A Mission of Privilege and Peril

The Phenomenon of Community Palliative Nurses Caring for the Suffering

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Certificate

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text. I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

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Abstract

The experience of 12 community palliative care nurses has been investigated in a phenomenological study. The study described the phenomenon of caring for people who were suffering. The phenomenological description of the community palliative care nurses' role uncovered the structures of meaning of what it is to care for people who suffer. Following a sequence of steps aimed at analysing, interpreting and reflecting on the nurses' description of caring for people who are suffering, it was judged that this experience could be described as an experience of privilege and peril.

Five themes were drawn from the nurses' descriptions of caring for people who suffered. These five themes refer to the nurses' experience of caring for people who suffer as: making the journey knowing suffering, giving care, receiving, and keeping a balance. The essences of the phenomena were revealed in further reflection as Being a sojourner, Being initiated into the world of suffering, Being all that they can, Being enhanced, and Being mindful. The final hermeneutic description of the nurses' experience of caring for people who suffered as a mission of privilege and peril is drawn from each layer of meaning.

Chapter 1 – Introduction

1.1 Background to the study

The purpose of research is to verify, or improve on, existing knowledge and to uncover new knowledge. The primary goal of research activity in nursing is to increase the quality of care provided to the recipients of that care by the development of professional nursing practice. Various types of research can contribute to these outcomes in nursing. The investigation in this study explores one of the most challenging and profound experiences of nurses, caring for people who suffer. Since the study aimed to provide a comprehensive description of the experience of nurses caring for people who suffer an investigative style suited to considering this phenomenon was the key to this creative outcome.

The practice of nursing, as it relates to the nursing care of the suffering, is a human experience. An investigative approach suited to this purpose is required. Human experience requires interpretation and understanding which are best achieved using a human science approach. A variety of approaches underpinned by the perspective of a number of disciplines, have been employed to investigate human experience. Phenomenology is increasingly recognised as a qualitative method that can be employed for the investigation of phenomena salient to the practice of nursing. Caring for people who suffer is a profound human experience of nurses and the investigative approach used needs to provide both knowledge and understanding of what it is to be a nurse caring for someone in this situation. A phenomenological methodology, which looks to both transcendental and hermeneutic approaches, was the choice for this study of nurses to determine what it means to care for suffering people.

1.1.1 Choosing the topic

Human beings are faced with many instances of witnessing and experiencing suffering throughout their lives. Much of the suffering in the world is unrelated to disease and illness but results from the cruelty inflicted by others or the forces of nature. This suffering is something seen on television each day and has become something distant that happens to others. The suffering that nurses see daily is personal and close. This suffering happens to individuals similar to those who care for them and cannot be ignored. I have nursed people I believed were suffering and felt my response was inadequate. Although I believe my awareness of, and ability to respond to, the suffering of others has increased there have been many times when I have felt ineffectual when faced with the suffering of others. I wondered how nurses who caring for suffering people on a daily basis managed to be empathic without suffering themselves.

Most health care settings require nurses to care for suffering clients. This care is not improved by reduced hospital stays and fewer nurses. There is less time for nurses to know or assess patients. In such an environment suffering may be unrecognised or ignored. Those nurses who do recognise the suffering of their patients but are unable to respond may experience increasing stress. The nurses' inability to respond to the suffering of others may relate to a lack of preparation for this role or structural barriers within the health care setting.

In exploring the experiences of the nurses caring for people who suffered, my intention was to learn something of how these nurses were able to continue in a caring role in the midst of suffering. I sought to know what they could offer as guidance for other nurses in their professional nursing roles and in their personal lives as caring human beings.

1.1.2 Nurses and suffering

Being with people who suffer is universally recognised as part of nursing. Nurses both care for people in pain and who suffer and nurses sometimes cause suffering. Suffering is not always related to disease or physical pain and there are many causes of suffering. Whilst suffering may occur in any health care setting those often associated with this experience include patients in psychiatric or mental health, burns, oncology, palliative, and aged care settings. The setting chosen as the focus for this study is the provision of palliative nursing care in the community. Increasingly people are choosing to die in their own homes and community nurses provide support for both clients receiving palliative care and their carers.

Nurses have always cared for people who suffer. Women most often carried out the care of the sick, the suffering and dying in the home. There is a long history in Australia of formalised palliative care provided in a hospice setting. This form of care began in the late 19th century and was provided by religious organizations (Aranda, 2000). Aranda

(2000) described two structures for the provision of palliative care in the community in Australia.

The nurses in this study were employed in community health programs and most were clinical nurse consultants supporting generalist nurses in their care of those clients who were dying. They were part of teams that included palliative care physicians, allied health professional and generalist nurses. The clients' general practitioner most often provided medical care. This structure was consistent with one model described by Aranda (2000).

There are differences between nurses who provide care in a hospice and those providing palliative care in the community. Much nursing work is argued to be invisible. This invisibility is considered even more prevalent for community nurses (Austin, Luker, Caress & Hallett, 2000). Nursing care is provided in the client's home and therefore not subject to the gaze of others. The nurses most often work alone so do not have others to turn to when in need of support. Community nursing is liberating in one sense but also isolating and lonely at times.

The literature review that was undertaken before commencement of the study revealed a lack of a full description of the experience of community nurses caring for people who suffered. The literature reviewed focused on suffering generally rather than any context of care.

Suffering is a difficult concept to define and there has been confusion between the concepts of pain and suffering. Recent definitions of suffering indicate that pain can occur in the absence of suffering and one can suffer without being in pain. Nurses' experiences of caring for people who suffer and the effects of this care have been ignored in the literature until recently (Gregory & Longman, 1992; Morse & Johnson, 1990: Rogers & Cowles, 1997). The literature reveals that nurses can also suffer when giving care to clients they perceive to be suffering (Kreidler, 1984; Rushton, 1992; Steeves, Kahn & Benoliel, 1990). The literature has demonstrated that nurses have difficulty when caring for suffering patients which results sometimes in distress in nurses' personal lives and difficulty in caring for their patients (Artinian, 1995; Rushton, 1992; Steeves, Kahn & Benoliel, 1990).

Nurses have been educated in the past to maintain an emotional distance from their patients but many nurses have chosen to become emotionally involved (Artinian, 1995). In attempts to cope with the suffering of others, nurses may become over involved or distance themselves from the suffering. Neither of these strategies is helpful to the nurse or their patient (Carmack, 1997). There is increasing discourse in the literature on the concept of emotional labour involved in nursing (James, 1989, Smith, 1992). Further exploration of this concept is required to understand the nature of nurses' experiences when caring for people who suffer and the effects of this on nurses.

1.2 The study

The study's findings are described in depth and these finding are argued to provide an understanding of caring for the suffering as a nurse. The human experience of caring for suffering people is investigated thoroughly. The field of study is the experience of community nurses as palliative care nurses caring for dying clients and their carers. The setting of palliative care was chosen since these nurses are constantly confronted with the suffering of others. All nurses face the suffering of others but some disease processes result in worse outcomes for the sufferers. Most clients seen in palliative care settings have been diagnosed with cancers for which there are no cure so they are facing death.

