painful. [emphasis] The look that says a million words...sometimes a patient will come up to you and say: I know you're going on a day off and shake your hand...it's as if they also know they're weak and "thanks for everything" or something, and you get that awful sense of: oh my God they know they're not going to see me again".+

Preparation for death was interpreted by some respondents as involving a process of "letting go" of past events in order to move on. It appeared that past life events had prevented patients from preparing for death and it seemed as if they needed the

respondents to listen to their stories. Experts sensed that this was an integral aspect of being in a position to help patients in some way to prepare for death. One respondent described this as follows:

+Nurse 33: “ ... the great need for the patient to tell the story about what has gone on, about their life, more about themselves, they felt there was a need for them to divulge themselves...talk about themselves, maybe a particular instance in their life so I identified that as a very important part of my nursing practice...I was there to hear the patients’ story and that I sometimes knew when the cue was coming, [moving towards me] that they would want to talk to me about something... what was important about their life, what their values were, often times there were quite sad parts with things they had regretted they hadn’t done or maybe the anguish they had, they were departing this life sooner than they had anticipated [frowning] so that to me was probably one of the most important aspects of my nursing practice, that patients were able to tell me things or able to talk to me about things like that”.+

The above excerpt indicates the diversity of ways that patients needed the respondents to be available to them in order to help them prepare for their deaths. Being there to listen to their stories appears to indicate a sense of value on patients’ lives and experiences, that they needed confirmation regarding the self worth of their lives to date.

A number of patients who were admitted to the hospice appeared to have their preparation complete. It was as if they had accomplished all they wanted to do in this life and were satisfied to accept their current situation; however, nurses acknowledged that they had a role in supporting them in whatever manner they could.

+Nurse 14: “I have very little to do for some, its just to confirm with them they’re all right, they know what’s ahead. That knowing, it differs, sometimes it’s hard to know how much they know, I can only presume at times. They’re ready, so all I have to do is listen to them and maybe enforce what they’re saying and give them the assurance to stay with their feelings and it’s ok, it’s ok for them. But it doesn’t stop there. I still let them know I’m here for them if they want to talk about dying. So it’s as if, there’s a kind of closure for me with them, having built up a relationship with them, then they get weaker and die, so it’s like coming a full circle ”.+

It appears from the above that the relationship that builds up between the respondents and patients is one that is constantly being developed and changing. As patients share

their stories with the respondents, it's as if there is a form of trust and seeking feedback from the staff, a type of confirmation from them that they (patients) are all right. However, as patients die, the complete circle, as described above, appears to have taken the form of building the relationship, maintaining independence, dealing with issues as they arise and then bringing closure; it is all based on trust and confidence in the nurse. The impact of such a relationship for one patient respondent provided the opportunity to create the awareness that her condition was deteriorating; the reality of her situation was becoming clear to her. She commented:

+Patient 4: "I'm not as strong as I was. No, I'm getting weaker. And what she's doing for me, it puts it all in front of me, and I thank her for that ... but I thank her for letting me see what's really happening to me. She does it in such a gentle way ... the walks are getting shorter and the times in bed are getting longer ... at least if there is anything I need to finish off now, I know now is the time to do it".+

For some respondents, preparing for the inevitability of death was built around a mutual relationship and understanding between the experts and patients. It appeared as if a partnership had developed and there was input into the partnership from both the expert and the patient. There seemed to be a two-way process in action, one of giving and one of receiving. One respondent describes this as follows:

+Nurse 27: "I suppose in some ways it's a case of feeding back to them the change maybe that they're really tired today and haven't any energy left and you sort of point out to them that they had, but during the week the energy was getting less as well but to try and get them to verbalize it rather than you know, feed it to them all the time because if they realise something themselves, sometimes the penny drops better than it would, because they feel we're telling them, whereas in fact we're not, we're just trying to jog their memory as to what is happening for them".+

For some patients, there appeared to be an open awareness of the onset of death. It seemed that some patients looked for confirmation that death was approaching. Honesty and openness appeared to form part of the nurses' role in preparing patients for their death. Such an approach set the foundation for patients to live in harmony with the events that were occurring and adjusting their behaviour to the reality of their situation. This open approach went hand in hand with reading the signals and acknowledging these signals with patients.

+Nurse 24: "Sometimes, very often with a patient, it's a very gradual, well obviously there's a weakening, perhaps the person is sleeping more and more ... some people recognise it and will say it and will ask: is this it, am I dying, am I going to die soon and certainly when somebody does ask like that... I try to answer as honestly as I can. If I think yes, this is it, you are starting to die, the time is getting closer... the person is weaker and weaker and won't come through... a good part of our role at that time would be explaining what is happening so they are preparing... and that the terminal phase is coming soon".+

Data from my field notes supports the above respondent's actions in preparing a patient for the inevitability of death. This is based on the actions of one of the experts in dealing with a seventy seven year old man who was dying with prostate cancer.

+Field notes: Nurse 24 for the second day. Looking after patients in the single rooms. John [pseudonym used] is here for five days. Nurse 24 told me that John is getting weaker. As she is washing him, he asked her how he was doing. She sat down and held his hand. There was silence, he looked at her. There were tears in his eyes. He said "You can tell me, I'm ready to hear it, I know it's coming". She said, "Your breathing is more difficult, you're not eating or drinking as much, you are not as strong as you were yesterday. I'm here to help you, make you comfortable, and I'm here to be with you". He said "Thanks for being honest with me, I know it will be in the next day or two, thanks. I want you to ring Joan and ask her to come in, I want to say good-bye to her". Nurse 24 telephoned Joan and she arrived shortly after that. John died that evening. +

Another respondent further described how there were occasions when patients were in denial and did not verbally acknowledge the reality of their situation, however, they had prepared for death in their own way. Despite the evidence of denial, patients continued to sustain their reality of living within dying to their full extent. This varied between patients: for some there was acceptance, for others this was absent. One respondent described this when she said:

+Nurse 27: "Sometimes it can be very drawn out [emphasis] and some patients still die in denial and some patients need to be allowed to die in denial as well, because that's how they've coped with their illness right along. And I have to say that I think it would be really cruel to shock them into reality at the end if that's what it was... I think they don't want to talk about it".+

Interview data suggests that there were occasions when patients were tuned into the situation and they found it hard to present the reality to their families. This seemed to be particularly difficult when it came to children, especially when it was a mother who

was ill. One patient said she felt that the expert nurse had been successful in helping her children to come to the realisation of the situation in which they were going to be in the near future. This patient found it difficult to put the reality of her situation to them; however, the nurse had successfully done this:

+ Patient 10: "I know what's ahead, but how do you prepare the children; there's only so much they can take. I feel most for them, what will they do when I'm gone. At least they have me when I'm here, but 't will be a different story when I'm not around any more. The nurse understands though, she's on top of it; she's in there with the children and in her own way working on them to get ready for when I'm not here, and it seems to be working". +

In summary, preparing for the inevitability of death was a process that commenced for some patients prior to their admission to the hospice. In those instances, the role of the experts was to support the patients' acceptance and be available to them. It required the experts to possess the skills to identify the degree of preparation patients had achieved and to gauge the extent their skills were required to facilitate patients in their preparation. While nurses prepared patients for the inevitability of death, they also prepared them for the management and prevention of symptoms related to their illness. The degree of preparation was guided by the nurses' skills in determining the extent to which patients accepted the reality of their situation and the extent to which they gauged the task ahead of them. A large proportion of preparing patients was centred on the relationship with patients, while the nurses' range of skills and personal development as they enhanced their expertise influenced their input into preparing patients for the inevitability of their death. It appeared that the relationships which the respondents developed with patients were based on mutual confidence, providing information, meeting the challenges that the relationship presented, and then finally coming to closure. The next section presents the category of "comforting in dying" as an element of the nurses' role in preparing patients for death.

THEME FOUR: COMFORTING IN DYING.

7.4 Introduction.

This section presents the findings of the theme “comforting in dying” as it was illuminated through the practices of expert palliative care nurses. “Comforting in dying”, as an integral aspect of expert palliative nursing practice, provided both a relational and interactional basis for their nursing practice. Experts appeared to gauge the need for comforting measures that they offered to patients, and observation data indicated that they involved patients in negotiating the level and extent of comforting measures that were needed to provide adequate and appropriate comfort measures to patients. It involved actions that formed a thread between the various other caring activities that contributed to the composite of expertise. From my analysis of data, the “comforting in dying” practices of the experts presented themselves in relation to “physical caring as comforting in dying”, “symptom control as comforting in dying” and “spiritual care as comforting in dying”. These will be discussed and appropriate excerpts from nurses’ interviews presented to support my analysis.

7.4.1 “Comforting in Dying”: An Interpretation.

“Comforting in dying” refers to the nurses’ ability to soothe, console and relieve distressing symptoms with which patients present at different stages throughout the dying trajectory. It provides calmness and contentedness within patients. “Comforting” involves an attunement of the nurses’ skills to recognise the physical, psychological, social, cultural and spiritual needs of patients. It encompasses a “connectedness” and “relatedness” that both patients and nurses sense internally and externally. Comforting actions are multi-dimensional and are incorporated into holistic expert care of patients.

7.4.2 CATEGORY 1: “PHYSICAL CARING” AS COMFORTING IN DYING.

7.4.2.1 “Physical Caring” as Comforting in Dying: An Interpretation.

“Physical caring” as comforting in dying refers to the nurses’ ability to provide appropriate physical caring interventions in order to ease patients’ discomfort. Optimal comforting is the degree to which patients continue to demonstrate a positive sense of being in their living in dying. It draws on the nurses’ ability to read the overt and covert signals that indicate the extent to which comforting interventions are required. Comforting interventions are interpreted individually within each patient situation and are enacted with varying degrees of intensity.

7.4.2.2 “Physical Caring” as Comforting in Dying: Findings.

While methods of organising patient care ranged from primary nursing, to patient allocation or team nursing, patient acuity required that a large proportion of nursing activities centred on physical care. It appeared that for all of the respondents, while the physical care could be provided by focusing on the task, there was a clear demonstration of concern and interest in patients. Physical care was provided in an unhurried manner and completed thoroughly. Furthermore, nursing actions being carried out that provided physical care was delivered with feelings of genuineness and compassion. This is evident from the following excerpt:

+Nurse 31: “For me, the bed bath is more than just giving patients a wash in bed. No, it’s much more. [emphasis] I know when I’m doing the wash, every stroke of the cloth matters to me, ‘cause I know it matters to patients. [speaks slowly] I give it 100%. It’s, if I could call it, the love, the intentions that go with the wash, you know, I want them to feel that it makes the difference, it’s worthwhile, it’s soothing for them”.+

Data from my field notes supported my interpretation that physical care was provided in an unhurried manner and in a way that provided an indication of the patterns of care that the respondents delivered. Furthermore, it also appeared to enhance the nurse-patient relationship through contact with patients.

+Field notes: Observed Nurse 31 this morning. She was doing bed bath on patient. Procedure undertaken slowly. Patient given choices as to what he

wanted done, and each time she checked with patient if what she had done was to his satisfaction.+

One respondent considered that providing physical care constituted a key aspect of her expert nursing practice. The focus of the physical care was that of ensuring comfort for the patients she cared for. She described her role in making a patient comfortable for the night as follows:

+Nurse 26: "I go through what the patient wants all the time ... do what the patient wants, make the patient happy, make the patient feel safe ... and I love tucking people in and making them cosy for the night, fixing their pillows right. There are some people who just can't do pillows right and you just say, let me in there and I enjoy it".+

The significance of the above nursing actions for patients was affirmed by a patient respondent as he described the impact of such actions as follows:

+Patient 4: "In the general hospital before I came in here, the beds weren't comfortable, the pillows were hard ... it's different here ... she makes sure I get the soft pillows ... it makes all the difference ... it's like being at home in my own bed again".+

Comforting strategies in the provision of physical care appeared to be closely linked with connecting to patients. This connection appeared to promote a well-being within the patients in an attempt to create a situation that was conducive for patients to possess a sense of self worth in their dying process. It appeared as if this connection was nurtured throughout patients' time spent in hospices, and that nurses responded to patients' needs for physical comfort intuitively. This is evident from the following excerpt.

+Nurse 13: "I just know when they're not comfortable. They don't have to tell me. Even though they might say, "No, I'm ok", often times they're not. I get the feeling I need to do something to make them comfortable. [moving away from me] And it might be just to change their position, give them a hug, you know, that's all it might take".+

Physical comforting was also provided intentionally. The intentional actions were centred on patients' choice or they formed part of the patients' plan of care. This was particularly evident when one respondent described her practice as follows:

+Nurse 11: "You get to know what they like and I make the effort to do what ever they want. And if they have their own way of having their wash, or doing the leg exercises or putting a cushion at their back when they're sitting out, if that makes them comfortable well, I go with that".+

This was supported by a patient in her care who described the caring she received from the above respondent:

+Patient 1: "She reads me like a book ... and knows when I'm not right".+

Intentional physical caring actions as providing comfort to patients was described by another respondent as follows:

+Nurse 8: "I would think I would do my best to try and make their final days or final weeks ... as comfortable and peaceful as possible. You know, just by being with them, giving them a massage, if they want it, I find massage ... a great thing for the patients. It's extremely relaxing... or if they're able enough to give them a Jacuzzi, it relaxes them as well, or just put lavender cream on them as well, they're very relaxed. You know, just like that".+

From the respondents' perspective, providing physical comfort appeared to take require taking cognisance of choice in what comfort measures were instigated. Nurses involved patients in making choices regarding the activities that added to their comfort. It appeared that some comfort measures instilled a sense of security for patients in maintaining continuity with their home environment. Such an approach by the expert nurses seemed to make a difference in some small way to patients in their care. Respondents described the measures they took to ensure comfort for a number of patients by maintaining continuity for them.

+Nurse 25: "It can be down to the simple thing like getting special sheets or pillows. These things matter to them. If I can't get them here, well, I get the family to bring them in from home. It just makes it more homely for them. It's bringing in the comforts from home into the hospice, that's all. And there's nothing wrong with that".+

In summary, providing physical care as comfort to patients appeared to comprise an important aspect of comforting in dying. The acts of providing physical care, such as washing, grooming and changing patients' positions were purposeful, the aim being to address discomfort that patients may be experiencing. Furthermore, providing physical

comfort measures sustained the “self” of patients in that the nurses were working in partnership with patients where patients’ contributions ranged from complete to minimal involvement in achieving maximum comfort within their dying process. While the comforting actions described by the respondents may be considered as an integral aspect of nursing practice, the comforting strategies enhanced the patterns of nurse-patient relationship and provided an indication of the styles of care delivered by the respondents.

7.4.3 CATEGORY 2: “SYMPTOM CONTROL” AS COMFORTING IN DYING.

7.4.3.1 “Symptom Control” as Comforting in Dying: An Interpretation.

“Symptom control” as comforting in dying refers to the nurses’ ability to provide adequate pain relief and control of other symptoms as experienced by patients, either pharmacologically or by alternative methods in order to provide relief from their symptoms. It requires a comprehensive assessment of patients’ status and an ability to implement appropriate therapeutic interventions, with the aim of relieving pain and symptoms and promoting comfort.

7.4.3.2. “Symptom Control” as Comforting in Dying: Findings.

Invariably, patients receiving palliative care require pain relief and symptom control. Most patients experience pain at some stage throughout the palliative care phase as a result of the disease process. When patients present with pain, a comprehensive assessment by the experts is required in order to make the appropriate decision regarding what type of analgesia to administer. Management of pain was a high priority for the experts in this study in order to provide and maintain maximum comfort to patients. The process of providing pain relief appeared to be staged, commencing with oral analgesia and gradually increasing to subcutaneous or intravenous analgesia. Data suggests that the incremental stages of increasing analgesia were based on the experts’ assessment of the patients’ pain.

+Nurse 13: "I've got to know the different kinds of pain the patients have here...I try and get in there before the pain gets bad, so I'm trying to work ahead all the time. I need to keep them comfortable".+

While analgesia needed to be prescribed by medical practitioners, the respondents constantly monitored its effectiveness, with the emphasis being on comfort. On several occasions, respondents highlighted the need to have alternative analgesia and co-analgesics prescribed in order to provide appropriate symptom control. One expert expressed how she considered the regime that was prescribed for a particular patient was unsatisfactory and requested alternative medication in order to provide adequate pain relief and comfort to the patient. This is evident when she said:

+Nurse 17: "I started to draw it up [the analgesia], but I wasn't happy. I knew it was too much for her; [emphasis] she hadn't reached the stage where she needed that concentration of Cyclomorph. I felt if we increased her oral co-analgesia it would be more effective for her. At least she would be comfortable without being zonked out of it. It would have been enough to keep her comfortable. So I got the order changed and it made all the difference to her".+

When I invited the respondent to tell me how she knew the alternative analgesia would provide her with the desired effect, she replied:

+Nurse 17: "I just know her. I know it wouldn't suit her. I've seen it so often before, it's not the way to go with some of the patients, and she is one of those. It comes too from knowing her, in a special way, in a deep way."+

The excerpt above indicates the value of the nurses' knowledge and experience in dealing with symptom control issues, complemented by the nurses' knowledge of patients where they needed a "connection" with them. The implications of the above actions ensured that the patient was in a position to partake in living activities to her full extent, while overcoming any dysfunction related to experiencing pain. The focus of providing comfort in the above exemplar was not solely on the relief of pain, but incorporating a whole person response to comforting measures.