1.1.3 The purpose of the study.

The purpose of this investigation is to describe the phenomenon of caring for suffering people as experienced by palliative care nurses in the community. It does not set out to investigate suffering per se; the focus is the nurses' understandings of suffering and their experience of caring in this context. The description is obtained by analysing the nurses' accounts of their experiences. This process was informed by concepts drawn from phenomenology.

1.1.4 Structure of the thesis.

The thesis is presented in 11 chapters. The necessary information about the study, the subject of the study, methodology and method are presented in the initial chapters followed by the analysis and findings of the study.

Chapter 2 contains a literature review showing the field of the study. The methodology in Chapter 3 outlines the philosophical stance and theoretical perspectives underpinning the research methods. Chapter 4 describes the methods with the design and procedures carried out to conduct the study. The themes derived from the nurses' conscious experience form a thematic description of the phenomenon of caring for people who suffer. These are contained in Chapters 5,6,7,8 and 9. Chapter 10 puts forward a phenomenological interpretation, according to hermeneutic convention, of the experience of nurses caring for people who suffer. This is their lived experience of the phenomenon. The final chapter provides a full description of caring for people who suffer as an experience in which nurses are on a mission of privilege and peril. . This description is followed by a discussion on the implications of issues of the findings for clinical nurses, nursing education and administration.

The introduction has presented background issues and concerns that led to the study. An outline of the structure of the thesis is provided giving an overview of the thesis contents.

Chapter 2 – The Literature on Suffering

2.1 What it means to care for people who suffer

Suffering is ubiquitous and inescapable. Human concerns about the meaning and purpose of life, though often lost in daily routines, emerge in situations of crisis and suffering. The individual seeks an answer to the problem of suffering. The nature and the meaning of suffering have long interested philosophers. Literature is replete with moving testimonies of suffering (Camus, 1947/1960; Kafka, 1916/1961; Kushner, 1982; Lewis, 1961; Tolstoy, 1935/1960). Because caring professions aim to alleviate suffering, the literature on suffering will interest anyone who cares for people immersed daily in a world of suffering.

This literature review explores suffering as it relates to the practice of nursing, and identifies knowledge gaps that offer research opportunities. The review reveals a need for further clarification of the nature and meaning of suffering for nurses, and how they experience the suffering of others. The subsequent, empirical section of the thesis provides the evidential basis for that clarification.

2.1.1 Traditional concepts of suffering

Historically, the exploration of the nature and meaning of suffering was confined initially to theology and philosophy. The theme of suffering is woven through religious writings, as attempts were made to interpret this experience (Bowker, 1970; Ferguson, 1972; Sia & Sia, 1994). Bowker (1970) and Heitman (1991) explored the meaning and interpretation of suffering according to major religions. Bowker (1970) asserts that the ubiquity of suffering earns it a central place in religion, and points to suffering as a major factor in its development. Religion can reassure believers facing death or other calamity, and what a religion says about suffering uncovers its further beliefs about the nature and purpose of existence (Bowker, 1970).

Individuals who suffer, and witnesses to others' suffering, seek a cause or reason for suffering. Biblical authors have proposed reasons for suffering. Suffering may be punishment for wrong actions; it may be the work of the devil, a test of faith, or a means to redemption.

Suffering may be a fact of human existence, but it becomes problematic when its distribution seems unjust (Bowker, 1970). A frequent question is why an all powerful and beneficent God allows innocent and good people to suffer while the sinful escape.

The link between sin and suffering has persisted in some traditions, despite having been challenged. The biblical story of Job explored suffering from a Judaic perspective and has provoked much discussion. The author of the book of Job challenges the notion of suffering as punishment, a standpoint that persists in Kushner (1982), a contemporary writer seeking to understand reasons for the suffering and early death of his son. Many who suffer still question their past actions when seeking to explain their present situation. The Christian tradition, though retaining beliefs from traditional Judaism, presents an innocent Christ who suffers to redeem others. This view exemplifies the Christian response to suffering as the path to resurrection and an afterlife.

2.1.2 Modern concepts of suffering – the quest for meaning

Battenfield (1984) extensively reviewed the literature on suffering and concluded that writers on the topic could not find a clear definition of suffering that was relevant for both the writer and the sufferers. Battenfield (1984) developed a schema of attitudes held by sufferers. Building on the work of Frankl (1963), which assumed that the highest level of suffering was to find meaning in life, Battenfield identified three phases of an individual's response to suffering. The first phase is the initial impact, which is followed by the stage of turmoil without resolution. The final stage is recovery. This last phase was subdivided into coping, accepting or understanding, and finding meaning. The schema was field tested by conducting nine interviews with suffering individuals. Battenfield (1984) believed the dimensions of suffering in her schema were detected, and that the schema serves as an objective guide for observing responses to suffering. Information obtained from the schema had potential to guide nursing interventions. Kahn and Steeves (1986) critically reviewed literature on suffering and the individual and cultural factors that influence the experience of suffering, and developed a comprehensive definition of suffering. Suffering is experienced when:

> Some crucial aspect of one's own self, being or existence is threatened. The meaningfulness of such threat is to the integrity of one's own experience of personal identity. Pain, for example, may or may not invoke suffering. Whether

> suffering is invoked by pain depends more on the meaning the individual gives to pain in relation to the personal identity than it does to the amount, degree or type of pain. Any threat to personal integrity, whether painful or not, can invoke suffering. (p. 626)

Morse and Carter (1996) aimed at further clarification of the concept of suffering. They developed a model illustrating the relationship between enduring, suffering and the reformulation of the self. The concepts of enduring and suffering were seen as separate, contrary to previous definitions (Younger, 1995). Enduring refers to “the ways the individual ‘gets through’ extraordinary physical or psychological assault or stressful conditions and remains intact” (Morse & Carter, 1996, p. 47) and is characterised by a lack of emotion and a focus on the present.

Morse and Carter (1996) argued suffering to be the emotional response to the event that has been endured, the loss or destruction of an anticipated future or an unalterably changed present or future. Enduring is a state in which emotion is suppressed, whereas suffering is a highly emotional state with a behavioural response (Morse & Carter, 1996). This description contrasts with Cassell (1991), who claimed that one can only know if someone is suffering by asking them. Morse and Carter (1996) questioned whether Cassell was writing of enduring when his suggested intervention was to focus the patient on the present.

The conception of enduring and suffering have implications for nursing practice because Morse and Carter (1996) argue that endurance should be facilitated and the individual not be moved prematurely into suffering with the accompanying loss of emotional control. The individual moves into suffering when strong enough to do so. Interventions to facilitate endurance differ from those suggested for suffering. Comforting and energy conserving strategies are suggested for facilitating endurance, while suffering requires the individual to seek emotional release and finds ways of coping with their changed situation.

Meaningless suffering can be viewed as useless and absurd. Camus (1942/1975) wrote his philosophical text during the Second World War, a period of apparently senseless death, destruction and suffering. Camus argued for one serious philosophical question. That question related to suicide. Camus (1975) held the meaning of life to be an important and urgent question. If a life with suffering had no meaning, then one is left with absurdity. Suicide provided an answer to the absence of meaning according to Camus (1975).

> You continue making the gestures commanded by existence for many reasons, the first of which is habit. Dying voluntarily implies you have recognized, even instinctively, the ridiculous character of that habit, the absence of any profound reason for living, the insane character of that daily agitation and the uselessness of suffering. (p. 13)

2.2 Suffering as a concern in health care

While the meaning and purpose of suffering have been explored over long periods in theological writings and in other literature, writings on suffering in medical and nursing literature began only in the latter half of the 20th century. The understanding of suffering should be a central concern to anyone providing health care and cure, because suffering is a part of everyday life of individuals facing illness, disease and loss. There is now an increasing discourse on suffering in both medicine and nursing.

2.2.1 Medicine and suffering

Whilst much of the commentary on the nature of suffering and its meaning to physicians has come from sociology and bioethics there is some contribution from the medical perspective. Freud (1930/1961) concluded that suffering arises from three sources. The first of these was one's own body, which is doomed to decay, and must experience pain and anxiety as warnings. The second source of suffering is from the external world and its means of destruction. The final and most painful source of suffering is from relationships with other human beings. The last of the three sources interested Freud as psychiatrist. Freud (1930/1961) explored how suffering could be avoided and a state of happiness achieved.

Frankl (1963) was one of the first post Second World War medical writers who addressed suffering conceptually. The founder of a form of psychotherapy known as *logotherapy*, and a psychiatrist, Frankl survived the Holocaust during which he experienced and witnessed much suffering. He believed that the search for meaning is the primary motivation of life for humankind. The meaning of existence is unique to the individual and varies over time. This meaning can be discovered in three ways: firstly through creativity or the undertaking of some deed; secondly by experiencing something or encountering someone; and finally by the way one deals with unavoidable suffering. Frankl (1963) emphasises that, whereas meaning is available in spite of, or through suffering, suffering is not necessary to the discovery of meaning. However, Frankl left suffering undefined, instead accepting it as inevitable. He focussed on interventions to assist the suffering individual to find meaning in their experiences and to take responsibility for their lives. Frankl proposed that one might transcend suffering by finding meaning in the experience. This perspective was drawn from personal experience and observation of how people either survived or ceased struggling while incarcerated in a concentration camp.

Personal experience of their own suffering has informed some physicians. Moore (1991) described his suffering following a motor vehicle accident, which could have been fatal and certainly changed his life. Moore (1991) spoke of his suffering and loss.

> I was distressed by the feeling that the person I had been no longer existed. He had become passive, truce seeking and conciliatory. I felt a primordial sense of indignation that the guiding fates had abandoned me. Years passed before I understood that the accident was an inevitable event in the journey of my life. "You were lucky you weren't killed," they said kindly in the early weeks. I wanted to scream at them, "I was [killed]!" (p. 28)

Moore's career altered when, following his recovery, he changed his practice context to rehabilitation, as he now understood the needs of people with damaged bodies. Although Moore believed he had learned a lot and had achieved acceptance and healing, part of him never recovered. "Although my public humour and irreverence have returned, a core of sorrow remains and it can't be shifted" (Moore, 1991, p. 144).

Frank (1991), a medical sociologist, wrote of his personal experience of suffering. Frank had experienced a heart attack and after recovery from that illness was diagnosed with cancer. Frank (1991) felt that to get the medical help needed, he must become passive and submit his body to all investigations the doctors requested. He described this process as being colonised by medicine, with attention directed to his diseased body, and little interest in what the experience meant for him.

> For the person, pain is about incoherence and the disruption of relations with other people and things; it is about losing one's sense of place and finding another. Medicine has no interest in what pain means in a life; it can see pain only as a symptom of a possible diseases. Medicine cannot enter into the experience; it seeks only cure or management. It does offer relief to a body that is suffering, but in doing so it colonises the body. (Frank, 1991, pp. 52-53)

Neither Moore nor Frank could share the experience of suffering with others. Their narratives indicate a sense of partial loss of self, and consequently having to find another way to exist. A sense of having died was also documented by May (1991) as being experienced by a young man disfigured by burns. This man relinquished his name and took another, as his former self was now dead.

Not all physicians and commentators on medicine accept that technology should or can prevent suffering. Boeyink (1974) challenged the view that all suffering and pain should be eliminated, suggesting that pain has value as a warning, and assists diagnosis. Boeyink also suggested that the sufferer's attitudes to pain and suffering, such as acceptance, could give the experience a redeeming quality.

Illich (1976) criticised medicine and took issue with the view that all suffering could or should be eliminated. Illich argued that what he saw as the medicalisation of life actually caused illness and suffering, firstly by removing individuals' capacity to manage their own health. Secondly, individuals and families were deprived of the conditions required to maintain their health through the creation of needs and encouragement of dependence upon medicine. Cultural iatrogenesis was the third way in which health was impaired. Illich believed that professionally organised medicine promoted the expectation that individuals should not suffer, and that medicine's brief is to wage war against suffering. Illich (1976) maintains that this perspective robs individuals of "the means for making pain tolerable, sickness or impairment understandable, and the shadow of death meaningful" (p. 124).

Kleinman (1988) added a new dimension to the concept of suffering. He focussed not on attitudes, but the significance of culture and social conditions to how pain and disease are experienced. His work broadened the understanding of what it means to suffer and how the sufferer might be helped. Kleinman (1988) considered that "the cultural meanings of illness shape suffering as a distinctive moral or spiritual form of distress" (p. 26). Kleinman, a physician and anthropologist, argued that modern Western society, having no generally agreed interpretation of reversals of fortune, tends to medicalise these problems and seek answers from science and health professionals. Suffering becomes "a problem of mechanical breakdown requiring a technical fix" (Kleinman, 1988, p. 28). Kleinman criticises medical diagnostic categories as not accounting for the experience of illness and suffering. The more meaningful moral or spiritual responses to the problems associated with illness have been replaced by scientific therapeutic interventions. Emphasis on the body leads to ignoring the link between the body and the mind, and the effect of culture. Himself a physician, Kleinman believes that physicians in general can gain valid information by listening to the narratives of patients. These narratives reveal the meaning of the illness for the patient from a cultural, personal and interpersonal perspective and involve narratives of suffering.

Frank (1995) emphasised the importance of narrative to suffering individuals. Stories can help repair the damage from illness, make sense of the experience and enable the person to explore future possibilities. The stories should be retold to health workers, friends, employers and others with an interest.