Providing comfort from symptoms to patients appeared to span across all stages of patients' illnesses. While all of the hospices provided respite and terminal care to patients, it appeared there was a need for comforting measures to be instigated from a

nursing perspective, irrespective of which stage patients presented in the dying trajectory. One respondent described this as follows:

+Nurse 36: "We'd have a range of ill patients coming in that would go on the scale of dependency of nursing care. We'll have people coming in for symptom control that would be up and about and relatively self caring, but they will have particular symptoms that need to be managed, for instance pain or nausea and vomiting, those types of symptoms. So we may do minimal for them from a basic nursing point of view but we would be very involved in assessing their symptoms and monitoring the effectiveness of interventions that we would be putting in place and then... it would range from that to patients that are becoming a lot weaker, [speaks slowly] to patients that are actually in the terminal phase and they would be very dependent and need full nursing care".+

Achieving adequate symptom control in patients was based on individual assessment of each patient. While patients may be suffering from similar forms of disease, their response to symptom control measures varied. The respondents' knowledge of the pharmacodynamics and pharmacokinetics of drugs was essential as they attempted to instigate symptom control measures while observing for other causes of their symptoms.

+Nurse 25: "You know, their response to the same drug can be so different. You might be able to get on top of the pain very quickly in some and when you give the same medication to someone else for similar symptoms, there might be no or very limited response. So you have to juggle a lot of the time to actually get what is right for each patient and go with that. So it's a matter of combining what I know about the drug with what I know about the patients".+

Despite the nurse respondents possessing an in-depth knowledge of pharmacology, they were regularly challenged to adjust drug management regimes in order to achieve the desired affect for patients' symptoms. This was influenced by the array of symptoms with which patients presented. The nurses combined their knowledge of the actions and side effects of drugs in order to achieve an appropriate regime. One respondent described this challenge as follows:

+Nurse 14: "Sometimes it's a balancing matter, you know like, when you treat the pain and nausea, then there's the other side of that ... you have to watch for the constipation. It is a balancing between it all, but I've got to know it now ... I know what to watch out for ... I try to be a step or two ahead all the time ... mostly it works well".+

A respondent in another research site supported this as follows:

+Nurse 25: "Pain management is only one part of symptom control. The other symptoms, like nausea, vomiting, constipation and breathlessness, you have to try and balance it all ... I would be very tuned into keeping the patient well covered, especially when they're on so much medication".+

Providing symptom control as comforting in dying not only focused on pain control but also on symptoms such as nausea and vomiting. Nurses utilised their knowledge and skills regarding the effectiveness of the interventions they initiated. Strategies used to provide symptom control were also based on the nurses' knowledge of patients and their intuitive decision making skills.

7.5. CATEGORY 3: "SPIRITUAL CARE" AS COMFORTING IN DYING.

7.5.1 "Spiritual Care" as Comforting In Dying: An Interpretation.

"Spiritual care" as comforting in dying refers to the nurses' ability to assist patients find meaning in their living and dying process. It involves an astute awareness of the patients' thoughts and feelings, and an ability to be present to those experiencing spiritual pain, discomfort and discontentment. Providing spiritual care requires the need to be open to the wholeness of the patient, to read their signals as they search for meaning in their lives. It is anchored in the uniqueness of the nurse and the patient as they both listen to each other with dignity and respect.

7.5.1.1 "Spiritual Care" as Comforting in Dying: Findings.

Expert nurses in this study appeared to be instrumental in assisting dying patients to achieve a degree of self-acceptance and self-contentment. Apart from physical pain that patients may experience during the dying process, they may also experience non-disease related pain. This pain is commonly referred to as spiritual pain. While spiritual pain infers an array of meanings, it is frequently associated with the person's fear of facing death and patient's reflections on past life events. Furthermore, as it may present itself in many forms, its symptoms may be difficult to recognise. This results

in spiritual pain being frequently overlooked in the management of patients in palliative care.

The experts frequently spoke about the presence of spiritual pain in patients for whom they cared. They described how they attempted to provide relief and comfort for this pain. One respondent described spiritual pain as an obstacle to patients' dying process and one that needed to be addressed as follows:

+Nurse 13: "It's not easy for them. There may be something that's troubling them, something that's maybe stopping them from moving on. It's like as if it's a stumbling block that hurts, and as they try to get over it, it causes them pain. I try to bring them some comfort through this time, being non-judgemental, having some empathy for them, and being there with them and for them. [emphasis] I think too it's being extra sensitive towards them at that time that lets them know that I'm genuinely interested in them and I'm here to help them, [pause] comfort them, trying to put meaning on what is actually happening for them. It needs to be looked at in some way with them".+

One patient respondent spoke about the difficulties she encountered regarding the presence of pain she experienced prior to being admitted to the hospice. Data suggests that this 'pain' was spiritual related as opposed to being disease process related. This resulted in the respondent being unable to address the issues with which she was presented. However, as she described in the excerpt below, this pain was addressed through the interventions of one of the nurse respondents:

+Patient 10: "Before I came in here, I think I couldn't accept what was happening to me, what was all this that was going on. [deep sigh] And it all seemed to be happening so fast; I was like as if I was in a spin ... 'T was frightening ... and then I came in ... to get on top of this pain ... it became so clear to me when she (nurse) came and sat down and went through everything with me".+

Unlike disease related pain that may be treated pharmacologically, the management of spiritual pain presented various challenges to the respondents. This may be in part related to the difficulty in describing the constituents of spiritual pain. Data gathered suggests, however, that spiritual pain appeared to be gauged by the respondents on the extent of forward movement that patients demonstrated in their living and dying processes. This movement was unique for each individual patient, and nurses strove to

address the disabling elements of spiritual pain with which patients presented. This was linked to assessing patients' spiritual journeys as they progressed through their living in dying trajectory. For some respondents, physical and spiritual pain formed a reciprocal relationship where both presented themselves together. The difficulty in differentiating between both sources of pain is described by one respondent as follows:

+Nurse 30: "Sometimes it might seem to be physical pain, and no matter how much analgesia we give them, there is no relief from it. [pause] Then I feel it's related to spiritual pain as opposed to physical. It could be something that has sprung up for them from years ago; [emphasis] it's all brought back to them at this time in their lives. And treating the spiritual one, well, you can often see there's less analgesia needed then".+

When the above respondent was asked to describe how she addresses spiritual pain in patients, she responded:

+ Nurse 30: "There's no set remedy. Sometimes it's allowing them the time to let them be themselves, [moving towards me] let them share it with you. Then I can offer some, shed some light maybe on what's going on for them. Sometimes it's letting them see you care about them, you feel for them. It's like being their friend".+

For some of the respondents, spiritual pain was regarded as being a component of disease related pain. Providing comfort for spiritual pain constituted an extended process; one that involved a period of time for both nurses and patients to address. Furthermore, providing relief for spiritual pain appeared to take place while also addressing physical pain. This is evident from the following respondent:

+Nurse 5: "Like, mmm, the way of dealing or should I say the way of helping [emphasis] someone with spiritual pain, it's not something I do in one go. It's a long process and it can take time to be able to tap into the point of where the pain is at ... I sense yes, this is the right time to maybe talk about what's going on for him or maybe just being there and actually not saying anything at all... spiritual pain, [reflecting] I think it's important to keep the spiritual pain in the picture of what Saunders put it in total pain for the patient. Like, what I see here often times, the way the physical pain and the spiritual pain can go hand in hand, you can almost sense [emphasis] the spiritual pain or discomfort in the patient and then there is the physical pain that can come with it, so do you see how it's all part of what I call a 'big pain' picture. It's a matter of giving them the signs I'm there with them, there to listen and to offer them help and support through all of this".+

Strategies for dealing with spiritual pain and providing spiritual comfort appeared to require an attunement from the nurses to recognise and deal with the pain. Part of this attunement was related to the respondents' own spirituality. This is evident, as one respondent described the manner in which she addresses spiritual pain in patients.

+Nurse 31: "It's a matter of being open to them [motions with hands] in every way I can. It can be as simple as sitting in silence, holding their hand. Or it could get so complicated, [nods head] that it can take a long time to pick away through talking, silence and maybe companionship that gives them the comfort to get them through it all. It comes back too to me as a person, as a human being, being able to acknowledge my own spirituality".+

Spiritual pain appeared to accompany the dying process for a number of patients. While patients may not have addressed it as "spiritual pain", the respondents read the signals from patients. These signals varied and ranged in degrees of overtness. However, there were occasions when the comfort that the experts could bring to patients experiencing spiritual pain was that of awareness of its existence and allowing privacy to the patient to deal with it in her way. One respondent describes one such incident as follows:

+Nurse 10: "Now this woman was somebody who used to get out of bed and walk on her own and pain written all over her face... that was her way and yet, there was a profound sense of loss and grief and everything about her. All you had to do was be in her presence and you felt the whole hopelessness [emphasis] that was around her, even though her reactions and her verbalisations were the complete opposite. But I remember speaking with her husband and he said that, that was her way for the children, albeit adult children at this stage. But for themselves, when they were together, they had their own moments. So I suppose I had some sense of yes, she is acknowledging what's happening for her but just we're not privy to it. We're not to be privy to it... but it's her and her husband, her soul mate".+

The above excerpt highlights the necessity for awareness of spiritual pain accompanying the dying process and allowing patients the freedom and autonomy to deal with it in the manner that they wish. While the respondent was focused on the patient as the recipient of care, she had the awareness to address the patient's spouse to ascertain further information and to confirm his coping with the particular situation.

For some respondents, spirituality was connected with religious beliefs and practices. One expert described how she used prayer as a means of comforting for a patient who had difficulty in accepting her illness and moving on in her illness. She described this as follows:

+Nurse 7: "And that actually for a few patients, and one patient in particular I remember, mmm, a young woman, I used to actually pray [emphasis] with her, and she found it so comforting and so consoling [nods head] that it did actually help her to move on, it gave her a kind of a deep, that peace she was looking for, and it did actually give her profound peace and was able to, kind of face her death that little bit easier".+

Patient respondents also acknowledged their dependence on religious beliefs to help them through their journeying process and in dealing with their living and dying processes. While they relied to a large extent on the nurse respondents to help them through this process, a number of patients acknowledged the value of their religious beliefs in helping them through this process. Patient 10 described this in the following excerpt:

+Patient 10: "As I'm getting weaker in this, they're there with me. I couldn't do it without them. I know I need their help to get me through it. She gets me through the highs and the lows, I know at the end though, I'm the one that has to go all the way. [tearful] I know God will help me along as well". +

The acceptance and effectiveness of providing spiritual comfort appeared to be based on the extent of the relationship that the respondents had with patients. Where the relationships appeared to develop over a period of time, it seemed as if patients were more accepting of the respondents' efforts to address the spiritual pain. It appeared to be centred on the patient building the confidence and understanding in the relationship with the nurses before engaging in dialogue with them regarding the extent and source of their pain. One nurse respondent described this as follows:

+Nurse 5: "Now it can be hard, mmm, hard to get to help someone with spiritual pain [emphasis] 'cause it's a kind of a personal journey they are going through and it's tapping in to where they are in the journey that can be a difficult thing. But easing the spiritual pain that patients have requires me to care, to be honest, and to get them to trust me. Then I take it from there. I listen, give them time, and listen. Sometimes there's no answer, and that's all right. But just doing what I said can be enough to bring them some kind of comfort from the pain".+

This is supported by one of the patient respondents as she said:

+Patient 1: “She knows and understands what I’m going through and I know she listens to me. She takes it all in and takes heed of what I’m saying. That makes it easier for me. I know she understands me”. +

While preparing the patient for death formed a central part of the nursing practice of experts in this study, “spiritual comforting” brought about a form of healing for many patients. Although healing is frequently associated with medical interventions, spiritual healing emerged as a result of nurses providing spiritual comfort to patients. Many of the respondents realised the value of spiritual comforting in providing for the basic human needs of patients receiving palliative nursing care. Healing is commonly linked with granulation, a visible entity, a physical repair and a process that occurs over a period of time. However, the healing that nurses refer to in this study indicates that the extent of healing that they promote is not just physical healing, it transcends the visible aspects of responding to physical care. It results in a sense of self-acceptance, an ability to live in dying, an ability to address the disabling aspects of living in dying. Invariably, providing healing encompassed the provision of “spiritual comfort” as an element of preparing patients for death. This is evident from the following respondent as she described her practice in providing spiritual care to patients.

+Nurse 29: “When I do what I consider the ‘spiritual care’ of patients, I see it in a way as a kind of healing. [speaks slowly] It’s a healing of the person as a person. It’s helping them to accept themselves as they are. It’s like a, giving them permission to feel the way they do, to be angry, sad, whatever. And it’s also an affirmation that the person is human, and they are ok”.+

The above excerpt highlights the link between spiritual care and healing. The respondent’s interpretation of healing infers a focus on the patient’s self, and is also connected to the patient’s affect. It infers a willingness of the respondent to connect with patients so as to affirm their self worth and achieve a form of inner strength. It overcomes the disablement associated with living in dying. Another respondent described a focus of her nursing care as one that involves “healing”. She described this role as follows:

+Nurse 38: “While palliative care is not about curing, as a palliative care nurse, a lot of what I do is what I consider to be healing. It’s a broad healing [motions with hands] the scars of maybe the turmoil of life, the maybe the humps, the bridges and the rocky roads they’ve travelled, and you know ... but the healing comes from being open, creating the peace and moving on to the next stage in living and dying. It’s a kind of getting the person to look inner and coming to a greater sense of knowing themselves”.+

The above data is supported by a number of patient respondents who acknowledged the healing elements that emerged from the actions of the expert nurses. While patients knew they were not going to be healed from a disease process perspective, many of them acknowledged the healing that emerged from the respondents as they engaged in their caring activities. Healing emerged in the form of contentment, of acceptance of their current state of health, and movement within their journeying process. One respondent spoke at length about his illness as a journey up to the current time. He considered the journey had changed for him once he came into the hospice, and was being cared for by the expert nurses. He felt he was no longer trying to battle against the illness; the nurses had provided him with the direction to go in and deal with his situation. This is evident from the extract below as he described how he felt when he was admitted to the hospice:

+Patient 2: “I was so confused when I was at home, I couldn’t accept it at all. There was the pain, the loneliness, I was so angry that all of this was happening to me. And then, it changed when I came in here. I’m only here less than a week yet, and things are different. ‘T isn’t as big and as lonely as it was. I’m getting a hold of the whole thing now. I know I’m not giving up yet, no, I’ll stay going. ‘T is easier now that I’m not on my own in this. They [the nurses] are with me in this now, and it’s so much better”.+

Spiritual comfort as a catalyst for healing is a process that appears was not possible to facilitate in all patients receiving palliative nursing care. This may be due to the reluctance of patients to accept the nurses’ interventions as a form of healing. Alternatively, spiritual discomfort may not be an issue for the individual patients, particularly if they have already dealt with their own inner feelings and attained a sense of fulfilment regarding their lives. The above respondent described this as she said:

+Nurse 38: “It’s not everyone you get to a deep level with. Some just close you out. Others have travelled a long way anyway, so they’re ok. And that’s ok as well. Then I don’t force the issues. That’s their choice”.+

As with any form of healing, facilitating the process involves assessing the need and the strategies required to implement the spiritual healing process. This process requires an array of knowledge and skills that allows appropriate information to be compiled in order to facilitate appropriate healing. Unlike the process of wound healing, where visible granulation becomes evident, spiritual healing appears to require vigilance in order to monitor its effectiveness. One respondent described the intricacies of healing, as follows:

+Nurse 3: “You know, like any other type of healing, like, healing a wound or something, there needs to be mmm, a kind of base to start from, [emphasis] you know, what are you working from. And from my own experience, I mmm, I suppose I would look on the person as being composed of so many different parts that the healing is intricate, it’s fragile, it’s special. For some there’s a lot of wounds to heal, so I need to nurture the tools to work on and in this case it’s the patient, [looking away] and I just absorb from them where they’re at and what is it in them that needs the healing, what is it that needs to be done to kind of help the granulation to take place”.+

An inherent aspect of the nurses’ role of providing comfort was that of patient advocate. The extent of advocacy varied according to the stage of illness with which patients presented throughout the dying trajectory. For some patients, nurses had a major advocacy role, while for others it was limited. Nurses acknowledged this role, and it appeared that the role had a direct influence on patients’ spiritual comfort. One respondent considered that her advocacy role increased as patients’ conditions deteriorated, however, her focus on being an advocate was on their contentment and happiness. This is evident when she said:

+Nurse 17: “As you’ve seen yourself, we have patients here at all different stages, some can make their own decisions, others can’t ... if this is what patients want, [emphasis] if this is their wish and gives them a stage of happiness and contentment, well that’s the road I go. It’s an individual thing, but it gives them some control over their situation”.+

An innate component of the respondents’ advocacy role was that of mediating between patients and their families. This appeared to be dependent on the extent of

family involvement in patient care prior to admission to hospice and the degree of openness that existed between patients and their families. A number of patients preferred to have minimal information available to family members, while others accepted a high degree of input; this was influenced by the patient-family relationship. There were numerous occasions when respondents considered their role as one of mediating between patients and their families in an attempt to achieve a sense of harmony. However, it was not always possible to achieve a full resolution of issues between patients and their families. One respondent describes this as follows:

+Nurse 24: "It's trying to be a go-between at times, between the patients and families. Sometimes, it's like trying to sort out a lot of issues that are already there. And we can't, 'cause a lot of the times, it's not clear. Sometimes, there are clear issues and we can help there. But when it's not clear, it's very hard to help. Then I just listen".+

Another respondent commented regarding her role as a mediator, as follows:

+Nurse 38: "Sometimes, it might be just clearing up a misunderstanding. Other times, it might go further than that, having to have extra family meetings to sort out issues. But what I keep in mind is I need to be open to what the patients say and what the family say. And I take it from there and do my best to find the best solution".+

In summary, providing "spiritual care" as comfort in patients who are dying is complex. This is in part due to the lack of clarity regarding the nature of spirituality and spiritual pain. The nursing interventions described by the respondents appear to address spiritual pain and spiritual discomfort while aiming to provide spiritual comfort throughout the dying process. Providing spiritual comfort enhanced nurse-patient relationships while it also nurtured a sense of healing within patients throughout the dying trajectory. Frequently the nurses acted as patient advocates while also acting as mediator between patients and families as necessary.

7.6. Conclusion.

This chapter has presented the themes "preparing for death" and "comforting in dying" as encompassing the essence of expert palliative nursing practice. The process of preparation and comforting nurtured both the respondents and patients as they engaged in these processes. For some patients, there was limited time for them to avail

of the benefits of the knowledge and skills of the respondents, while for others the dying experiences were greatly enhanced by these interactions. The next chapter presents findings related to the experts' role in providing care for families as they experienced a family member receiving palliative nursing care, and the manner in which the experts supported these families.

CHAPTER EIGHT

PRESENTATION OF FINDINGS

THEME FIVE

THEME FIVE: FAMILY CARING.

8.1. Introduction.

As the nurse respondents reflected on their expertise, they described caring for family members as an integral component of nursing practice. They considered that it required equal attention to direct patient care. Many respondents acknowledged that it presented multiple challenges for them. The focus of family care was to provide appropriate care and support to them as their relative progressed throughout the 'living in dying' phase of their illness. On occasions, this presented respondents with challenging issues to confront, and difficult choices regarding the appropriate course of action to take. Respondents felt that families needed to know the reality of the situation; however, not all families were in a position to acknowledge this. The onset of death poses shared challenges to family members that require immediate and long-term adaptations within family functioning. They need to confront, in their own unique manner, the reality and inevitability of death of one of their members. For some, it may be the anticipation of a prolonged illness and retaining hope that helps them to adjust to their changing situation, while for others, denying the reality of their situation may be a coping mechanism to deal with their inevitable loss. Family care presents nurses with a challenge that requires a commitment to the family, that encompasses a process of seeking to understand their situation through engagement with them and an ability to move forward with them. Data obtained from the respondents indicates that there was a movement, a dialogue, an attempt to seek an understanding of family members through engagement with them, followed by a movement forward in coming to the realisation of what was happening within the family unit. Providing support so that families could function as units, whatever that may consist of, was the focus of family care.

Family caring as an attribute of expertise in palliative nursing practice presented itself as encompassing the following categories: "creating the awareness of living and dying", and "dealing with death and loss". These categories will be presented and

appropriate excerpts from the nurses' interviews and field notes will be included in order to reveal this component of expertise.

8.2 Family Caring: An Interpretation.

"Family caring" refers to the nurses' role in helping family members come to terms with the inevitable loss of one of its members and supporting them during and after the death occurring. As the onset and meaning of death are entrenched in the social construction of the family, family caring requires an ability to deal with the intricate elements of family functioning. Definitions and perceptions of families vary by culture and social group, so the nurse must take cognisance of the various factors that interplay in each family situation. This involves observing the prototype of family organisations, communication and the different levels of family functioning. Furthermore, the nurse needs to adapt interventions to encompass different levels of family functioning, and the state of family relationships prior to and following the loss of one of its members; he or she must act with tolerance and respect for different responses to loss.

8.2.1 CATEGORY 1: CREATING THE AWARENESS OF LIVING AND DYING.

8.2.1.1 "Creating the Awareness of Living and Dying" as Family Caring: An Interpretation.

"Creating an awareness of living and dying" for relatives involves bringing into the consciousness of the family member that fact that such events are occurring. It entails the creation of a consistent and cooperative milieu where a family's awareness of the reality of their situation becomes apparent to them. It involves a cohesive approach between the family members and the nurses to move forward in bringing to consciousness the inevitability of the approach of death. There is need for support for family members as they begin to let go of past events; the memories of such events that may in the future provide them with moments of joy and sorrow, accomplishments and failures, words spoken and unspoken. It demands a balance

between, creating a secure environment to deal with their situation on the one hand, while avoiding the creation of a threatening ordeal for family members.

8.2.1.2 “Creating the Awareness of Living and Dying” as Family Caring: Findings.

At a time when death is approaching, families encounter difficulties in maintaining both family integrity and the well-being of each family member. The approach of death in itself involves a long process, for some spanning a number of weeks, for others, ranging from a number of days to a number of hours. Furthermore, it is influenced by the families' perception of what “approaching death” means. For some, it may commence when their relative is admitted to the hospice, while for others it may be viewed as the stage of unconsciousness, when all communication ceases, to the time of death itself. Irrespective of their interpretation, it is a time when their ability to provide for their own needs, in terms of physical and psychological well being is jeopardised. The ability to function as a family may frequently be under threat as a result of the inevitability of death occurring within its structure. From the respondents' data, there was an ongoing awareness and concern for family members evident in each of the research sites. Nurses read the signals, both overt and covert, from families regarding their awareness of the onset of dying in their relative. The respondents interpreted the extent of the awareness family members had in relation to the reality of the situation they were going through. Reading and interpreting the covert signals regarding this awareness was one area that often challenged the respondents. This was in part related to an unwillingness of family members to acknowledge their situation and to allow the respondents to act as catalysts to build support systems within the hospice that were available to them. Overall, however, the majority of respondents encountered families that were willing to accept the respondents' input in providing family care. One respondent described her role in family care as follows:

+Nurse 36: “To me [family care] is a central focus of my care. ‘T is just the opportunity to get them to, to tune in to what the reality actually is. Sometimes

... the non-verbals that tell me, no, they're not aware things are as they are. It's a challenge for me..." +

Another respondent supported this when she said:

+Nurse 5: "They [families] are equal partners in all of this, we care for them as if they were patients too. And often times they're more fragile than the patient, we look out for them all the time" +

Creating the awareness in families of the onset of death seemed to be influenced by and centred on the nurses' own values regarding the nature of caring in dying. Data indicated that there was a sense of relatedness between the respondents, patients and patients' families. A number of nurse respondents attempted to enmesh themselves with the patients and their families so that they could attempt in some way to provide clarity regarding the ongoing events. This varied according to families' openness and willingness to become attuned to their situations and to read the signals that support from the nurses was available to them. There seemed to be a heightened awareness in the respondents to provide family members with the appropriate information about the patient's journey, which invariably was towards death, as they felt that family members were part of the caring process. One respondent described this as follows:

+Nurse 21: "Well, I suppose, quite often in palliative care we talk about somebody being diagnosed, and we talk here certainly about their journey towards death. And I suppose, you would want them to feel that they were being minded (e) and that anything that was going to occur could at least be explained ... And I think that particularly for family, (mh) some patients won't ask because they're feeling what's going on as it's happening, it's being explained. But it can be more difficult sometimes to the family who are watching, without feeling and without experiencing it, by being an outsider and it's to try and bring them in on it and feel part of it as well, which they are" +

The above excerpt infers the nurse's values about providing families with appropriate explanations as to what is happening with their relative. It infers a holistic approach to caring at this particular time with a focus on family inclusion.

For many of the respondents, getting to know patients' families and forming a connection with them provided the foundation of family care. The severity of patients' illness and the length of time they were in the hospice influenced the opportunities that

respondents had to get to know patients' families. Due to the fact that patients frequently died within the first few days following admission to the hospice, there was often limited time for respondents to get to know the families. This limited the extent to which the respondents were in a position to support them at that particular time. Furthermore, it limited the respondents' abilities to assess family situations. At times, families were present when the respondents were carrying out the patient admission assessment and were actively involved in providing information. For others, the opportunity to meet family members occurred at visiting time where patients provided the link between the respondent and the patient's family. One nurse described how she makes the connection with family members as a basis for providing care to them throughout the later stage of the patients' illness as follows:

+Nurse 16: "When families visit, sons, daughters visit, I try and make it my business and go to the bedside and introduce myself as a staff nurse working on the ward ... I hate going in at the very end, (moving towards me) introducing myself to sons or daughters without having contact with them on a prior basis, so I like to do that".+

Making the connection was considered as being important to the respondents, as it formed the basis for ongoing relationships with family members. Respondents regarded it as a means of getting a sense of the family situation in order to deal with issues that may arise for families at this particular time. There seemed to be a reciprocal exchange taking place from once this connection was made. This involved the family members receiving input from the respondents, while the respondents obtained valuable information from families in order to guide nursing interventions and deal with both patient and family issues.

While data revealed that making the connection with families was an essential aspect of creating the awareness in them regarding their relative's situation, the complexity of family structures called for a period of strengthening the connection with them. There was a need to maintain an open relationship with all of the members, as getting to know them and meeting them is a process that occurs over time. One nurse described this as follows:

+Nurse 24: “It goes through stages, obviously, as we’re getting to know the family, as we’re getting to know the patient because there’s a getting to know phase when people first come in. The first person you see is whoever comes in with the patient but often, closer family members or other family members who might be very significant in the patient’s life might appear later on or you might only meet them very gradually. Families are so complex [emphasis] and so different, it’s very hard to generalise about families actually because they are so unique and the dynamics can be so different”.+

Due to the fact that nurses provided continuous care to patients in all of the research sites, they formed a very valuable part of a multi-disciplinary team. It was considered important in all of the research sites that members of the multi-disciplinary team were aware of patient and family issues while they were in the hospice. Nursing staff made ongoing assessments of these situations and they were catalysts in arranging family meetings with the multi-disciplinary team members in order to extend the link to the other disciplines. These meetings took place on a regular basis in each of the research sites, often times being co-ordinated by the respondents. While these meetings provided a forum to address patient and family issues, the respondents’ input appeared to provide a holistic view of the pertinent issues that were arising in the course of caring for patients. These family meetings were described by respondents as follows:

+Nurse 7: “... we’re discovering where people are at. And they also discover where we’re at in relation to the patient. And I feel the family meeting is the big stepping-stone to link the patient with the family, and the family with us as the carers”. [emphasis]+

Another respondent described family meetings as follows:

+Nurse 36: “I think a lot of the time the one starting off strategy we would have would be to try and organise what we call family meetings. That might only involve one relative or two relatives. Generally we’d start off with some member of the nursing team who is comfortable with doing it and one of the medical team as well and we would just instigate a meeting initially just to fill them in on what’s going on, the progress, the care of the relative and that, and then a lot of issues can come out of that. We might subtly [emphasis] then try to ascertain whether there is anything else bothering them or anything else of concern going on and you will find that something will be said, a cue will be given for you to pick up on, and then we might decide maybe to get other family members involved if they’re concerned”.+

Field notes recorded in one site describe the process in which the above respondent facilitated a family meeting, attended by a spouse and two daughters.

+Field notes: Attended family meeting today. Nurse 36 was there and she directed the meeting. The consultant, social worker and one of the pastoral care team were there also. Nurse 36 introduced those present, including me. [I had already spoken to the family members and obtained their permission for me to be present, having explained my role in the meeting]. Initially, Nurse 36 invited the family to talk about the way they saw the situation at present. As they spoke, the daughters became tearful, however, the spouse remained composed as he spoke about the situation as he saw it. Nurse 36 paraphrased what she heard and invited them to expand further. They did so, and as each of the three family members spoke, Nurse 36 listened to them, nodded in acknowledgement of what they had to say and then synthesised the key points they had spoken about. When she did this, other issues emerged that were important for the family.+

While family meetings with the multi-disciplinary team provided a forum for sharing information between families and staff, respondents' also considered that the true picture of what was going on within the family situation may not be evident from the meeting. They considered that this was influenced by the relationship that members of the family had with each other. In such instances, families were provided with information in more informal ways, as described by this respondent:

+Nurse 24: "Quite often families are on their guard, because of three or four professionals who would attend (family meetings) and many of them together and they have their own ways of interacting and there are things they don't show in front of the others and so on, so families will often feel most comfortable to ask you things in the corridor, away from the patient's bedside rather than in front of the patient. That does happen a lot. Sometimes they need just to express how they're feeling, there's something significant going on with them".+

There appeared to be different reactions among families when they came to realise that death was approaching. Respondents attempted to create the awareness in families through dialogue, spending time with them and inviting them to participate in caring for their relative. Frequently family members participated in caring activities, such as helping with feeding activities, washing and grooming and in some cases, administering medications. Taking part in these activities promotes active involvement for families and it also creates an opportunity for partnership with nursing staff in providing care. One respondent described the value of such engagement in caring activities as follows:

+Nurse 1: "When I get them involved ... it can be a feel good factor for them. Suddenly they have a purpose, they're not as helpless, because they know they're making a difference and not just sitting and watching. And it might be the simplest of things like holding a cup, brushing their hair, you know what I mean. 'T is like they're crossing a boundary too, and often families say it makes things easier for them".

While the above respondent described the role of family members in caring activities, not all family members were in a position to become actively involved in caring. Some families struggled to accept the reality of their situation. This struggle frequently resulted in families expressing emotions, such as anger and denial. Furthermore, there seemed to be an effort on behalf of families to protect themselves from the reality of their situation. One respondent aptly described this when she said:

+Nurse 19: "Sometimes, families can get so angry at what's happening and going on. I try and work with them, talk to them, spend time with them and get them to see what's happening. It's not that they're angry with us, no; I think part of it is anger about their own loss, about the whole family upset. And I think too, there's some of that anger towards themselves, especially if they suddenly see what's going on. It's as if they've been living in the midst of all the changes, the illness and haven't confronted it. [emphasis] Then they feel guilty [moving towards me] they haven't done more and ask themselves why they didn't see what was happening".+

The above excerpt highlights the necessity for the respondents to accurately interpret families' reactions to the onset of death. Interpreting anger as a reaction to death needs to be considered in the context of each family situation. This interpretation needs to be guided by the nurses' knowledge of the family system and how this system actually functions. Furthermore, cultural differences in relation to the living and dying process in palliative care need to guide this interpretation. It was necessary therefore for respondents to form a connection with family members at an early stage in order to help families to deal with the shortfalls they may feel they had in caring for their family member. This assessment is ongoing; the respondents continued to support families in order to maintain their optimal functioning capacity.

All family structures are unique, and the process of creating the awareness of the onset of death was more difficult in some families than others. This was in part influenced by the presence of children in families where staff attempted in some way to help them

understand what was happening to their relative. Patients who were dying, in a number of cases, were parents or grandparents, sons or daughters, brothers or sisters. In cases where a parent was dying, it appeared more difficult to make the reality of the situation visible to the children. One respondent described this as follows:

+Nurse 17: "In some families it's easier than others, depending on the circumstances. If it's a young family, children involved, it makes it much more difficult and I'd say, sometimes, but not all the time, the awareness is lit up very dimly, almost as if the wattage is reduced to 20%, and mmm, I try to light it up brighter, [motions with hands] but this might not be possible".+

The above extract indicates that creating awareness in children regarding the onset of death posed a greater challenge for respondents than it did when adults were concerned. This in part may be influenced by the age of the children and the extent of their involvement with their relative in the stages of the dying trajectory. The above excerpt also indicates possibility that the awareness may become clearer as time goes by, when it may be illuminated further.

There were occasions when the respondents felt they were successful in creating the awareness of the reality of the situation, but they were conscious that this awareness may be influenced by the extent of the relationships they had with the other nursing staff and the rapport they had built with the family members over a period of time. For other respondents, creating the awareness never seemed to occur, despite their attempts to create that awareness.

+Nurse 5: "Yeah, I remember on a few occasions, yeah, I even remember the families, and I thought [emphasis] I had described things to them as they really were. 'T was as if they understood, but then 't was as if they lost what it was I had told them. And I think as a nurse, I have to keep this in my mind all the time, yes, just to remember it comes back to the listening and hearing when it comes to creating the awareness. Like, you know, I suppose, initially I thought from once things were explained as I felt in a language that they understood, I can never take it for granted".+

Families' presence with their relatives as they were dying was a frequent occurrence in all of the research sites. Where possible, family members were contacted when patients' conditions deteriorated and when it was felt that death was approaching. The respondents spent time with relatives as they arrived to be with their family members

as they were dying. The respondents made time to speak with the family members in order to explain their relative's condition to them before going into the patient's room. Having family members present at this particular time provided them with the opportunity to experience the reality of their situation and in some way, be present to the family member as they died. It also provided the respondents the opportunity to be present with the family members also. One respondent described this:

+Nurse 24: "In the terminal phase, a lot of about being there might be for the family rather than for the patient, as the patient slips further into an unconsciousness or reduced consciousness. Certainly there is total nursing care for the patient, a lot of our time would be spent really with relatives [motions with hands] and people often seem to really need explanation around that time of what is happening and what might happen. People sometimes look for answers [emphasis] that you don't have: can they hear me now? I think around that time, a lot of our actual time would be spent with families, and families are comforting a lot for the patient, in terms of their presence, in terms of their touch".+

For some of the respondents, creating the awareness of the onset of death consisted of identifying the actual physiological changes that take place as death approaches. While family members may not have an in-depth knowledge of these changes physiologically, the respondents explained them in terms that they easily understood.