Telling one's story of illness is discouraged in the health care system. Frank (1995) argued that defining the conversation between doctor and patient as taking a history changes a conversation to a clinical task, thereby interrupting and curtailing the patient's story or narrative. Suffering during illness gives rise to a need for stories. Frank (1995) described the narrative structures of these stories that then become testimonies of suffering. The suffering individual, on hearing their own testimony, can understand or make sense of their suffering (Frank, 1995).

Cassell (1982, 1991), a physician, emphasised that the whole person not just the physical body experiences suffering. Suffering occurs when the person perceives their impending destruction; and can relate to any aspect of the person. Consistent with Kleinman (1988), Cassell (1991) rejects reductionist notions of person as dehumanising the individual who suffers. Reductionist thinking narrows the scope of medicine, and actually causes suffering. Whilst arguing that the individual must be considered holistically, Cassell (1991) does offer "a simple topology of person" (p. 47). This topology includes the individual's personality, family, personal meanings of disease, its treatment, culture and its relationships. Perceived destruction of any of these areas may lead to a person suffering.

Cassell (1991) considered that a failure to grasp the essential quality of suffering could result in an intervention that not only fails to relieve the suffering but also can actually cause suffering despite its technical adequacy. Cassell (1991) noted medicine's traditional primary concern for the body and physical disease, and that the mind-body dichotomy has influenced medical theory and practice. Cassell considers this dichotomy as promoting the paradox of doctors causing suffering while trying to relieve it. Cassell (1991) believes that physicians fail to recognise how all aspects of the person, not just the body, are susceptible to damage leading to suffering.

Barnard (1990) explored the failure of medicine to consider the existential aspects of human experience. Barnard refers to philosopher Marcel who distinguished between "the realm of the problematic and the realm of mystery" (as cited in Barnard, 1990, p. 130). Marcel stated that the *problematic* required technical solutions, whereas *mystery* is a facet of human experience that technology cannot solve, but can only be faced with faith and commitment. The physician focuses on objective and measurable elements of illness and disease, ignoring narratives of the patient's subjective experiences of suffering. The mysteries underlying the pain, disability and sickness are the mysteries of vulnerability and death (Barnard, 1990). The mysterious elements do not respond to technical solutions offered by medicine; and suffering is ignored.

More recently, Kearney (2000) discussed experiences of pain and suffering. A palliative care physician, Kearney concurred with Cassell's (1991) definition of suffering, and the belief many forms of suffering could not be analysed, understood or eased. Kearney (2000) argued that individuals must find the means of healing within their suffering, and this comes from deep within their psyche. Helping someone in suffering, according to

Kearney (2000), “means creating the environment that best facilitates this process of inner healing” (p. 5). Facilitating this healing requires effectual care combined with caring human relationships. Kearney (2000) also noted the importance of carers of the suffering having developing the ability to live with their own suffering.

There has been interest from medicine in relation to the nature of suffering, its causes, and means of relieving suffering. This commentary has for the most part come from sociologists, bio-ethicists, and medical practitioners with an interest in psychotherapy or, more recently, palliative care. Personal experience of suffering has also triggered the exploration of suffering and how individuals can be helped through this experience. In summary, the literature notes that physicians avoid narratives of suffering, and their focus is on objective data and observable pathology rather than patients’ subjective experiences.

2.2.2 Nursing and suffering

As already mentioned, there has been little in the nursing literature on the nature and meaning of suffering until recently, although the alleviation of pain and suffering is generally considered as very much part of the tradition and role of nursing. Nursing espouses a commitment to holistic care, but holistic nursing practice requires an understanding of how suffering results from illness.

Travelbee (1971), a nurse theorist, addressed the nurse’s role concerning suffering. She described nursing as an interpersonal process between two people. One person needs assistance because of illness and the other gives assistance. The role of the nurse is to assist an individual, family or community to prevent or cope with the experience of illness and suffering and, when necessary, to find meaning in these experiences.

Suffering eventually confronts everyone, especially during illness. Travelbee’s (1971) interpersonal process involves developing the nurse-patient relationship to a point where rapport occurs. At this stage, the goal of nursing is to assist the patient find meaning in suffering, and eventually the development of hope in the patient. Travelbee (1971) argued that for a nurse to help another cope with an illness, the nurse must find personal meaning in each encounter with the sufferer. A nurse who considers the suffering to lack meaning cannot assist a client to find meaning in their suffering.

Travelbee (1971) defined suffering as:

> A feeling of displeasure that ranges from simple transitory mental physical or spiritual discomfort to extreme anguish and to those phases beyond anguish: Namely, the malignant phase of despair, the feeling of "not caring" and the terminal phase of apathetic indifference. (p. 62)

Other nursing definitions of suffering can be unclear. Some nurses rely on the biomedical model used by doctors, which diminishes the mysterious aspect of suffering. A number of studies found that nurses' inferences about suffering related significantly to the nurse's socio-economic and cultural background, and the patient's diagnosis, age and ethnicity (Davitz & Davitz, 1981; Davitz & Pendleton, 1969a, 1969b, 1969c, 1969d). Suffering therefore might be inferred where it does not exist, or might be missed when it is present.

Nurses are increasingly interested in exploring the perceived nature of suffering and the experience of suffering for clients and their families (Benedict, 1989, Hinds, 1992; Nokes & Carver, 1991; Pilkington, 1993) but there is still difficulty in recognising suffering in others. Steeves, Kahn, and Benoliel (1990) investigated nurses' interpretations of their patients' suffering. Graduate nurses, when interviewed, described assumptions, beliefs and ideas held about the suffering they encountered in daily practice. Findings indicated that the meaning of patients' suffering for nurses changes as they are socialised into nursing. The several themes that emerged were ordered in the following way. Initially the nurses conceived of suffering as a condition described in terms of causes, that is, the cause and effects of the condition. This conception proved unsatisfactory to the nurses, as other characteristics of suffering were identified and these did not match the notion of suffering as a medical condition. One such characteristic was that the person must be conscious to suffer. Participants also viewed suffering as an experience. Characteristics of the experience such as loss of control and coping emerged. The nurses spoke of the emotional content of suffering and recognised their own emotional reactions to the suffering of others (Steeves, Kahn, & Benoliel, 1990).

Lindstrom and Eriksson's (1993) phenomenological study sought to help in the understanding and alleviation of suffering. The informants were 5 patients and 11 care providers in what was described as a social psychiatric unit operating along Christian principles. The care giver group consisted of nurses, doctors and hospital clergy. The nurses were reportedly hesitant and uncertain when verbalising their interpretations of what patients experience when suffering, and what they really believed suffering to be. Nurses tended to explain suffering in terms of presumed causes rather than descriptions. Nurses interviewed reported that patients' expressions of suffering varied according to personality and that they, the nurses, were intuitively aware of suffering. The study found that suffering is a part of life and caring. It may be alleviated but not eliminated by compassionate and loving care. Suffering was perceived to be more than pain, and perhaps could be conceived as a form of dying which leads to a new life when transcended. Suffering has no intrinsic meaning, but humankind can give meaning to their experience of suffering. These findings were consistent with the Christian ideology of the informants and their employing organisation.

2.2.3 Pain and suffering

There has always been confusion between pain and suffering. The two terms are often invalidly coupled. Suffering can occur in the absence of pain, and pain without suffering. Copp's (1974) distinction between suffering and pain inspired a shift in emphasis for research from pain to suffering. Copp explored the experiences of pain related to surgery. She found that patients suffered in anticipation of pain and not just because of pain. Suffering was defined by Copp (1974) as "a human state of anguish of one who bears pain, injury or loss" (p. 40). Kahn and Steeves (1986) noted that work before their research claimed that suffering differs from pain and that suffering and pain have different causes. Whilst this difference had been identified, there was still no clarification of the difference, and blurring still existed between the two concepts.

Davitz & Davitz (1981) noted that the relationship between pain and suffering was complex, but in their studies suffering was described and measured in terms of the degree of physical discomfort or pain and psychological distress, thereby taking a more narrow perspective of suffering and one that sits more comfortably with the biomedical or clinical model of health and illness.

The International Association of the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual and potential damage, described in terms of such damage" (Chapman & Gavrin, 1995, p. 5). This definition suggests that pain involves no less than two distinct processes in the central nervous system. A sensory process providing relevant information to the brain is coupled with an affective process that gives a negative feeling about the sensory experience of the tissue damage. Pain is therefore partly an affective state, Severe, unrelieved or chronic pain may lead to suffering, but suffering is considered "a more complex experience than the simple bodily pains which include emotional and mental pain" (Stratton Hill, 1991, p. 79).

Woodruff (1996) argued the distinction between pain and suffering to be necessary for a number of reasons. Consistent with Cassell (1991), Woodruff argued that suffering affects the whole person, and is not just a bodily or mental experience. Suffering may result from interference with any aspect of the individual whether it is physical, social, psychological, cultural or spiritual. Individuals may vary considerably in the degree of suffering they experience from a particular threat. Woodruff (1996) concluded that no amount of well prescribed analgesic medication would relieve the client's pain when other aspects of suffering that aggravate or compound the person's pain have not been addressed.

Boeyink (1974) commented that a physician would be confused when his intervention for pain does not relieve the suffering of his patient, which can be the result of grief or fear. Continued suffering for the patient, despite analgesia, may confuse and distress nurses. Nurses should understand the difference between pain relief and the relief of suffering in order to realise that analgesia is not the remedy for all forms of suffering.

2.3 Nursing's response to the suffering of patients

Whilst some have attempted to define suffering and determine how nurses make inferences about the patients' suffering, hardly any research investigates how nurses experience caring for people who are suffering, and the effects of the experience on the nurses.

2.3.1 Witnessing the suffering of others

Davitz and Davitz (1981) addressed the effect on nurses who witness suffering by noting the nurse's responses to their patient's pain and illness. They argued that society often expects nurses to be above human feelings and without reactions to the pain and illness of their patients. In their investigation, Davitz and Davitz asked several hundred nurses about their reactions to pain and distress in others, and whether and how these reactions had changed since they first began to practise. The nurses' self reports indicated that changes do occur. Most reported becoming more practical and realistic, whilst others reported increased sensitivity to and understanding of the suffering of their patients. The nurses reported feeling especially sensitive to certain categories of patients. These categories related to the ages of the patients or the type of illness. For example, children, younger persons and patients with the most serious illnesses gave rise to a more sensitive response than those perceived as having less serious illness. In another study, patients considered complainers were sometimes avoided (Davitz & Davitz, 1975).

The most common problem identified for the nurses was that of over-involvement with the patients. The most difficult aspect for nurses was the emotional suffering of their patients, which may have caused the nurses' overemphasis on pain rather than psychological distress when evaluating suffering. Pain was something that the nurse felt he or she could deal with (Davitz & Davitz, 1981). The effects of over-involvement of the nurse affected their home and family life.

Kreidler (1984) explored the dual suffering of clients and nurses when confronted with situations that appeared to be without meaning for the nurses, and wrote of the notion of "the ideal nurse who is able to control patients, situations, schedules, other staff and his or her own emotions" (p. 74). Kreidler suggested that nurses have been unprepared for situations where meaning is questioned, and asked whether nurses respond only to needs with which they can cope. Kreidler (1984) suggested that nurses cope with their inadequacies by distancing themselves from the patients, and as a result they lose the very human quality of the work that initially drew them to nursing. Nurses may be overwhelmed by suffering that makes them feel helpless and inadequate or to which they cannot relate. Kreidler (1984) argued that the spiritual distress of nurses in the face of suffering must be explored and understood for nurses to be able to care appropriately and meet the patients' needs.

A study by Steeves, Kahn, and Benoliel (1990) on nurses' interpretation of their patients' suffering found that once the nurses recognised their own emotional reactions to the suffering of others, suffering became personalised for them. The nurses also suffered. With this process came the realisation that they, as nurses, at times actually cause suffering for their clients. For some nurses this led to the desire to either leave nursing or a particular clinical setting.

Sherwood (1991) interviewed a variety of care givers, including nurses, who witnessed suffering constantly in their daily work. A common theme was a "reaction of awe and a feeling of privilege to be allowed to enter the world of suffering" (Sherwood, 1991, p. 108). There was, however, an expectation that the care giver will give care and of themselves to improve the life of the other and alleviate suffering. Inability to do this could lead to feelings of frustration and failure. Individual nurses and other care givers in this situation were seen to require a level of dedication to the client that could be detrimental to the self (Sherwood, 1991).

Suffering and its manifestation can threaten nurses. Joseph (1991) wrote of nurses absorbing fear and pain, and so being sapped of strength by the needs of their clients. Nurses may identify too closely with the feelings expressed by their patients or clients. Joseph (1991) argued that these outcomes are dangers only when the nurse is unaware of them or ill prepared to respond in a way that sustains rather than drains them.

Rushton (1992) wrote that caring for critically ill and dying patients frequently causes moral conflict and suffering for nurses. This suffering may occur because the nurse understands and identifies with the suffering of their patient. Rushton (1992) argued that the nurse's suffering could facilitate the personal and professional growth of the nurse and lead to more compassionate care. Prolonged and unrecognised suffering could be detrimental to the nurses, which supports Joseph (1991).

Nurses may suffer because of the conflicts they experience in the work setting. Some of these conflicts include the opposing moral responsibilities, such as the duty to prolong life against the duty to diminish pain and suffering and promote a peaceful death. Other conflicts arise when the patient's interests are at odds with those of the nurse's colleagues or the nurse's employer. The promotion of patient's wellbeing may also clash with the interests of their family. Rushton (1992) argued that some degree of personal suffering for nurses is to be expected, but that in order to be compassionate to others, caregivers must receive compassion. Rushton (1992) suggested strategies are required to create a more compassionate environment for care givers.