+Nurse 23: "I would take a family aside, estimate the time and explain what was going to happen down to sort of their breathing is going to change, the gaps you'll notice will get wider, everything is slowing down, there will be no urine in their bag, all those sorts of things".+

Another respondent said:

+Nurse 33: "Keeping them up to date, explaining to them maybe how the focus of care was changing now... what they would expect, things like the patient's breathing, how it might change, how the coldness of the limbs, the colour of the patient".+

In summary, creating the awareness of dying as an element of family care provided several challenges to the respondents. It required an awareness of the overt and covert signs that families were aware of the reality of their situation. The process of creating the awareness was influenced by the relationship the respondents had with family members and also the type of relationships family members had with each other. The foundation for creating the awareness was getting to know family members. The

respondents made the connection with patients' families through personal interaction with them as they delivered care and when patients were admitted to the hospice. Family meetings also provided a forum for the respondents to assess families' knowledge and understanding of their situation, together with highlighting any further issues that may be present in families. For some, the awareness was created as their relative was dying when the physiological changes associated with dying were described; for others, their awareness of the onset of death resulted in anger and denial. However, irrespective of families' reactions to the dying process of their family members, the respondents created a supportive environment and instigated appropriate interventions in order to help them survive the reality of their situation so that they could continue to function as a family unit. The next section presents the findings related to dealing with death and loss as it emerged from the data.

CATEGORY 2: DEALING WITH DEATH AND LOSS AS FAMILY CARING.

8.3 Introduction.

Providing family care to family members in helping them to deal with death and loss constituted a large proportion of the respondents' activities when dealing with families. The process of helping families to deal with death and loss commenced by creating their awareness of death, as described in the previous section. However, data indicated that the focus of care in helping to deal with death and loss appeared to differ between families. This was influenced by family relationships, the extent of their awareness that death was inevitable and the acceptance of family members of the respondents' support throughout this time. This section presents the findings of the theme "dealing with death and loss" as family caring as it emerged from the respondents' practice and from the data analysis.

8.3.1 "Dealing With Death and Loss" As Family Caring: An Interpretation.

"Dealing with death and loss" refers to the nurses' ability to provide support to family members, both as their relative is dying and following their relative's death. It requires an ability to interpret individual losses for family members, both in the context of patients' gradual loss of physical, psychological, social, spiritual and cultural

functioning and with the loss of their presence following death. It involves nurturing both hope and acceptance within the family members; hope of a peaceful death and acceptance that the end of life has come for their relative. It is an enabling process that helps families in coming to terms with their loss. Activities centred on helping family members deal with death and loss are context specific and vary in intensity and duration.

8.3.1.1 “Dealing With Death and Loss” As Family Caring: Findings.

In an attempt to help family members deal with death and loss, data indicated that there was a form of movement taking place. This movement signified a journeying process, one that increased the focus on family members’ needs. The awareness of the impending loss of a family member prior to the actual death was a significant time for respondents to help family members come to terms with their loss. Throughout the dying stage of a patient’s illness, the extent of family-patient communication and interaction appeared to be limited. This seemed to provide some families with the insight as to what was ahead of them in dealing with the death of their relative. While patients continued to receive the nursing care they required, the focus on families increased at this time. One respondent described the change of focus on journeying as follows:

+Nurse 9: “OK, well some people [patients] come to their journey very quickly ... and some people come, you have time and you can see the signs [emphasis] are progressively getting worse ... Well, at that stage when the person is getting weaker, your journey is more with the family than with the person. So in actual fact, your journey is finished [motions with hands] in some sense with the patient ... we do communicate with them ... and we still talk to them, but most of my energy is going into the family at that stage. That can be very hard, because if the family have not been prepared, either by us or have refused maybe to allow themselves to think that they’re going to lose a loved one, it depends on what stage they’re at. So, I’m bringing them on a journey, more so than the patient. The journey for the patient has started a lot sooner before that ...”.+

The above excerpt highlights the significance of the journeying process for family members. It acknowledges that the time approaching death is just one aspect of a series of activities and events that families will encounter. Furthermore, while a focus

on patient care continued, the respondents' awareness of the families' needs at this time was apparent and of paramount importance. Another respondent described part of her role in the journeying process with families as follows:

+Nurse 23: "Sometimes, it's just sitting there, ... sometimes it's pre-empting the next thing that they're going to say to you. Just to be in and out of the room ... I don't stay out of rooms where people are dying, maybe that's the thing, I'm always in and out and around and sort of bringing them on the next little bit, the next little bit ... being with them".+

Findings indicated that providing opportunities for family members to become active in the journeying process appeared to help families come to terms with the death and loss of a family member. However, evidence of family cohesion and their willingness to participate in this role influenced the degree of activities in which family members participated. One respondent described how she facilitated a family member to become active in her spouse's journey shortly before his death as follows:

+Nurse 27: "I had one experience... there was a man with a brain tumour who had a partner and he also had children, [motions with hands] but he was so big, she couldn't look after him at home and he came in here and she wanted to be with him. So the night that I really thought was going to be his last night, I said to her, 'do you want to come to bed with him and hold him'. So she was delighted [emphasis] with that and I put her in with the cot sides up and put her in and she rang the bell in the morning and said, you know I think he's going, so I said, 'yeah, I think you're right, do you want me to stay with you or do you want me to go'. And she said 'no, I'll ring you when it's over'. But she just wanted confirmation that she was right in thinking that this was the end and that was obviously a very special time for her".+

While the respondent was conscious of providing the opportunity to the family member to stay with her husband, it is also evident that she was available to provide appropriate support to her throughout that particular time if needed. Not all family members were in a position to deal with the death of a relative as described by the respondent above. In contrast, one respondent described how her role in providing family care was that of "being with him" to support him in his grief. She commented:

+Nurse 16: "Well, I knew that the husband was very grieved and was finding it very difficult to see Lucy [pseudonym used] dying. So I was trying to support him really, be there, [speaks slowly] just what I think he wanted was just somebody to be there. He was frightened of being on his own. So I was conscious of being "just there", [makes inverted commas] not to say anything to him, but just to be there with him. Just to support him".+

Incorporating the religious elements of dying constituted part of the respondents' skills in helping families deal with death and loss. While some families did not consider it a priority to have a minister of religion present as death approached, a number of the respondents felt confident in praying with the family members. One respondent described this as follows:

+Nurse 20: "Well at the time of death, if it's a particularly religious family, I would always ask if they want any particular prayers said; [makes inverted commas] sometimes they ask for a priest and the priest isn't always here; I'm quite comfortable praying with them and they are usually grateful for that, some others aren't... for some people it's a special time, they want to be on their own".+

While the respondents participated actively in caring for families throughout the dying process, families were provided with the opportunity to direct activities with their dying family member. Relatives were empowered to co-ordinate activities at that time as respondents considered this as being an important aspect of the grieving process for families. One respondent described this as follows:

+Nurse 25: "Well sometimes you'll have somebody who will take the lead in the room anyway, an aunt, or somebody who will want to say prayers, she'll take the lead and you know there'll be somebody strong there that all the other relatives look to".+

However, the above respondent went on to confirm that not all families accepted the empowering role when dealing with death and loss. This in part may be related to their grief reaction, not having experienced the death of a family member previously or they may not wish to take on the role of leader at this particular time. In situations such as this, the respondent used the opportunity to direct the family activities. This is evident in the following excerpt:

+Nurse 39: "Other times, there's nobody taking the lead and there's emotions everywhere, [emphasis] and it's getting out of control. And I often find somebody has to take control of the reins at this point and that can be me. So you orchestrate it ... because they're emotional and you might have to say, like often there's family members who don't get on together so you're working out who can be in the room and who can't and make sure they're comfortable...sometimes, it's easier for me to do that".+

Findings indicated that being present for family members as death approached also allowed families the opportunity to commence a process of “letting go of the relative”. It is difficult to identify when the process of “letting go and moving on” from the actual death commences and ceases. In some instances, family members may not want to let go and they remain in a “status-quo” position. For others, the process commences as the patient loses consciousness and is no longer in a position to communicate with them. One respondent described her role in family care at this particular time when she said:

+Nurse 21: “I suppose it happens more when patients are unable to talk any more, or you know families, or as they lose consciousness, or as they sleep more, mmm, families tend to talk to us more because there’s less to do for the patient. You know, they don’t have to be company for the patient; the patient isn’t there for them to talk to, so they talk to us instead. And that’s the time we sit in the room for a little while with the family. That is often the time when they’ll, you know, start to tell stories about funny times and the olden days [swaying in chair] and that sort of thing, and that, I feel, is part of letting go, remembering how they were, which is what you do when somebody dies, you know. So it’s part of the grieving process, [pause] the beginning”.+

The respondent’s role in the above excerpt highlights the importance and value in giving time to family members, so that they can share significant events with them. It infers a time of reflection for families when they talk about past family events and occasions. Furthermore, listening to the relatives at this time also provided the respondents with an insight into family relationships, both in the past and in the present. It also presented itself as a time for family members to be supported.

Moving on from the event of a death can be difficult for family members. However, as staff were aware of this, they attempted to facilitate the family members in some way to let go and move on. In some cases, this process appeared to start at an early stage, even when the patient was still alive. It seemed as if the respondents anticipated the possible reactions to death and tried in some small way to help reduce the impact that the death would have on family members. This is when they commenced preparing them early for the onset of death, when they would have to part with their family member.

+Nurse 13: “I think as patients are admitted, I like to bring the family along with what is happening. [pause] A lot of it is having some way to start from an early stage by putting it to the family that well, they need to be thinking about what’s likely to happen soon and help them get ready for that. And it’s often a matter of connecting [frowning] with them early on and putting it to them’ in plain language, that this is it. So when the time of death comes, well they’re somewhat prepared to deal with their loss”.+

It appears from the above excerpt that the respondent was aware of the value of keeping family members informed of the reality of their situation through frequent conversations with them. While for this respondent, the input was valuable in helping families to move on and let go, it appears that allowing families to move on from the situation at their own pace promotes a sense of healing from the situation. It also helps them to return and maintain a family functional role following the death. One respondent described how she helps families move on at their own pace in their effort to deal with the situation.

+Nurse 20: “I let them dictate the pace, the actions, the whole thing as much as possible, and I’m there for them. Like, [pause] as you’ve been here yourself for a few deaths and they’re all so different, some families aren’t able to go with it or think of what’s to be done. Like the other day, you saw them able to say exactly what they wanted and they did it. You know, for them, that was a kind of moving and letting go, yes, I think that was their way of starting to let go, when they played the music, talked a lot about the times they shared...and there’s the others that can’t talk, so profound [emphasis] in grief that they want to hold on, keep things as they are. And I like to let them go with that for as long as I can ... and I feel that helps, definitely. It’s a healing for them in a way”.+

The above two excerpts provide insights into the process of letting go and moving on from a relative’s death; the different approaches used to facilitate this process highlight the need for the respondents to assess the most appropriate method to use in each family situation. It also signifies the importance of creating a connection with family members and addressing their reactions to the dying process according to the families’ responses to the situation.

A number of the respondents facilitated the patients creating their own way of helping families deal with their loss. It appeared as if patients sensed their families’ loss and wanted in some way to help them in coming to terms with this. This form of family

care, while focused on patients' actions appeared to instil a deep sense of meaning for patients. Some of the respondents assisted patients with activities in order to help families deal with their loss. One respondent described how she worked with patients to create memory boxes as a means of helping their families after their death.

+Nurse 32: "I suppose it was just working with them ... letting them talk out their fears and trying to ... sort of help them, maybe with devising memory boxes or writing letters for their kids for when they're sixteen, for a lot of them it's their family, oh how's my family and my husband going to cope ...".+

Another respondent described how one of the patients she cared for creatively constructed visual memories of his life through significant photographs of life events to leave his wife and family.

+Nurse 13: "He loved photography [emphasis] and he had a lot of his albums here with him. So he came up with the idea of making a special album for his wife and family and he wrote something under each of them, a little message to them, so it would be a memory of him for them. So we did that and he had it in his locker so when his wife would be taking home his belongings, she would get it then after he had died. He died three days after finishing it".+

The expert's input into the above activities highlights the influence of the respondent's personal values in having significant memories created by the patient as a means of helping to comfort his family members and in some way, help them to move on from his death. It also adds to the possibility of families continuing to function within the realm of absence and grief and retuning to normality after the death.

While the nurse respondents provided support to family members, data suggests that throughout this process, family members generated a link with the respondents. While the extent and significance was varied between family members and the respondents, it also presented a challenge to many of the respondents to break the link and to disengage from families following a patient's death.

+Nurse 40: "You can only come so far with the family ... the travelling with them can be a time of great sadness for them on one hand. On the other hand, there's the satisfaction when you see how you have brought them on their journey and come out the other side of ... but some have difficulty in letting you [emphasis] go, they still might want you to travel with them for longer".+

Another respondent expressed similar views, as follows:

+Nurse 1: “You get to know them so well and they get to know you, that it can be hard to let go of them. [reflecting] Mmm, the time comes when you have to cut away from them ... they have to go on their own from a certain point ... and you have to be happy with that ... you have to break that bond”.+

While the above respondents acknowledged the necessity to allow families move on in their situations, immediate responses and reactions to the death of a family member formed part of a major adjustment to this event. While the respondents were active in caring for patients and relatives, their contact after the death often continued for a period of time. This time varied from person to person, depending on the families’ needs to return to the hospice for further support. Many of the hospices offered bereavement follow-up sessions where families were invited back to the hospice for a service of remembrance. They were also provided with the opportunity to receive further support in dealing with their loss. Many of the respondents were present at a number of these sessions and it marked a time for moving on for many families. One respondent described one such meeting as follows:

+Nurse 3: “A lot of the time it comes down to having the families back at a later stage. We have bereavement follow up sessions here and we meet them again when they come back. For some, it can be very painful and it’s a part of the journeying for them through it all too. It’s as if it’s time to break the connection with the hospice too, or others choose not to break it for years. So often when they come back, they talk about their relative and maybe mention the things the nurses might have done for them and their relative and that it meant so much to them. Sometimes they’ll actually acknowledge that they’re now moving on from it, leaving it behind, but that can take a long time”.+

As a component of the respondents’ involvement with families entailed getting to know them and developing a relationship with them, it was inevitable that this relationship would come to an end following the death of the family member. Some respondents felt they had developed a deep sense of knowing the family and felt as though they had become part of the family, in the sense of knowing them and interacting with them as they visited their relatives in the hospice. One respondent described her feelings when the connection with families ceases after the death of a patient.

+Nurse 23: “I’m also quite sad when families leave because you don’t know the rest of the story, so you sort of become that family or part of that family or

an added on bit to that family and then, the story ends for you there, but they continue on. So there is a part of you that goes with them or a part of you that's so involved with them that it's not just about being physically with them, not mentally, more spiritual than mental".+

Providing family care by supporting family members through their loss and dealing with death is complex. It required the respondents to possess a range of interpersonal skills and knowledge regarding family functioning in order to facilitate families to come to terms with their loss. The role of the experts in this study indicates that being with families helps families to come to terms with the events as they occur. Respondents seemed to journey with the families, and also offered them choice and support. Many of the respondents empowered families to orchestrate activities around the time of death, while they were there to support them if necessary. Assisting relatives to move on and let go, as a consequence of death was highlighted as being a significant part of the respondents' role. In part, respondents facilitated patients to create significant memories for families in an effort to provide comfort to them after their relative's death. The respondents also offered bereavement support in many research sites as part of their role in caring for families.

8.4 Conclusion.

The essence of expertise as it is revealed in the daily practices of expert palliative care nurses in in-patient hospice units in the Republic of Ireland highlights the role of nurses in providing essential care to families in dealing with the dying and death of a family member. Because family structures vary and are unique, there is a demand for care that takes cognisance of these unique family structures and the manner in which they respond to the death and dying of one of its members. A key aspect of providing appropriate family care is in the nurses' ability to form a connection with the family in the early stages of their family member's illness. Making this connection forms the genesis of enhanced relationships so that appropriate family care can be provided that is based on each unique family situation.

CHAPTER 9

DISCUSSION OF FINDINGS

9.1. Introduction.

The purpose of this chapter is to provide a discussion of the findings that emerged from this study. These findings generate valuable insights into the nature of expert palliative nursing practice. Findings presented in Chapters 6, 7 and 8 provide enlightenment as to the complexity of expert palliative nursing practice. Analysis of data from this study indicates that the nature of expert palliative nursing practice consists of the processes of presencing, comforting, journeying, preparing patients for death, and family caring. These practices were performed at various levels of intensity and duration and were governed by individual patients' needs. These practices were delivered along patients' living-dying trajectory, where nurses endeavoured to meet the various needs that arose during this time.

The focus of caring centred on maintaining the personhood of patients in their care. The constituents of patients' personhood varied; however, patients' personhood remained central to all nursing actions. The degree of nursing interventions required by patients in order to maintain their personhood depended on the degree of integration of patients' personhood. While practice focused on maintaining patients' personhood, this took place within the sphere of helping patients function at their optimal level through living with their dying, hence, the conceptual framework: "Fostering an Optimal Functioning Self Through Living with Dying" was generated from the study findings. This framework is grounded within the practices of the respondents and provides new insights through which to understand the nature of expertise in palliative nursing practice.

9.2 Limitations of this Study.

This study has the following limitations:

1. The study focused on palliative care of patients suffering from cancer; hence the findings are limited to the concept of expertise within caring for patients with cancer.