Seale (1992) studied the care given to a random sample of individuals who had died by using accounts of relatives and the nurses who gave the care. Two questionnaires, a general and a patient specific questionnaire, were administered to the community-based nurses who participated in the study. Half of the 92 nurses who answered the general questionnaire reported coping with the emotional distress of their terminally ill patients and their families to be difficult o rather difficult. For 37% of the nurses their own reactions to death and dying were difficult to cope with and 73% found giving care to terminally ill patients to be more difficult than caring for their other patients. Their responses to an open ended question as to why they found giving care more stressful a common response was that they became emotionally involved in these situations.

Nurses do at times choose to risk involvement with patients who are suffering. Artinian (1995) studied how nurses form special relationships with cancer patients. The nurses described their experiences in risking involvement in special relationships with clients as either allowing the involvement or resisting it. Consequences of involvement included accepting sadness and grief, and physical responses to these emotions that sometimes interfered with their ability to work. Nurses who decided not to risk involvement used strategies to control their involvement, including distancing themselves from their patients. The decision not to risk involvement was taken for reasons such as unresolved grief or the intention to leave the health care setting.

Nagy (1995), in her study of nurses' reactions to the pain of their patients in burns units or neonatal intensive care, found that distancing was the most common coping strategy. At times, the nurses could not relieve pain, or may actually have caused it during procedures such as dressings. Whilst distancing gave the nurses a greater sense of competence and control, and protected the carer, it had a cost. Nurses who distanced tended to become desensitised to their patients' pain. Some participants in Nagy's (1995) study were aware of this, and worried about becoming callous and cold. The pain of their patients caused anxiety, particularly for the nurses in burns units, because the mutilation associated with burns was conspicuous and the nurses seemed to identify more closely with their patients compared with the nurses caring for neonates.

Carmack (1997) addressed distancing or detachment by nurses from their patients, and how nurses balanced engagement and detachment when giving care. Carmack argued that in order to both care for themselves and show concern for their patients, nurses had to determine appropriate levels of engagement and detachment, enabling them to function with compassion while taking care of themselves. An overemphasis on either detachment or engagement was argued to be problematic for effective care giving.

Gunby (1996) explored the impact of suffering on nursing students via phenomenological analysis of 12 undergraduate students' experiences in a baccalaureate program in North America. All participants reported concerns about suffering and identified how they were affected. They confirmed that the meanings and purposes attributed to suffering by both the sufferer and the carer profoundly affected the reaction of the whole person. A common view among participants was the impossibility of genuinely understanding and caring in the context of suffering unless carers had experienced some form of suffering themselves.

A study by Maeve (1998) examining 9 nurses' experience of caring for the dying included at least one nurse who was employed in the community. These nurses learned strategies to limit involvement with their patients. They also learned what was morally responsible action and how to act when faced with dilemmas. The nurses incorporated this learning into both their personal and professional lives.

Overall, the literature amply demonstrates that nurses have trouble in coping with their patients' suffering (Davitz & Davitz, 1981; Kahn & Steeves, 1994; Kreidler, 1984; Steeves, Kahn, & Benoliel, 1990). Nurses' responses to others' suffering may range from avoidance, leading to distancing from the sufferer, to the other extreme of attempting to meet impossible ideals of caring and over identification with the sufferer (Davitz & Davitz, 1981; Nagy, 1995: Rushton, 1992). Nurses have reported frustration, helplessness and distress in situations where they could not relieve the suffering they witnessed (Bennett, 1993; Steeves, Kahn, & Benoliel, 1990); and they believed that they sometimes contributed to the suffering of their patients (Kahn & Steeves, 1994;

Rushton, 1992). The personalising of patient's suffering by nurses may lead to their withdrawal from the clinical area (Steeves, Kahn, & Benoliel, 1990). Nurses' ability to provide the most effective client care may be impaired and their personal life affected by their exposure to suffering (Artinian, 1995; Davitz & Davitz, 1981; Rushton, 1992; Steeves, Kahn, & Benoliel, 1990). The nurses' lives may also be enhanced, both personally and professionally, by the experience of caring for the suffering (Maeve, 1998). These experiences rarely receive mention outside of the specialist literature.

2.3.2 Emotional labour and nursing

Caring in nursing involves an emotional component that has been insufficiently recognised or valued. This component has been termed *emotional labour* and is particularly relevant when considering the caring of those who suffer.

Hochschild (1983) was an American sociologist who studied air hostesses, and was the first to coin the term *labour* to describe the emotional component of their work. Emotional labour refers to generation or suppression of emotion required to induce an emotional state in others. It involves face to face or voice contact. Hochschild argued that the outward presentation of the hostess as courteous, friendly and pleasant was required for the job. This requirement permitted the employer to control the emotional responses of the employee through training and supervision.

James (1989) explored and broadened the concept of emotional labour in her doctoral research on care and work in nursing the dying in a hospice. James defined emotional labour as "the labour involved in dealing with other people's feelings, a core component of which is the regulation of feelings" (p. 15). James (1989) also commented "emotional labour is hard work and can be sorrowful and difficult. It demands that the labourer gives personal attention which means they must give something of themselves, not just a formulaic response" (p. 19). James (1989) argued that the social regulation of emotions occurs in the home and the workplace, and is primarily carried out by women. The role is undervalued and mostly unseen in both contexts. While male dominated professions, such as medicine, may determine the limits and actions for emotional control, the female semi-professionals do the labour.

Smith (1992) applied the concept of emotional labour to her doctoral work with patients and student nurses. Smith researched emotional labour as a component of caring, finding that patients identified the emotional component of caring, and were aware of how they must manage their emotional responses. Some settings were more demanding of the students in terms of emotional labour compared with other settings. Specifically, Smith (1992) found that oncology wards were the only clinical settings where the student nurses clearly identified their work as having an explicitly emotional component.

The failure to recognise emotional labour in nursing helps explains the silence over the effect of patient's suffering on nurses. The control and denial of emotion required by nurses itself amounts to hard emotional labour.

2.4 Barriers to discussion and research on suffering

Medical and nursing writers alike mention the paucity of theoretical writing and studies on the nature and meaning of suffering in health care literature (Cassell, 1991; Duffy, 1992; Gregory & Longman, 1992; Morse & Johnson, 1990; Steeves, Kahn, & Benoliel, 1990).

Gregory and Longman (1992) wrote that although the alleviation of suffering is "extolled as an essential component of nursing's mission" (p. 335), there is discrepancy between nursing rhetoric, which argues for attention to the nature of human suffering, while almost ignoring the concept. Gregory and Longman (1992) suggested that, in the nursing literature, suffering is *psychologised* and reduced to general euphemisms such as *changes in body image* and *psychosocial stress* that weaken or wholly deny the moral significance of suffering. Rodgers and Cowles (1997) noted that "it seems that health care providers more often talk around the subject of suffering, enveloping it in a 'conspiracy of silence' common to the equally difficult subjects of death and dying" (p. 1048). Suffering is rarely confronted directly, leading to a lack of a conceptual base for its exploration. There is also a lack of research aimed at enabling nurses to identify and provide appropriate interventions for the suffering of their patients and themselves. Barriers to the development of discourse on suffering, as opposed to pain, in nursing and medical settings arise from various sources.

2.4.1 Structural barriers to medical and nursing research into suffering

Cartesian dualism in the 17th century saw medicine becoming focussed only on the body, leaving the mind and spirit for others to mend. Formal care of the mind and spirit was largely a Church responsibility. With the development of medicine and its emphasis on somatic disorders, the mind and spirit were still the province of religion, at least until the advent of psychiatry.

Marty (1982) discussed the split of medicine from religion, and argued that the processes of modernity tend to separate aspects of existence that might better have remained whole, because division brings the twin problems of specialisation and failure to consider the individual holistically. Marty claims this separation to be most apparent where religion and health care conventionally diverge. Physical sickness requires a physician, whereas the clergy attend to spiritual needs; or perhaps now the mental health care system carries the latter responsibility.

The separation of roles was not always so and remains incomplete. In some traditional societies and small-minority religions, medicine and religion remain blurred. Romanucci-Ross (1983) argued that for societies that are more traditional the mind and the body are connected as a single unit and in turn connected with family and community. For these people, mind, body, society and the world are interrelated; therefore, they seek healers who will meet both spiritual and medical needs.

Another reason, advanced by Cassell (1991), for lack of knowledge about the nature of suffering is the reductive methods of science. Although successful in other areas of human biology, reductionism offers less for the understanding of whole persons. This claim is compatible with Cassell's (1991) aforementioned paradox of doctors causing suffering in efforts to relieve it. There is a failure to recognise that all aspects of the person, not just the body, are susceptible to suffering.

The alleged universality of suffering, and the threat and dread it holds for all human beings, may be another implicit reason for its oversight by health care providers. Copp (1974) noted that the comparative lack of study and theorising on the nature of suffering, despite nurses confronting it daily. Copp (1974) proposed that suffering, like death, was seldom studied because it is too closely linked with each individual's own existence, and if faced could become a personal threat.

Cassell's (1991) book owes its origin to the project on suffering commenced in 1979 at the Hastings Center, an organisation dedicated to research and teaching about ethical issues emerging from biomedical advances. Cassell and his colleagues observed that the increasing interest in death and dying had minimal impact on the dimensions of personal loss and pain that they observed among their dying patients and their families. The popularity of the subject of death may have amounted to a denial of suffering, which is an experience possibly even more painful than dying.

Exposure to another's suffering may present such a personal threat to health care providers that avoidance is preferable to confrontation, let alone daring to explore its meaning (Copp, 1990; Kreidler, 1984; Reich, 1989). Younger (1995) explored the nature of this threat, and stated "suffering discloses the frailty of being, not only to the sufferer but also to all who enter into its experience" (p. 64).

Discussion of suffering by nurses is not encouraged. Nurses often witness human suffering, and frequently are the primary carers for the client and their family. Despite their familiarity with suffering, nurses seldom speak about the suffering they see, especially to those who are not nurses (Kahn & Steeves, 1994). Suggested reasons for this silence are that suffering is hard to talk and hear about. Kahn and Steeves also argued that the health care system tends to obscure suffering because of medicine's focus on the body.

Even more strongly, Frank (2001) argues that the experience of suffering is beyond the power of words. Trying to articulate what one had felt would only reduce feelings experienced by those who suffer. Frank (2001) drew on his personal experience while he and his wife waited to discover whether he had cancer.

> Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful.... To suffer is to lose your grip. Suffering is expressed in myth as the wound that does not kill but cannot be healed. (p. 355)

Frank (2001) questioned whether suffering can be researched and conceptualised. Frank argues that suffering is not a concept but a lived, embodied experience and the sufferer cannot speak of aspects of this experience. As a social scientist, Frank described medicine's (and perhaps nursing's) attempt to locate, identify and address suffering as being like:

> Napoleon's invasion of Russia; the enemy continues to withdraw while the conquering army becomes increasingly hungry, flea and frost bitten, homesick and depressed. The problem… is that suffering has no necessary connection to illness. Illness is only one occasion for suffering. (p. 355)

Taking a more positive view of inquiry and discourse into suffering, Vaux (1982) argued the importance of this line of investigation for the wellbeing of health care professionals as well as their clients. He commented that nurses, physicians and other health care professionals work daily with people and treatments that no single profession should have to face alone. Vaux (1982) maintained that whilst medicine may reject a responsibility for human suffering, it must be addressed in some way for the benefit of both patient and healer.

Rawlinson (1986) proposed two questions about suffering. The first asks what suffering is and the second what response it requires. This literature review has addressed both of these questions. It reveals an ongoing investigation aimed at clarifying and defining the term *suffering* in a way that serves nursing care and research. An important distinction between the concepts of pain and suffering is identified, despite acknowledged overlap in common thinking. There is also growing interest in the experience of patients, their friends and families in contexts of suffering, and some directives about expectations from nurses in response to suffering. Interest in exploring the concept of suffering may partly be explained by the increased interest in aspects of the person, a deeper interest in the nature of caring, and acceptance of qualitative approaches for the development of nursing knowledge.

The review of the literature revealed that further clarification of the nature and meaning of suffering is required and how nurses experience witnessing suffering. While some work has been carried out that reveals something of the experience for nurses of caring for people who are suffering, there is a significant knowledge gap in understanding how it is to be nursing a suffering person.

2.5 Conclusions from Chapter 2

Caring for people who suffer is central to nursing but at times, this task is difficult and emotionally gruelling. The literature review included an overview of suffering from the perspective of traditional, religious approaches, more recent secular thinking, from medicine, and from nursing practice in health care settings, with those settings dominated by the medical model. This model has been subject to criticism by medical practitioners, bio-ethicists and other commentators on the medical system. This model was considered to focus excessively on disease and the physical body, thereby ignoring the subjective experiences of illness and suffering.

While there has been exploration of the nature of suffering, there is still a lack of clarity of this concept in the minds of nurses. The effects of witnessing suffering have been explored, and it is clear that nurses also suffer when witnessing the suffering of others. Inability to relieve suffering and other conflicts experienced by nurses in the health care setting sometimes leads to nurses distancing themselves from the sufferers or leaving the health care setting altogether. Neither choice is desirable.

Literature on the emotional component to nurses' caring roles is beginning to emerge. This aspect of nursing needs further exploration, as do the self protective strategies that nurses employ. Although ideas about suffering and nurses' responses to the suffering have been explored in various health care settings, little is known about the experience of palliative care nurses in the community. Much of the literature relates to palliation in hospice settings rather than the community. This setting is more of a mystery, where nurses encounter the suffering, not just of the client, but also the family and the carer. As more people choose to spend their last days at home with their loved ones there will be an increasing need for knowledge on how experienced nurses survive in this context of practice and what might assist them. This study aims to answer the question not yet fully dealt with: What is it like for nurses caring for suffering people in the community?