2. The findings focus on the practice of expert palliative care nurses within in-patient hospice units only. These findings cannot be generalised to expert palliative care nurses who are engaged in palliative nursing practice in other palliative care settings, such as home care services and hospice day care units.
3. The translation of the writings of the philosophers Schleiermacher and Dilthey to English increases the variations of meanings that emerge from the original text. The generation of each reader's interpretation therefore may not be consistent with the authors' original meaning and understanding.
4. The use of hermeneutics as a research methodology has resulted in one interpretive understanding being presented. Additional interpretations may emerge from different readers of this thesis.

9.3 Statement of the Problem.

The literature review presented in Chapters 1 and 2 provided an overview of the nature of caring, nursing, knowledge, expertise, palliative care and palliative nursing. This literature presented both theoretical and empirical findings that attempted to clarify the nature of the above concepts. While numerous attempts have been made to explicate the nature of caring, the debate continues as to what constitutes caring, particularly within a specific specialty of nursing. This problem is further compounded by the uncertainty regarding the nature of nursing. While Nightingale (1992) is regarded as being the founder of the discipline of nursing, numerous theorists have attempted to conceptualise nursing practice, focusing on the paradigms of nursing, namely, man, health, nursing and the environment. Nonetheless, while the works of theorists provide a systematic framework within which to view nursing, there is an absence of direction as to how each paradigm is operationalised within a specific discipline of nursing. There is an affinity between caring and nursing, however, a deficit remains within the literature as to how caring is operationalised within various specialties in nursing. Such a deficit increases the risk of devaluing the nature and contribution of nursing to the caring process and ultimately may result in a reduced standard of care.

The possession of knowledge for practice forms an essential element on which nursing practice is based. Carper (1978), White (1995), Silva, Sorrell, and Sorrell (1995) and Liaschenko and Fisher (1999) provided valuable frameworks within which to conceptualise the nature of knowledge. Despite this, however, the nature of knowledge within nursing remains intricate and difficult to describe. Furthermore, the manner in which knowledge for nursing practice is operationalised varies within nursing specialties, making it difficult to articulate the nature of specialist nursing practice.

Expert practice in nursing has been the focus of numerous studies, including ambulatory care settings (Brykczynski 1989), psychiatric nursing (McElroy 1990), critical care nursing (Walters 1992), nurses working on surgical wards (Logan and Boss 1993; King and Macleod Clark 2002) and public health nursing (McMurray 1992; Langley 1997). Benner (1984) has been credited with initiating several studies regarding the nature of expert practice, and findings from these studies have been used in the generation of competencies and skills in nursing practice. However, there remains a deficit in explicating the practices of nurses working in the specialty of palliative nursing practice, where nursing practice is focused on providing care to patients who are dying. Caring for the dying is complex and multidimensional. Identifying the specific nature of expert palliative nursing practice and how it differs from other areas of nursing practice will help identify the unique nature of palliative nursing practice. Identifying the constructs of caring in palliative nursing practice will allow for the development of nursing practice that meets the needs of dying patients and their families. Furthermore, it will contribute to the development of curricula on which to base theoretical and practical guidelines for practice.

The nature of palliative care has been presented in the literature review, and while studies have been undertaken that describe aspects of palliative nursing practice, no other study was located that provided an all-encompassing description or account of palliative nursing care. Additionally, no other studies were located that make explicit the practice of palliative care nurses who are considered to be experts in palliative nursing care. It is essential that these practices are made explicit so that they may be understood. Without this understanding, the care of dying patients may not be

delivered to optimal capacity, where all the needs of dying patients are met. Furthermore, without this information, educational preparation of nurses practising in palliative care falls short of meeting their needs, potentially reducing the quality of care at this critical time of life.

9.4 Research Design and Methods Used in this Study.

This study was guided by hermeneutics, the philosophy of Schleiermacher (1977, 1990), Dilthey (1990), Heidegger (1927 / 1962) and Gadamer (1975, 1989, 1996). Various researchers have used hermeneutics as a guide to nursing research. These include Eberhart (1992), Diekelmann (1993), Walters (1992), Reed (1994), Draper (1997), Peden-McAlpine (2000) and Spence (2001). While these studies provide insights into the value and use of hermeneutics as a research design in nursing research, they lack clarity as to the manner in which the authors engaged, in order to make their understandings explicit. The use of hermeneutics in this study has attempted to overcome these limitations. Interview and observation data were obtained from forty registered nurses who were considered to be experts in delivering palliative nursing care to patients suffering from cancer in in-patient hospice units in the Republic of Ireland. Interview data were also obtained from eleven patients who were cared for by a number of these expert nurses. These patients provided information regarding their views and experiences of receiving expert palliative nursing care. The inclusion of these data supports the nurse respondents' views and enhances the credibility of the research findings.

9.5 Expert Practice in Palliative Nursing Practice: A Hermeneutic Analysis.

9.5.1 Research Aim.

The overall aim of this study was to make explicit the caring practices of expert palliative care nurses in caring for patients who are dying and to develop a conceptual framework that depicts the practices of these nurses.

9.5.2 Research Question.

This study was guided by the following research question: What is expertise in palliative nursing practice?

9.5.3 Research Findings: Development of a Conceptual Framework.

The essence of expertise in palliative nursing practice is a complex phenomenon. The phenomenon, as it has emerged from my interpretation of the data, suggests that expertise in palliative nursing practice is comprised of five themes: “presencing to the patient and family”, “journeying”, “preparing for death”, “comforting in dying” and “family caring”. Data obtained from interviews with eleven patients who were cared for by a number of these experts supports this interpretation. The practice of expertise in palliative nursing practice that emerged from this study may be understood within the conceptual framework “Fostering an Optimal Functioning Self Through Living With Dying”. This conceptual framework provides a new perspective through which to view the essence of expert palliative nursing practice. This practice framework is centred on patients’ personhood, which guides the extent to which nursing interventions are instigated in an attempt to foster optimal functioning in patients who are dying.

The conceptual framework is multidimensional and, while each concept of the framework is presented individually, there is constant interaction between each of the elements of the framework. In the presentation of my findings, I have highlighted the approaches used by the respondents that led to the development of each concept. While a number of these approaches to caring have been identified in the literature, the findings of this study highlight new strategies and relationships in caring, particularly within the context of death and dying. The complexity of expert practice in palliative care, as interpreted by me through interviews and observation of the expert nurses’ practice, provides a new way to consider expert practice and adds to the body of knowledge and to the development of palliative nursing practice. “Fostering an Optimal Functional Self Through Living with Dying”, as it emerged from the findings

of this study, is discussed within the constructions of “self” as described in a number of theories on dying.

The results of this study contribute to developing a conceptual framework within which to make explicit the essence of expertise in palliative nursing practice. Figures 9.1 to figure 9.5 provide a diagrammatic representation of the manner in which nursing practice is influenced by the location of patients within the living-dying trajectory. This representation provides a mechanism to understand the intricate nature of expert palliative nursing practice; the numbers of concepts are in constant interaction and constantly shifting as patients’ progress through the living-dying trajectory. The personhood of the patient provides the centrality for practice. Expert nurses never lose sight of the individuality of patients in their care. The personhood is located within the living-dying trajectory, which is not a linear process. As patients progress along this trajectory; there are various needs that require attention. Findings indicate that these needs include the need to be present to the patient, the need to provide family caring, the need to help patients prepare for death, the need to journey with patients and the need to provide comfort. The extent to which each of these needs is demanded depends on where the patient is located within the living-dying trajectory, and the extent to which their personhood is maintained. The aim of maintaining the personhood of patients is to support the patient in maintaining optimal functioning throughout their living in dying. Each patient dictates the degree of optimal functioning as they strive to maintain their living in dying.

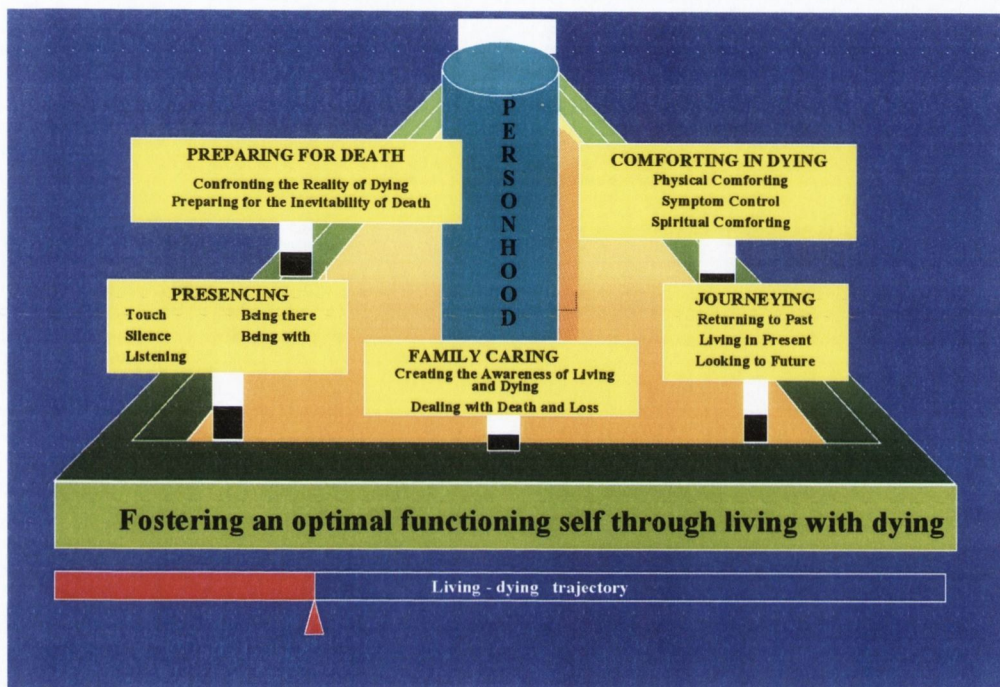


Figure 9.1 Conceptual Framework of Essence of Expertise in Palliative Nursing Practice as Depicted Within “Fostering an Optimal Functioning Self Through Living with Dying” Framework.

Figure 9.1 depicts the “personhood” of the patient as the recipient of care as being the central at a given point within the living dying trajectory. Nursing interventions focus primarily on “preparing for death” and “family caring” in order to foster patients’ optimal functioning through living with dying. While “comforting in dying”, journeying” and “presencing” also form elements of care, they are required to a lesser extent than “preparing for death” and “family caring” at this particular point in the “living-dying trajectory”.

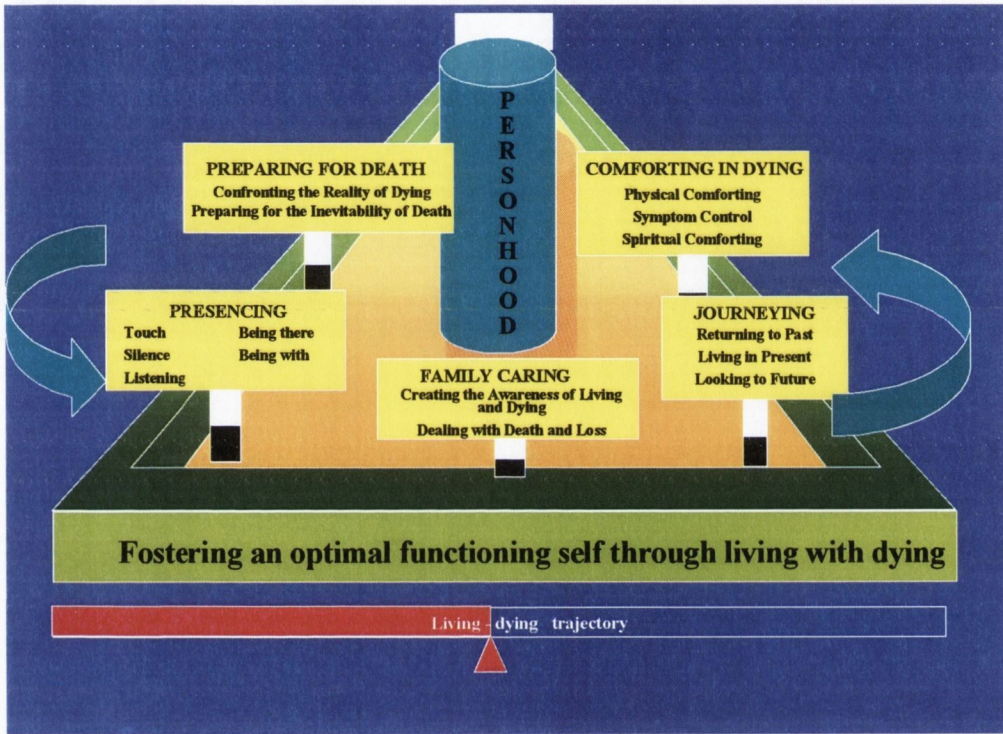


Figure 9.2 Conceptual Framework of Essence of Expertise in Palliative Nursing Practice as Depicted Within “Fostering an Optimal Functioning Self Through Living with Dying” Framework.

Figure 9.2 depicts the onward progression of the “living-dying” trajectory. The personhood of the patient remains the central aspect of care. In an attempt to foster optimal functioning in the patient, there is a shift in the need for nursing interventions. This shift is in constant motion, the degree of which is influenced by patients’ requirements in maintaining their optimal functioning self through living with dying.

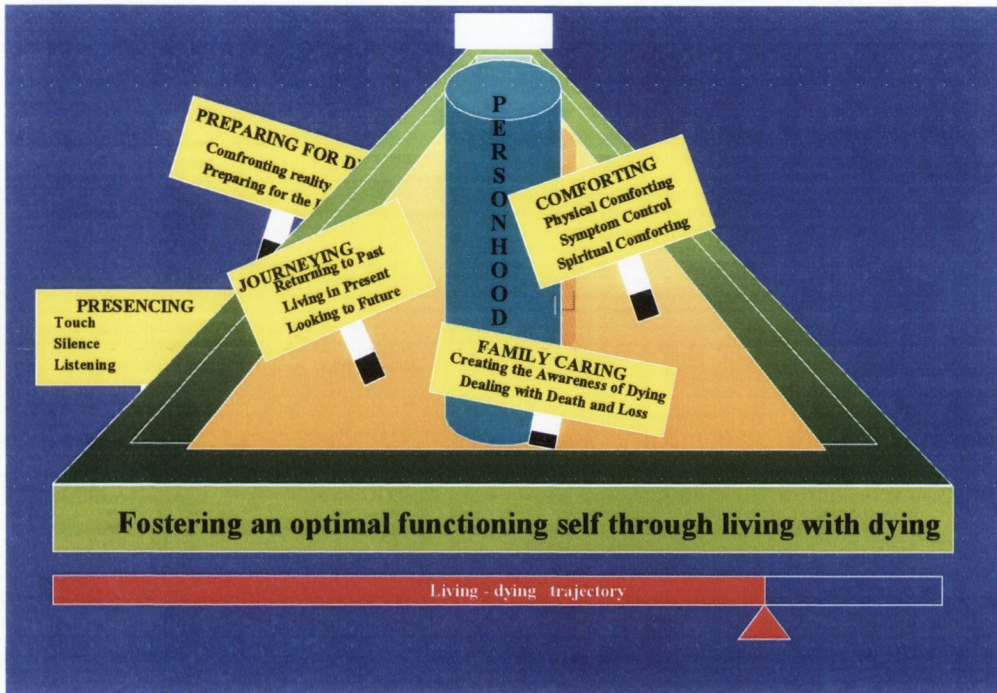


Figure 9.3 Conceptual Framework of Essence of Expertise in Palliative Nursing Practice as Depicted Within “Fostering an Optimal Functioning Self Through Living with Dying” Framework.

Figure 9.3 depicts the onward progression of the living-dying trajectory. The personhood of the patient remains the central aspect of care. As the “living-dying trajectory” progresses onwards, the extent of nursing interventions required through “presencing”, “preparation for death”, “comforting”, “journeying” and “family caring” changes. Within each element of care required, there is a variation in the need for care. Each aspect of care is required at different degree of intensity in an attempt to maintain patients’ “optimal functioning self” through living with dying.

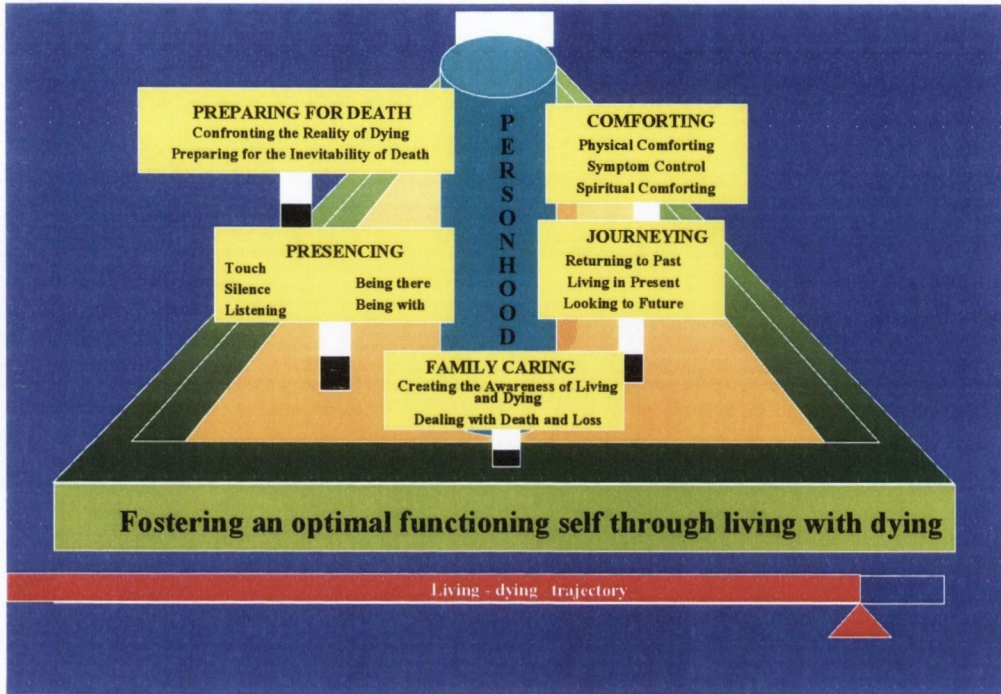


Figure 9.4 Conceptual Framework of Essence of Expertise in Palliative Nursing Practice as Depicted Within “Fostering an Optimal Functioning Self Through Living with Dying” Framework.

Figure 9.4 depicts the onward progression of the living-dying trajectory. The personhood of the patient remains the central aspect of care. As death approaches, there is an increase in the need for assistance to maintain an “optimal functioning self”, within the person of the patient. The extent to which nursing interventions are required are guided by patients location on the “living-dying trajectory”, degree of functioning and the patients personhood.

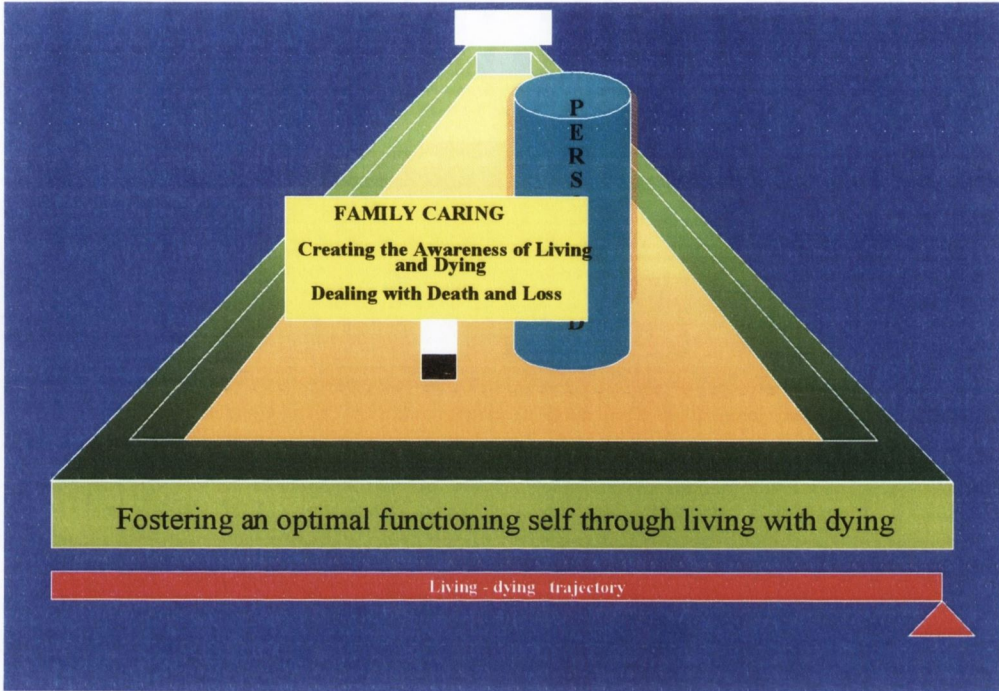


Figure 9.5 Conceptual Framework of Essence of Expertise in Palliative Nursing Practice as Depicted Within “Fostering an Optimal Functioning Self Through Living with Dying” Framework.

Figure 9.5 depicts the completion of the living-dying trajectory. Death has occurred for the patient, however, the patient’s personhood lives on for the family members. Nursing interventions focus on family members through “creating the awareness of living and dying” and “dealing with death and loss”. There is a continuous challenge for family members to maintain their “optimal functioning” through living with the dying of their family member.

9.6 Conceptual Framework of Essence of Expertise in Palliative Nursing Practice as Depicted Within “Fostering an Optimal Functioning Self Through Living with Dying” Framework.

9.6.1 Fostering an Optimal Functional Self Through Living with Dying: Background.

The concept of “Fostering an Optimal Functioning Self Through Living with Dying” provides a conceptual framework through which to describe the essence of expertise in palliative nursing practice as expert nurses care for people in their living in dying. This framework, set out above, depicts the phenomenon of expertise as it emerged from the data gathered in the study. Each concept was realised in the practice of experts, and this required helping patients to achieve an optimal functioning self. Five concepts emerged from the findings of the study. These are “presencing”, “journeying”, “preparing for death”, “comforting in dying”, and “family caring”. Each concept is subsumed within the context of “the nurse-patient relationship”, which forms the core of expertise in palliative nursing practice. The centrality for optimal functioning is that of maintaining the personhood as much as is possible for each specific patient. The degree of function for each patient differed and was influenced by their location within the living – dying trajectory through their dying process.

9.6.2 Fostering A Functional Self: Origins.

The notion of self is not a new concept in the nursing literature. Reference has been made to “self” in the work of Goffman (1971), Neisser (1988), Peplau (1988), Gullickson (1993), Greene and Ugarruza (1995), Orem (1995), Copp (1999), Dobratz (2002) and Lawton (2000). Additional studies by Siegel and Morse (1994), Morse and Carter (1995) also provide valuable insights into the concept of self throughout the progression of acute and chronic illness. Freshwater (2002) provides a comprehensive review on the nature of self, citing work addressing the notion of “self” in the context of psychology, biological terms, modernist terms and post-modern terms. However, while the “self” has been addressed in the literature, it was not until Geanellos (1997) attempted to explicate the practice knowledge in adolescent mental health nursing that the concept of “Fostering a Functional Self” emerged.

Geanellos (1997) first developed the notion of “Fostering a Functional Self” in the context of adolescent mental health nursing in an attempt to explicate the knowledge that informed the nursing practice on residential mental health nurses. The study was guided by the research question: “What do nurse’s and adolescent’s stories, arising from experiences of nursing or being nursed on residential adolescent mental health units, reveal about the knowledge informing practice within that context?” (Geanellos 1997: 1, 220).

Guided by the philosophy of Heidegger, Gadamer and Ricoeur, Geanellos (1997) surveyed and interviewed seven nurses and seven young people being cared for by them in an attempt to answer the above research question. The findings of her study indicated that the elements of practice knowledge emerged as a) engaging in a therapeutic relationship, b) providing a therapeutic milieu, c) guiding potential for change and d) facilitating a positive outcome. The above sub-elements were then developed and defined and from this process, the meta-element of “fostering a functional self” emerged. For Geanellos (1997: 214), fostering a functional self was reflected in the way nurses “...strove to assist adolescents to change the thoughts, feelings and behaviours that resulted in dysfunction in themselves, their relationships with others, or social systems”.

Geanellos (1997) described how nurses accomplished a functional self within the adolescent mental health unit through helping adolescents develop a positive image of themselves, by helping adolescents perceive themselves differently through role modelling behaviours, and through drama. The outcome of fostering a functional self resulted in a change in the adolescents’ behaviour. Adolescents moved from a state of dysfunction to a state of function as a result of nurses’ interactions and interventions. Both dysfunctional and functional states differed according to individuals; however, Geanellos (1997: 215) argues that: “ All hope for some form of resolution...for change, for enhanced well being, for improved relationships and the ability to move on in their lives”. The process and outcome of achieving a functional self was unique for each individual. Nurses in Geanellos’ (1997) study facilitated movement towards a

functional self, based on the adolescents' individual needs. The outcome of achieving a functional self in adolescent mental health nursing resulted in the individual being in a position to "... live more ably in relation to self and other" (Geanellos 1997: 219).

I propose that the composite of expertise in palliative nursing practice extends this framework within the realm of expert palliative nursing practice. Expert palliative nursing engage in optimising a functional self through living with dying for patients and their families. "Optimal functioning" in the context of this study is one that helps patients to continue living with their dying. "Living" for each patient was different, and hence the degree of optimal functioning within patients' lives differed. Furthermore, the actions of the expert nurses also differed in the degree in which they were required to support patient functioning, as patients progressed in their living in dying through the living-dying trajectory.

9.6.3 "Fostering an Optimal Functioning Self Through Living With Dying": New Framework.

The previous section provided an overview of the work of Geanellos (1997) in developing the framework "Fostering a Functional Self"; I propose that I have expanded the work of Geanellos (1997) within the context of this study. As the nature of dying involves the duality of roles, that of living with life and living with dying, there is a need to provide care and support to dying patients so that they may live optimally within both of these roles. Additionally, there is a challenge for nurses to maintain patients' personhood as they progress along the living-dying trajectory. Without centring practice on patients' personhood, there is a danger that the patient will experience a phase of unravelling, increasing the risk of pain, suffering, rejection, trauma and turmoil within their living-dying process (Byock 1997; Byock and Merriman 1998). As there is no clear demarcation between the roles of living with life and living with dying, there is an increasing challenge for nurses as caregivers to provide optimal support to patients throughout this particular time.

I propose that the word "optimal" is added to the title of the conceptual framework, as it implies that the level of optimal functioning is personal, unique and transient as the

patient progresses through the living-dying trajectory. The degree of optimal functioning changes as patients progress through the dying trajectory, thereby requiring the nurse to gauge, monitor and instigate appropriate care and support within the realm of optimal functioning for the dying person, while also supporting the patient's personhood. This is necessary so that optimal functioning is attained. "Optimal" is defined in Collins English Dictionary (2000) as "best possible, most favourable" and infers the transient nature of the concept and also the individuality of the concept for the person concerned, as there are no boundaries, no maximum or minimum level for it. In other words, it is what the patient says it is, and it is also within the construction of the self within the living – dying trajectory. There are various degrees of optimal functioning, and I propose that the degree of optimal functioning is influenced by the stage of the dying process people are at within any given time. However, the degree of optimal functioning is contextual - that is, it is within the living-dying process.

9.6.4 Context of "Fostering an Optimal Functioning Self Through Living with Dying" Within Theories of Death and Dying.

A number of theories have attempted to conceptualise the nature of dying. These include the work of Glaser and Strauss (1965), Kübler-Ross (1969), Pattison (1977), Corr (1992), Buckman (1998) and Copp (1999). As these theories indicate, the various constructions of self in dying that have provided numerous insights into the progression of living towards death. These range from Glaser and Strauss's (1965) "Context of Awareness Theory"; and Kübler-Ross's (1969) "Five Stage Model of Dying" to Copp's (1999) "Readiness to Die Theory". The various transformations that are portrayed within these theories require a variety of nursing interventions in order to help patients meet the challenges with which they are faced as they progress through the living-dying trajectory.

I propose that, from the findings of this study, there is a retransformation in the function of the dying person in their effort to deal with each stage of the dying process, particularly as the inevitability of death looms on their horizon. Charmaz

(1983), Lynam (1990), Gullickson (1993) and Jones (1993) consider that throughout a life-threatening illness, when death is imminent, individuals examine and redefine themselves. As re-transformation takes place within patients as their condition deteriorates, patients can no longer remain independent in meeting their own unique needs, not only from a physical point of view but also from a psychological, social, cultural and spiritual perspective. Such a progression poses a threat to patients' personhood and presents nurses with the challenge to maintain patients' personhood within their caring practices. As needs remain individual and unique, there is a demand for individuality in assessing and meeting these needs. The findings of this study indicate that the practices of expert nursing in palliative care practice are centred on facilitating patients to meet their needs, from an individual perspective. Nursing interventions meant that patients were in a position to maintain their optimal functional self as they progressed through their dying trajectories. Furthermore, this optimal functioning took place within the realm of each patient's personhood, so that nursing interventions took cognisance of the individuality of each patient. The expert nurses involved in this study were aware that patients' changing health conditions presented patients with different challenges and problems; however, in their nursing actions, the experts attempted to optimise patients' functional self in order to deal with these changes. The value of the findings from this study is that they provide direction for nursing interventions in order to meet patients' needs throughout the process of dying from a number of theoretical perspectives.

9.6.5 Context of "Fostering an Optimal Functioning Self Through Living with Dying" Within the Context of Personhood.

Analysis of data from this study indicates that the delivery of palliative nursing practice took place within the context of supporting and maintaining the personhood of patients in the expert nurses' care. While the concept of personhood has emerged in the literature in the past, particularly within the context of dementia care and long-term care (Jenkins and Price 1996; Kitwood 1997; Coker 1998; Pierce 1999), a major focus of fostering an optimal functioning self to patients as the focus of palliative

nursing practice may be understood within the concept of maintaining patients' personhood.

The intricate nature of personhood is evident from various models of personhood that have been proposed. The work of Warren (1973), Neisser (1988) and Cassell (1982) provide diverse conceptualisations of personhood through which nurses can understand what patients experience throughout the dying process. Neisser (1988) proposes that the person is composed of a number of elements, each contributing to the creation and development of the personhood. These include the biological self, interpersonal self, extended self, the private self and conceptual self. As death approaches, there are elements of disintegration of the personhood as the individual is no longer in a position to maintain the "self" in dying. While such a conceptualisation of self takes cognisance of numerous aspects of personhood, it appears limited in its focus. It provides limited insight into the complexity of personhood and the interplay that takes place in forming an integration of each of the elements of personhood.

Additionally, Warren (1973) points out that personhood encompasses six elements. These include consciousness, reasoning, self-motivating activity, capacity to communicate, the presence of a self-concept and self-awareness. Within the realms of palliative care, Warren (1973) provides a credible focus for care, saying that consciousness encompasses the persons' ability to experience emotions, such as joy, sorrow, and anger throughout the dying process. Additionally, the aspects of reasoning and capacity to communicate are relevant within the context of palliative care and palliative nursing practice. The presence of a self-concept and self-awareness as addressed by Warren (1978) also present important elements of holistic care during the dying process. However, Warren's (1978) model is limited, as the complexity of each element appears to take focus solely on the person, as opposed to incorporating the person's family within the domain of personhood. As the family form part of the unit of care within palliative care, the application of this model within the context of expert palliative nursing practice is restricted.

Cassell's (1982) model of personhood provides a suitable framework through which the practice of the experts involved in this study may be understood. Cassell (1982) puts forward the notion that personhood is a dynamic, multi-dimensional milieu that embraces the individual's experienced identity and sense of self. The dimensions of the personhood, as described by Cassell (1982) include the following eleven elements: "a past", "life experiences", a cultural background", "roles", "does not exist without others", "has relationships with others", "persons do things", "has a body", "has a secret life", "has a perceived future" and "has a transcendent dimension". The value of this conceptualisation of personhood is that it highlights the intricateness of the "person" in both living and dying, while it also clarifies the "whole" of living and life. Findings from this study indicate that the practice of the expert palliative care nurses took cognisance of several aspects of personhood as depicted by Cassell (1982). This was undertaken in an all-encompassing manner as opposed to compartmentalising the elements of personhood.

The respondents did this in a manner similar to Byock's (1996) description of the nature of suffering and opportunity at the end of life. These include a) a sense of completion of worldly affairs, b) sense of meaning about one's life, c) sense of completion in relationships with family and friends, e) acceptance of finality of life, f) sense of meaning about life in general, and g) letting go. Placing the practices of expert nurses within the context of maintaining the personhood of the patient provides a new perspective through which to view the practices of expert palliative care nurses. Such an approach extends the concept of expertise and makes explicit the practices of expert palliative care nurses.

9.6.6 Conceptual Framework: "Fostering an Optimal Functional Self Through Living with Dying" Within the Context of Family Caring.

This study highlights the key role that experts played in incorporating family care as an integral aspect of their expertise in palliative nursing practice. It emerged from the data that the focus on family care appeared to be one that fostered optimal functioning self within family members. This fostering of an optimal functional self was

interpreted as optimising family members' function to: create the awareness of death and dying and to deal with death and loss following their family member's death. Within the context of this study, the onset of patients' deaths occurred over differing lengths of time. The expert nurses were thus faced with the challenge of assessing the level of optimal functional self the family members would achieve and the extent of normal family functioning for each family member. The manner in which the nurses facilitated family members to function optimally throughout the living-dying trajectory of their family member can be partly understood within the framework of care as described by Chekryn-Reimer, Davies and Martens (1991), Degner, Gow and Thompson, (1991), and Andershed and Ternstedt (1998; 2000). I consider that the respondents initiated supportive nursing interventions in order to facilitate family members to deal with the uncertainty and range of emotions around the dying process of one of their family members, thus achieving optimal functioning throughout this time. The strategies used included listening to relatives' concerns and anxieties, initiating further discussion with family members, providing an environment for families to spend time with their dying relative, acknowledging family members' difficulties during this time, and orchestrating events leading up to their relative's death.

It appears that the manner in which the respondents were in a position to help individual families deal with the uncertainty surrounding the onset of death and the events occurring throughout the dying process was influenced by the respondents' individual attunement to their needs. This ability mirrors the notion of what Appleton (1993) and Tanner et al (1993) refer to as particularisation and personalisation. As the degree and level of functioning is personal for each family member, the degree to which this is achieved and maintained is variable. This requires supportive nursing interactions that are based on nurses' understanding and perceptions of families' experiences in dealing with dying and death. The respondents' ability to initiate appropriate nursing interventions to facilitate family members' optimal functioning may be understood within the context of the work of Davies and Oberle (1990), Horvath, Secatore and Reiley (1990) and Radwin (1995).

The degree to which the experts in this study supported family members to achieve an optimal level of functioning was influenced by the nurses' assessment of their readiness, willingness and ability to become involved in care giving activities or their desire for information regarding their relative's condition. Involvement, in this study, signifies more than "participation in care" activities. It incorporates the family members' desire for knowledge about their relative's progress, their need for support and their desire to maintain / sustain a family relationship with their relatives. While different levels of family involvement in caring for their relative was evident, the nurse respondents provided support to these families in response to their individual needs. For some, this involved listening to their needs; for others, it was a process through which they helped them come to terms with the inevitability of death of their family member, providing them with appropriate information regarding events as they occurred and helping them deal with the loss of their family member. The respondents in this study provided valuable insight into the extent to which nurses can involve patients and their families in the most effective way so as to have a positive influence on the manner in which family members can optimise their functional self throughout the dying process of their relative.

Throughout the family caring activities, the respondents focused on helping family members to deal with the uncertainty surrounding the dying process of their family member, to deal with the inevitability of death, to deal with the suffering involved in their potential loss and to provide a sense of hope for a peaceful death. Additionally, the respondents supported family members to deal with the loss of their relative following death. Various processes took place in order to help families address these issues. These include the awareness of events as they were occurring, recognising the reality and consequences of these events, and acknowledging and in some way accepting the reality of their situation. While these processes may be understood through the writings of Morse and Penrod (1999: 148) where individuals progress to achieve a state of "transcendence" through awareness, acknowledgement, and acceptance, findings from this study provide a different perspective through which to consider family caring. The main difference between the concept of a state of

transcendence and that of optimal functioning is the degree of stasis that exists with transcendence as opposed to a continuous movement within the achievement of optimal functioning for family members. The findings of this study provide new insights into the manner in which families deal with an impending death of one of its members and propose strategies that may be implemented in order to help families deal with their unique situations.

The speed with which death occurs within the hospice also seems to affect the nurses' ability to influence the families' functioning self. Glaser and Strauss (1968) acknowledge that it takes time to prepare oneself to become aware and understand the seriousness of the situation when death is involved. Kristjanson and Ashcroft (1994: 4) acknowledge that a rapid deterioration in the patient's condition leads to "intense and crisis-like" interactions with health professionals. On the other hand, where the illness is prolonged, families are left in a stage of waiting for death to occur. While death was a common occurrence in all of the research sites, there were a variety of time frames within which patients died in each of the research sites. Time duration varied from a number of hours to a number of weeks. As a consequence, nurses were limited in some instances in the extent to which they were in a position to foster optimal family self-functioning. Where patients lived more than one week, there was a greater likelihood that the respondents had the opportunity to prepare family members for the death of their relative; however, when death occurred within the first two or three days after admission, there was limited time for family preparation. It was evident from the data collection however, that the experts prioritised in this matter, and attempted throughout the dying process, to have families prepared for the inevitability of their relative's death.

In an attempt to maintain optimal functioning self, the experts in this study appeared to support family members within the theoretical framework described by Andershed and Ternstedt (1999: 46) as "to know", "to be" and "to do". In the context of "to know" as facilitating a functional family self, family members were provided with information regarding their relative's condition as they inquired and were involved in

family meetings, a forum for relatives to ask questions and address issues that they felt were necessary. Family members were facilitated “to be” by being allowed to be present as they desired and to maintain physical contact and show emotion towards their relative. In facilitating an optimal functional self through the process of “to do” respondents identified that they allowed family members to become engaged in the relative’s care if they desired. The extent to which the nurses supported family members in the process of “to do”, “to know” and “to be” appeared to be based on their assessment of the unique needs of individual family members. The findings from this study add to the knowledge of caring for family members throughout the dying process. It highlights the importance of family care as encompassing an equal and complementary role to patient care and provides a new horizon from which to consider effective family care for family members of patients who are dying.

In summary, the nurses’ role in this study in providing family care is centred on the notion of striving to maintain an optimal functioning self within the family members. While this interpretation is based on data obtained from expert palliative care nurses, further research is required to investigate the concept of facilitating an optimal functional self, so that appropriate nursing interventions may be initiated in order to achieve this state of being. However, the insights of the experts involved in this study provide valuable information on how best nurses can involve families in caring for one of their members within the realms of their own personal functioning processes. Providing family care with a focus of optimising a functional self provides new insights into the delivery of nursing care by experts, one that has not been identified in the expert literature in the past.

9.6.7 Conceptual Framework: “Fostering an Optimal Functional Self Through Living with Dying” Within the Context of Comforting.

Comfort, as a component of nursing care, has been acknowledged in the literature by many authors, (Jacox 1989; Ferrell and Ferrell 1990; Hunter McIlveen and Morse 1995; Jenny and Logan 1996; Wurzbach 1996; Potter and Perry 2000), however, they frequently lack specificity or they focus solely on pain control as opposed to the wider

dimensions of providing comfort. This study's findings highlight the key role of the respondents as one that encompasses the provision of comfort in a broader sense. Findings presented in sections 7.4.1 to 7.4.4 indicate that comforting extends beyond measures related to symptom control to include the provision of physical comfort and spiritual comfort. Within the context of physical comfort, the respondents described specific physical caring interventions as they endeavoured to provide comfort. These included providing a bed bath, changing patients' position, grooming, fixing patients' pillows, and massage. These physical comfort measures were undertaken in an attempt to help patients to endure their illness, promote their state of well-being and to help them maintain optimal functioning throughout their dying process.

The nature of comfort as described in the context of this study provides additional insights into nursing actions that promote comfort, and expands current knowledge regarding the nature of comforting in nursing practice. The findings of this study in relation to the provision of comfort encompass a wide range of strategies that are implemented at an early stage of the living with dying trajectory. These strategies comprise a major aspect of the respondents' work in caring for patients. The study findings expand the work of Kolcaba (1994) Bottorff, Gogag and Engelberg-Lotzkar (1995) and Morse, De Luca Havens and Wilson (1997). Providing a range of comforting measures as described in this study, acknowledges the often underrated and frequently unacknowledged aspects of nursing practice, particularly within the caring for the dying literature.

Kolcaba's (1994) theory of holistic comfort proposes that there are two dimensions of comfort. The first dimension consists of three states, namely relief, ease and transcendence, while the second dimension is the circumstance in which comfort occurs. Kolcaba (1994) contends that the need for comfort arises from three health-seeking behaviours, namely, internal behaviours, external behaviours and a peaceful death. However, there is little evidence from Kolcaba's (1994) work as to the processes that are employed in order to achieve these comfort states. While Kolcaba's (1994) theory provides valuable insights into the concept of comfort from a theoretical perspective, the findings from this study identify and describe specific comforting

strategies that may be instigated in an attempt to reduce negative tensions and to achieve a state of comfort. Additionally, this study provides a description of the strategies that nurses may introduce in an effort to attain a state of relief, ease and transcendence, particularly vital as these are elements of the state of personhood.

The findings from this study support the work of Bottorff, Gogag and Engelberg-Lotzkar (1995) who explored the work of cancer nurses in providing comfort to patients. Findings indicated that comfort measures were enacted within four contexts: which include: helping patients put experiences into perspective, helping patients stay in control, providing opportunities to function as normally as possible and providing emotional support. Comforting strategies were provided through the use of gentle humour, physical comforts, providing information, emotionally supportive statements and comforting and connecting touch. Additionally, increased physical proximity, providing patients with information, supporting patients' active participation in decisions regarding their care and engagement in social exchange also indicated aspects of comforting. Bottorff, Gogag and Engelberg-Lotzkar (1995) described the use of comforting strategies with patients when there was no overt distress or discomfort evident. Their findings were mirrored in this study, indicating the ability of the respondents to take cognisance of the covert signals of distress and discomfort that patients may experience.

Morse, De Luca Havens and Wilson (1997) advocate that comforting may be understood through the development of a comforting interaction-relationship model. The comforting interactional-relationship model proposes that comforting consists of a triad relationship, namely, nursing actions, patient actions and the evolving relationship. Comforting strategies, styles of care and patterns of relating influence nursing actions. Comforting strategies acknowledged include touching, talking and interventions, and the administration of medication. Styles of care are created in response to perceived patient distress. Patterns of relating are influenced by styles of care, practice speciality and the nurses' role in providing care. Patient actions include signals of discomfort, distress and patterns of relating. The relationship that develops

is in response to patients' level of discomfort and distress and the nurses' responses to these signals. While the comforting interaction-relationship model provides valuable insights into the nature of comforting from a theoretical perspective, the findings from this study provide rich descriptions of the processes in which the respondents engaged in order to achieve a state of patient comfort. Furthermore, the context within which the comforting strategies were implemented throughout the dying process is clearly described within the study findings.

The nature of spirituality and spiritual care within nursing practice remains difficult to describe (Dyson, Cobb and Forman 1997; McSharry and Draper 1997; Martsolf and Mickley 1998; McSharry and Draper 1998). While many of the respondents referred to their practice in providing spiritual care to patients, it was delivered as an innate component of nursing practice and based on individual nurses' understanding regarding its nature. However, the extent to which spiritual care was needed for each individual patient dictated the respondents' focus on spiritual caring and comforting measures. Findings indicated that spiritual caring and comforting were delivered through the processes of the nurses' presence, their ability to understand patients and locate them within their life's journey, interpreting patients' contentment within themselves, and nurses' ability to acknowledge their own self-awareness. While spirituality and spiritual needs of patients have been addressed in a variety of contexts, including terminally ill hospitalised adults (Reed 1987), cancer nursing (Mickley, Soeken and Belcher 1992; Taylor, Highfield and Amenta 1994; Newshan 1998), women in the Appalachian community (Burkhardt 1993), mental health nursing (Charters 1999; Greasley, Chiu and Gartland 2001), this study has provided additional insights in to the complex nature of spiritual comforting.

Findings from this study bear some resemblance to two studies in particular. Hermann (2001) proposes that comfort comprises the need for involvement and control, the need for companionship, the need to finish business, the need for religion, the need to experience nature and the need for a positive outlook. I consider that the respondents in this study possessed an awareness of the need for spiritual comforting, and

strategies that were identified in this study mirror what Hermann (2001: 69) refers to above. These include the need to take one day at a time, to look outside, to talk to others, to be helped by others and to be outside. These strategies were based on the respondents' level and intensity of knowing the patients' bodily responses to their illness and their particular physical functioning at any given time. This influenced the degree to which the respondents were in a position to instigate specific spiritual comforting strategies at any given time. Additionally, the nature of spiritual comforting can be understood within the work of Friedemann, Mouch and Racey (2002). These authors propose that spirituality is centred on the process of finding meaning through relationships while achieving a state of unity and rationality. While this may appear a straightforward task, its achievement is based on an individual's ability to harmonize the self with both internal thoughts and feelings, and external events. Within the context of this study, the provision of spiritual comfort helped the respondents to achieve optimal functioning within the realm of their living through dying. Additionally, this was instigated at individually specific stages of the living-dying trajectory.

9.6.8 Conceptual Framework: “Fostering an Optimal Functional Self Through Living with Dying” Within the Context of Presencing.

Findings indicate that the respondents engaged in presencing as an aspect of their expert practice. Strategies used to engage in presencing included “listening”, “touch”, “silence”, and “being there and being with”. There was a synthesis between each of these elements that created the basis on which nurses were present to patients in their care. There was no one overriding element within each of these, instead the degree of intensity of each element depended on patients' needs. New findings appear to focus on the nurses' ability to judge the intensity of the different elements of presencing that was required for patients in their care. Additionally, the state of patients' personhood influenced the intensity of presencing were required. For some patients, one aspect of presencing was adequate to meet their needs, while for others, it involved utilising all five elements of presencing.

While presencing infers a sense of engagement, it also encompasses the wider dimension of communication, understanding, empathy, respect and availability. The synthesis of the elements of presencing was evident throughout patients' living-dying trajectory and became apparent from once the initial connection with patients took place following admission. It was an all-encompassing presencing where the respondents entered the world of patients in order to provide support and maintain the personhood of the patients. This process is similar to what Pettigrew (1990:506) describes, "... the nurse enters the patient's world and will remain with the patient, enduring one's feelings of discomfort and awkwardness... and offer comfort".

While the elements of presencing presented above have, to a certain extent, been described in the literature, the intensity of these interactions has not been previously described, hence they may be only partly understood within the context of current literature on the concept of presencing. While Gardner (1992), Pederson (1993), Bishop and Scudder (1996), Osterman and Schwartz-Barcott (1996), Doona, Haggerty and Chase (1997) and Ersser (1998) have explored the nature of presencing, new findings from this study relate to how presencing encompasses the optimising of a functioning self through living with dying. This study also explores the process of presencing within the realm of providing a caring milieu for patients within different stages of the living-dying trajectory, and the extent to which nurses brought a sense of comfort to patients through their presencing.

In addition to the works identified above, the practice of the experts' presencing in this study may be partly understood within the work of Hagerty et al (1993). These authors define relatedness as "...an individual's level of involvement with persons, objects, groups or natural environments and the concurrent level of comfort or discomfort associated with that involvement" (Hagerty et al 1993: 292). While relatedness is considered to encompass four states, namely, connectedness, disconnectedness, parallelism and enmeshment, I consider that the levels of relatedness that emerged from this study, within the sphere of presencing, may be described as mirroring a state of connectedness. Connectedness is implied when there is active involvement with the

other person. This state of connectedness was also influential in supporting patients through their journeying process on the living-dying trajectory.

9.6.9 Conceptual Framework: “Fostering an Optimal Functional Self Through Living with Dying” Within the context of “Journeying” and “Preparation for Death”.

Findings suggest that a key aspect of the respondents’ practice consists of supporting patients in their journeying process throughout their living in dying. While the journeying process and preparation for death was unique for each patient, the respondents supported the patients throughout these activities. The extent to which nurses became involved in patients’ journeying processes varied according to the needs of individual patients. The nurse-patient relationship formed the centrality in supporting patients in their journeying process and in their preparation for death. Additionally, this relationship provided the foundations for creating an ambience of care that centred on maintaining and supporting the personhood of the patients. The respondents highlighted the necessity of getting to know the patients so they could support them through their dying process within the patients’ journeying process and preparation for death.

Findings suggest that there were times when nurses were limited in getting to know patients. This was in part due to the severity of patients’ illness and the onset of death. Despite this, however, the nurse respondents created conditions that they considered to be conducive to getting to know patients as soon as they were admitted. The respondents strove for developing a relationship where there was equal participation and partnership. As this relationship developed, there appeared to be a form of companionship that developed. This companionship was built around trust, genuineness, and feelings of authenticity, as a means of engagement with patients and their families. Such a relationship facilitated the nurse respondents to engage in the patients’ journeying process. Nurses frequently expressed feelings of empathy towards patients and openly expressed these feeling to them, while openly displaying feelings

of sadness when patients died. These actions provided the basis for assisting patients in their journeying process and in their preparation for death.

Support for the nurse-patient relationship as a component of nursing is frequently addressed and acknowledged in the nursing literature. Several nurse theorists, including Peplau (1952), Orlando (1961), and Travelbee (1966) developed nursing theory that centred the nurse-patient relationship as being an essential component of nursing practice. The interest in the nurse-patient relationship occurred in response to nurses' roles being viewed as one that possessed knowledge of the world of the patient (Armstrong 1983). Since then, numerous authors have encouraged the practice of nursing to develop the nurse-patient relationship in an effort to know the patient and to understand patients' experiences (May 1991; Tanner et al 1993; Lowenberg 1994; Benner, Tanner and Chesla 1996; Benner, Hooper-Kyriakidis and Stannard 1999, and Crowe 2000). More recent studies indicate that the nature of the nurse-patient relationship is multi-dimensional and multi-faceted and one that involves an interplay between the nurse and the patient (Benner 1984; Davies and Oberle 1990; Ersser 1991; Morse 1992; Jenny and Logan 1992; Ramos 1992; Appleton 1993; Jewell 1994; Wallace and Appleton 1995 and Ersser 1998).

Within the context of this study, knowing the patient formed a major aspect of the nurses' skills as they engaged with patients in their journeying process so that they could provide optimal support for them. Knowing the patient is not a new concept within the nursing literature. Benner (1984), Benner and Wrubel (1989), Horvath, Secatore and Reiley (1990), Jenny and Logan (1992), Tanner et al (1993), Radwin (1995), Radwin (1996), Benner, Hooper-Kyriakidis and Stannard (1999), Luker et al, (2000) and Titchen (2001) all make reference to the centrality of knowing the patient within a caring relationship. This study defends Tanner et al's (1993: 275) stance that getting to know the patient "...means an immediate grasp, an involved, rather than detached understanding of the patient's situation and the patient's responses, an understanding that is directly apprehended, and that may remain largely ineffable". Similar sentiments are expressed by Benner (1984), James (1986), Benner, Tanner and

Chesla (1996), and Conway (1996) in their studies on expertise. What is not clear from these studies is how nurses get to know patients and how an immediate grasp of patients' situations is obtained leading to nurses becoming involved in patients' journeying process and supporting them in their preparation for dying.

Many of the respondents demonstrated an involved understanding of the patients' situations as they cared for them throughout their dying. However, the extent to which this involved stance was nurtured was dependent on both the patients' condition and the nurses' ability to remain open to the overt and covert cues coming from patients as they progressed through their illness. I propose that the palliative care nurses succeeded in getting to know the patients and getting an immediate grasp of patients' situations through two interlinked processes, namely, "subtle interpretive work" and the process of "affect attunement". The process of "subtle interpretive work" within the findings of this study was grounded in discovering the stage at which patients were located in relation to their illness. This influenced the extent in which the respondents engaged in the patients' journeying process. For a number of patients, their journeying process involved a three-phase movement; returning to the past, living in the present and looking towards the future. For others, there was a need to become attuned to the present while also looking towards the future. Nurses were challenged to establish patients' locations within their journeying process so as to provide them with appropriate support.

I consider that, while the nursing assessment was overt and guided by a nursing admission assessment format in the research sites, there was also a subtle element involved in the nursing assessment due to the delicate nature of discussing the onset and progression of the dying process for each patient. The interpretation that emerged, I consider, formed the basis of the development of a nursing care plan for the patients around which expert nursing practice was instigated.

Discovering the stage at which patients were located, as described in section 6.4.3.1, appeared to be central to the nursing assessment. While the initial patient assessment

was embarked on following patients' admission to the hospice, it continued throughout their stay and up to the time of their deaths. I consider that the assessment was centred around "subtle interpretive work", particularly as it was established on the nurses' knowledge about the patients: personal life history, disease progress, patients' needs, anxieties and concerns. From this information, the nurses gleaned meaning that influenced the way in which care was delivered and influenced the nurse-patient relationship within the framework of "Fostering an Optimal Functioning Self Through Living with Dying". The composition of this interpretive work focused on patients' verbal and non-verbal modes of interaction, where nurses interpreted and sought meaning from patients' body gestures, facial expressions and in the manner in which patients expressed their thoughts and feelings regarding their illness and impending death. As death approached, the subtlety of their interpretive process increased as patients' input into their care lessened; this was grounded in the extent to which nurses "knew the patients". The presence of pain and discomfort, unrest and fear, as patients approached death, were interpreted through the non-verbal modes of communication, while nurses responded appropriately to their interpretation of what was happening with the patients. Furthermore, the nurses' knowledge of the patient, to the extent to which they "knew" the patient also contributed to the subtlety of their interpretive process. This information was used in an attempt to foster the optimal aspects of living, and formed the bases on which to generate the patient's plan of care. The outcome of this subtle interpretation of patients' conditions led nurses to optimise patients' functioning in their living in dying process, while also supporting patients through their journeying process towards death.

This study also provides enlightenment into the process in which nurses engage when attempting to get to know patients and getting an immediate grasp of patients' situations throughout their living-dying trajectory. This process can be understood within the perspective of Stern's (1985) theory on the manner in which human beings create a sense of themselves in relation to others. Stern (1985) considers that, within the interpersonal world of an infant and its carer, intersubjective states engender a state of interpersonal communication where there is reciprocal behaviour between

both the carer and the infant. This state, described as affect attunement, occurs when carers interpret feelings, such as fear, anxiety and happiness within the context of overt behaviour. Häggström and Norberg (1996) also used the work of Stern (1985) in describing the communication process between carers and patients in the context of dementia care. These authors described this process as being synonymous with maternal care. I consider that the notion of affect attunement is a new concept that has emerged as being inherent in the practices of the experts in this study. I propose that the nurse respondents in this study worked within this framework as they attempted to interpret patients' behaviours throughout different stages of their illness. This was evident through the practices of the expert palliative care nurses as they were involved in a process of scrutiny and interpreting the gestures of patients in their care, such as grimaces, facial expressions and silence. Moreover, through the participation in patients' daily activities of living, such as washing, feeding and promoting comfort, the respondents made sense of patients' affect, such as pain, fear and anxiety. The nurses' ability to become engaged in affect attunement and to interpret patient responses to their illness relied on their ability to understand the ordinariness of being a human being throughout the dying process. Without this understanding, there is a danger that patient responses to their current status may be misinterpreted, which in turn may lead to care that does not meet patients' needs throughout the dying process.

9.7 Expertise in Palliative Nursing: New Horizons.

The inter-related themes that emerged from the findings of this study provide a new illumination regarding the nature of expertise that differs from other studies of nursing expertise. While there are similarities in a number of the findings of this study with other studies on expertise, this study provides expression to the practices of experts in palliative nursing that have not emerged in previous studies.

The outcomes of this study indicate the nature of expertise in palliative nursing practice is understood with the conceptual framework "Fostering an Optimal

Functioning Self Through Living with Dying". For the respondents in this study, maintaining the personhood of the patients in their care formed the focus of maintaining patients' and families' optimal functioning. An understanding of the patients' personhood as highlighted within the work of Cassell (1982) guided the respondents' actions throughout their caring activities. This does not suggest that each patient and family were considered the same. While each expert nurse strove to promote optimal functioning for patients and their families, there was constant interpreting of each individual's situation so as to instigate appropriate nursing interventions. There was continuous awareness of and attentiveness to the uniqueness of each individual and to the constantly changing needs as they progressed through the living-dying trajectory. While the respondents possessed an attunement to each individual situation, their actions in striving to achieve optimal function for patients and their families resulted in a fusion of knowing, thinking and doing. These processes, which are similar to what Benner, Tanner and Chesla (1996: 152 / 154) describe as "embodied know-how" and "seeing the big picture" were constantly being refined throughout their caring practices. Additionally, the findings of Conway's (1996) study bear some resemblance to the findings of this study. Conway (1996) proposes that experts consist of four different types, namely, technologists, traditionalists, specialists and humanistic existentialists. Findings from this current study suggest that the respondents bear some resemblance to the human existentialists, who Conway (1996: 16) considers that experts view patients "holistically" and they are "passionate about nursing practice". The expert nurses in this study were committed to their practice and synthesised their forms of knowledge to provide appropriate patient and family care. Analytical thinking underpinned their practice while their knowledge of the social and behavioural sciences also provided valuable insights into their decision-making skills. This analytical thinking was underpinned by the respondents' ability to combine Carper's (1978) empirical, ethical, aesthetical and personal knowing, with White's (1995) socio-political knowing. Additionally, the work of Liaschenko and Fisher (1999), who describe knowing within the realm of case knowledge, patient knowledge and practice knowledge provides a basis for knowing within the context of the respondents in this study.

The findings of the current study on expertise in palliative nursing practice bear minimal resemblance to McElroy's (1990) study on expertise in psychiatric nursing. This may be due to the heavy reliance on Benner's (1984) work with the study and also the focus of care within McElroy's (1990) study. However, descriptions of the practices of the respondents in McElroy's (1990) study highlight the ability of expert nurses to demonstrate concern for patients and to develop a trusting relationship, both attributes that emerged within the findings of this current study. The focus of technology formed a major aspect of the role of expert critical care nurses within Walter's (1992) study. While Walters (1992) suggests that there is a dominance in the use of technology inherent in the practices of expert critical care nurses, the findings of this current study highlight the "hidden technology" of caring, as depicted within the practice of "presencing", "comforting", "preparing for death", "family caring" and "journeying". This does not imply however, that the practices of expert palliative care nurses are not considered as being within the realm of critical care. As this study's findings suggest, the knowledge, skills and competencies in caring for patients in the palliative care phase of their illness may be considered equally as important as those working in critical care units.

9.8 Conclusion.

The most significant findings from this study relate to the concepts of presencing, preparing for death, comforting, journeying and family caring. The merging of these practices is best understood within the framework 'Fostering An Optimal Functioning Self Through Living with Dying'. The focus of the caring practices of the nurse respondents was centred on maintaining optimal functioning within the context of the patients' personhood. While some of the findings bear limited similarities to other studies on expert in nursing practice, I conclude that the 'Fostering An Optimal Functioning Self' framework supports and is supported by other conceptual frameworks. However, these other frameworks lack a focus on palliative care.

CHAPTER 10

IMPLICATIONS AND RECOMMENDATIONS.

10.1 Introduction.

The aim of this chapter is to present the implications of this study. Additionally, recommendations from the findings in relation to education, research and practice will be presented.

10.2 Findings.

The findings of this study offer new insights and revelations regarding the essence of expertise in palliative nursing practice. The essence of expertise may be understood through the framework of “Fostering an Optimal Functioning Self Through Living with Dying”. The study set out to examine the nature of expertise in palliative nursing practice and was guided by the research question: “What is expertise in palliative nursing practice”? The respondents consisted of forty registered nurses considered to be experts in the delivery of palliative nursing care and eleven recipients of care from a cohort of the nurses who participated in the study. Data obtained from the study reveal that the focus of care is based on the personhood of the patients and is influenced by the location of the patient within the living–dying trajectory. Practice is delivered within five realms of caring; presencing, preparing for death, comforting in dying, journeying and family caring. The nurses endeavoured to deliver care within a philosophy of care that assisted patients and families to achieve an optimal functioning self through living with dying. Nurses did this through their knowledge and skills and through their engagement with the patients and their families. Findings highlight the manner in which the experts engaged in care, and hence have implications for education, practice and research.

10.3 Implications.

There are a number of implications arising from this study. The essence of expertise remains complex. This study reveals that the practice of expert palliative care nurses is centred on personhood of patients and patients’ families. The focus of care is on fostering an optimal functioning self through living with dying. This is influenced by the location of the patient within the living-dying trajectory. In order for nurses to identify where patients are located in the living-dying trajectory, it is necessary that they possess the knowledge, skills and competencies in patient assessment in order to

extract this information. The traditional models of education that are based on behaviourism and cognitivism no longer equip nurses with the knowledge and skills required to develop advanced skills in patient assessment in palliative care; these skills are specifically related to the humanistic elements of palliative nursing practice. This challenges nurse educators to shift the focus of curriculum development from an objectivist and behaviourist base to one that embraces the elements of humanism that are so essential within palliative nursing practice.

As the practices of experts involved in this study were delivered within the living-dying trajectory of patients, it is necessary to conceptualise this trajectory as one that is person specific. However, in conjunction with this, it is necessary to reconceptualise the living-dying trajectory as a non-linear process and one that is in a state of constant change. This also requires nurses to consider the starting point of the living-dying trajectory. While various theories of death and dying have been proposed, the findings from this study calls for a re-examination of these theories in an attempt to highlight the starting point of the living-dying trajectory.

The process of caring in which the expert nurses were engaged was reliant on a wide repertoire of knowledge and skills. These included knowledge of nursing theory and practice, social and behavioural science and also the biological sciences. However, practising at an expert level demanded an ability to synthesise and analyse this knowledge and skills within the context of a model of personhood.

The extent to which nurses were present to patients and to patients' families required a considerable amount of personal and emotional investment in the caring process. This laid the foundation for developing close caring relationships with patients and their families. While such practices promote reciprocity, connection and authenticity between the nurses and patients, it also has the potential of demanding more from the nurses than is ordinarily expected within a professional caring relationship. This requires nurses to be facilitated in the development of skills that enhance the nurse-

patient relationship while also provide support for them in their practice in order to promote and enhance the nurse-patient relationship.

Owing to the nature of palliative nursing practice, preparation for death was an inherent aspect of the nurses' practice. There is a need for nurses to assess patients' and families current position regarding the extent of their preparation, and to become attuned to their changing needs throughout the preparatory process. They also need to be in a position to respond to patients' and families' reactions to this preparatory process.

The nature of spirituality is multi-faceted. Spiritual caring activities form a major focus of the work of experts in this study. This results in an increased challenge for nurses to support patients in their quest for spiritual comfort. Initiating spiritual comforting strategies empowers patients to explore their spiritual needs and provides spiritual comfort to them. Spiritual comforting involves more than directing a prescribed format of caring. It involves an attunement to the patients' thoughts, feelings and emotions, together with the ability to adjust the processes of providing spiritual comforting. However, without nurses' awareness of their own spirituality, there is a risk that spiritual comforting may receive a limited focus as an aspect of palliative nursing practice; this in turn, may hinder the attainment of optimal function for patients in their care.

Family caring forms a central role in the caring practices of expert palliative care nurses. While this is an inherent function in the role of palliative care nurses, there is a need to possess a thorough understanding of each family's functioning in order to provide appropriate family caring. However, given the time frame in which some patients die, there may not always be the time or the resources to achieve this understanding. This may result in families feeling uninvolved and dissatisfied with the care that their relative receives. Hence, there is a necessity for nurses to assess family functioning within a short timeframe. This requires an appropriate family assessment tool to be utilised in order to implement appropriate family support interventions.

There is a risk that there may be dissension between organisational demands and those needed by the experts to maintain their practice at expert level. Among the factors that may cause such dissension include the prolonged engagement with death and dying, conflict within the interdisciplinary team, the onset of stress and burnout and the increasing demand for euthanasia within palliative care. The presence of such issues within the delivery of expert palliative nursing care may potentially result in conflict between organisational demands and the nurses' ability to meet those demands, hence increasing the difficulty in sustaining nursing practice at expert level.

10.4 RECOMMENDATIONS

10.4.1 Recommendations for Education.

Educators involved in curriculum development need to heighten students' awareness of the nature of caring and the nature of palliative care. While this study has focused on the nature of palliative care of patients within hospice care situations, there is a need for further education regarding the philosophy of palliative care so that it may be extended to include the care of non-cancer patients and patients in other care settings.

Additionally, the principles of care within the philosophy of palliative care may be taught across all domains of caring in order to deliver quality palliative care to patients. Within the current system of nurse education, there is a tendency for undergraduate student nurses to spend most of their first year of education in third level institutions away from clinical practice. This results in limited experience in dealing with patients, and particularly with patients who are dying. While the possession of theoretical knowledge is essential in providing skilled care, exposure to the 'Fostering an Optimal Functioning Self Through Living with Dying' framework of care may provide valuable insights into caring for patients who are dying.

The model on which palliative care curricula are developed needs to be built within person-centred models of care as opposed to behaviourist or objectivist models. The emerging of person centred models as the basis of such curriculum development will

allow the patient to be viewed from different perspectives, so that the totality of the persons' needs will be addressed. This model also needs to include advanced assessment skills that include not only nursing theory but also the biological and behavioural sciences. There is also a need to review teaching strategies to take cognisance of the skills necessary to engage in the nurse-patient relationship as described within the context of this study.

The needs of patients and families who receive palliative care are varied. This calls for a multi-disciplinary and inter-disciplinary team approach to delivering palliative care to patients and their families. Educational programmes need to be developed that address the needs of inter-disciplinary health care professionals in order to enhance the specialist knowledge across an inter-disciplinary group.

Additional nurse educational programmes need to be developed in order to educate nurses at different academic levels, i.e. diploma, degree, post-graduate diploma and masters level. The development of such programmes would assist in the continued advancement of nursing skills within the specialty. Such programmes need to take cognisance of the importance of linking the theoretical content of such courses with practical placements so that both forms of learning remain connected.

10.4.2 Recommendations for Practice.

As the need continues for palliative nursing care within in-patient hospice units, hospice daycare units, home care services and palliative care services within general hospitals, there is a need to facilitate nurses to develop their skills to an advanced level of practice. This may be done through role modelling, reflection, critical thinking and analysis. Additionally, core care practices, such as the provision of bed-baths, oral hygiene and helping patients to engage in daily activities of living need to be retained by registered nurses and student nurses, and these skills need to be valued.

Due to the frequent exposure to death and dying in palliative nursing practice, clinical supervision needs to be instigated for nursing staff in order to reduce the risk of staff

burnout. The provision of a palliative care framework for practice, such as that which emerged from this study, would provide a context specific focus for care.

The organisation of nursing work within either a primary nursing or team-nursing ethos needs to be considered within palliative nursing practice. Such an approach to care would allow nursing staff to practice within a milieu that promotes the development of the nurse-patient relationship that would foster the delivery of care within the “Fostering an Optimal Functioning Self Through Living With Dying” framework identified in this study. Additionally, it would allow for the development of nursing skills that promote quality individualised care in order to help foster optimal functioning for patients and their families.

A framework that assesses patients’ spiritual needs must be incorporated into patients’ plans of care in order to facilitate patients in addressing their spiritual needs as they approach death. Additionally, nurses need to become aware and alert to the overt behaviours associated with spiritual discomfort, so that the aim of care will focus on addressing these issues.

10.4.3 Recommendations for Further Research.

The study findings indicate the need for additional research into the practices of palliative care nurses. These include:

Is expert palliative nursing care practised in in-patient units different from expertise in hospice day care units and home care services?

What are the specific factors that influence the development of expertise in palliative nursing practice?

What are the differences between the practices of expert and non-expert nurses in palliative care and how does this influence the quality of care delivered?

As nurses involved in this study appear to have developed an involved stance with patients in their care, how do these nurses engage in debriefing from their practice?

What is the impact of caring for nurses practising at an expert level in palliative nursing care?

Is the development of expertise dependent on a combination of education and practice or can expertise be taught?

10.4.4 Recommendations for the National Council for the Professional Development of Nursing and Midwifery.

The National Council for the Professional Development of Nursing and Midwifery have recommended Clinical Nurse Specialist and Advanced Nurse Practitioner pathways for the development of specialist palliative nursing practice and specialist palliative care practice. However, they have omitted to recognise the necessity for, and the significance of, the role of the Clinical Nurse Specialist and Advanced Nurse Practitioner within the specialist in-patient palliative care setting. The development of Clinical Nurse Specialists and Advanced Nurse Practitioners within such units needs to be fostered. This is considered significant for both the professional and practice developmental trajectory of palliative nursing practice and specialist palliative care services within Ireland.

10.4.5 Recommendations for Institutional / Organisational Support Systems.

There is a need for the organisations included in this study to provide adequate and appropriate support measures for nurses working in palliative care. These include:

The provision of stress reducing strategies.

The implementation of clinical supervision as a means of supporting staff to address difficult situations.

The development of an inter disciplinary model of teamwork, so that there can be shared decision making process. In an attempt to nurture this, there is a need for organisational support, clear interdisciplinary goals set, and to provide adequate training and coaching facilities.

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