Chapter 3 – Methodology: A phenomenological approach

3.1 Phenomenology and nursing

Nursing's search for scientific knowledge is recent compared with other disciplines. Nursing research in the past has been influenced by the *quantitative*, otherwise known as *positivist* paradigm, which presupposes an objective reality external to the self. This objective reality can be observed, categorised and measured. Meleis (1991) wrote that some philosophers in nursing were concerned about the limited view of science adopted by nurse researchers. The scientific method or *received view* still influences nursing research. From the 1960s to the early 1980s there was debate, particularly in the North American nursing literature, about the nature and generation of knowledge in nursing (Dickoff, James, & Wiedenbach, 1968; Jacox & Webster, 1986; Silva, 1977; Watson, 1981). Nursing knowledge for practice was often borrowed, with quantitative research based on the medical model being the most valued.

3.1.1 Nursing knowledge

A paper by Carper (1978) on the fundamental patterns of knowing for nurses has influenced how nurses think about the epistemology of nursing. Carper identified knowledge areas that could not be explored using the quantitative paradigm. Carper's work raised awareness of other possibilities for nursing research. What it means to know, and the kinds of knowledge of most use to nursing were considered salient. Carper's doctoral research identified four fundamental patterns of knowing (Carper, 1978). The first is *empirics*, the science of nursing, which develops theory that can describe, explain or allow prediction that is more accurate and prescription for nursing actions. The second pattern is the aesthetic; and here empathy is important for understanding of the experience of the other. Pattern three is personal knowledge, which involves striving for self knowledge to enable the nurse to "actualize an authentic personal relationship with the patient-client." (Carper, 1978, p. 17). The final pattern of knowing is the moral, which focuses on obligation. Carper (1978) argues that each pattern of knowing contributes to mastery of nursing, but none is alone sufficient.

3.1.2 New paradigms for nursing research

The past few decades have seen growing acceptance of the *qualitative* or *interpretative* paradigm. This acceptance results from questioning whether the quantitative paradigm and the scientific method can answer all of nursing's questions. It is asserted here that the development of personal and aesthetic knowing requires a qualitative approach.

For some nurse researchers, a qualitative approach seems always the most appropriate for nursing questions. Taylor (1993) argued that questions of relevance in nursing are "answered by an approach which emphasises a holistic approach to people interacting in their world rather than a scientific approach" (p. 173). The scientific approach provides a reductionist perspective of people. Many of the nurses who initiated alternatives to quantitative research accept the idea of nursing being a human science and moved towards an interpretative approach (Meleis, 1991). Van Manen (1990) credits Dilthey with the term *human science.* Dilthey (1988) saw that a human science approach aimed for knowledge and understanding rather than the observation, explanation and mastery required by the natural sciences.

Munhall and Oiler-Boyd (1993) discussed the contribution of philosophy to distinguishing between qualitative and quantitative research. Quantitative methods are consistent with realism, which holds that the world is filled with independent objects that our senses can perceive (Vesey & Foulkes, 1990). This position contrasts with idealism, which, though acknowledging physical reality, argues that the mind registers perceptions and sensations, and creates knowledge (Munhall & Oiler Boyd, 1993). Crotty (1998) considered that the world seen "through the scientific grid is a highly systematic, well-organised world... of regularities, constancies, uniformities, iron-clad laws, absolute principles" (p. 28). This is not the world experienced by most individuals. The scientific approach is nevertheless valuable and fits with Carper's (1978) science of nursing, or empirics, as one of the patterns of knowing in nursing. Crotty (1998) argued that the problem with the scientific approach is its claim that scientific knowledge is completely objective, and the only valid approach to research.

Gerber (1999) has challenged the claim for the superiority of objectivity in the positivist, quantitative approach. Gerber argued that allegations of nonobjectivity in experimental studies occur as often as queries of qualitative studies. Gerber also argues that explanations of phenomena from experimental studies do not stand the test of time, being frequently rendered obsolete by scientific developments. Constructivist and interpretative researchers using qualitative approaches argue that quantitative research results are weakened by the separation of subject and object in a research project, so that “vital subjective and contextual data have been ignored” (Gerber, 1999, p. 19).

According to Crotty (1998), before developing a research method, the researcher must determine the methods and methodologies to be employed in answering the research question, and then must justify the choice. Crotty defined methods as techniques for gathering and analysing data. Methodology is the basis for choosing and using particular methods. The choice and use of particular methods are linked to the desired outcome. When choosing methodology and methods, researchers must explore their assumptions about reality, the theoretical perspectives underlying these assumptions, and the kind of knowledge generated by the research.

Minichiello, Fulton & Sullivan, (1999) consider qualitative research to “discover the nature of phenomena as humanly experienced” (p. 36), rather than to seek causal relations and test hypotheses. Minichiello et al. provide examples where qualitative methodologies are appropriate, namely, when seeking an understanding of the meaning of an experience. They are appropriate when little is known about a topic, and when the view of an individual who is living the experience is being investigated. Qualitative approaches enable researchers to identify ambivalence and inconsistencies in situations that superficially appear uncomplicated.

The position taken by this researcher is that both qualitative and quantitative approaches have value, but the question asked and the knowledge the researcher seeks should determine the methodology and methods chosen. This study describes the meaning of a human experience. Therefore, qualitative research is appropriate.

Whilst there are a number of qualitative research methods, phenomenology is the method of choice for the current research question. The reasons for this choice are the need for further study about the experience of nurses caring for people who are suffering and the required rich and thick description that can be obtained using this method. The following discussion addresses the assumptions and theoretical perspectives of phenomenology.

3.2 Phenomenology as method

Because this study seeks to describe accurately and authentically the nurse's experience of caring for someone who is suffering, a phenomenological methodology is appropriate. The following arguments support the choice of phenomenology for the research process.

Phenomenological research aims to understand what it means to be in a particular situation, to gain a deeper understanding of the meaning of daily life experiences. Van Manen (1990) wrote that:

> Phenomenology does not offer us the possibility of effective theory with which we can explain and/or control the world, but rather it offers us the possibility of plausible insights that bring us into more direct contact with the world. (p. 9)

Lawler (1998), when discussing the goals of nursing research, pointed out that those working in "more interactive research modes" (p. 105) are not seeking the answer to a problem or the most effective ways of dealing with problems, but rather they are aiming to answer different questions and to know the world in a different way. She argued that nurse researchers "seek to understand the experience of uncertainly for its own sake – not to control certainty, but to find ways to live with it" (p. 106). Life and suffering are experiences of uncertainty. The only certainty is that suffering is experienced by all humankind, and can arrive unheralded and without remedy. All that can be expected is that one learns to live with suffering.

3.2.1 Hermeneutic phenomenology

Phenomenology as a research approach is derived from philosophy. The term *phenomenon*, as used by philosophers, refers to the appearance of things, in contrast with the things as they really are. (Spinelli, 1989). Philosophers used the term in the 18th century, but it was Husserl who gave it new meaning (Spinelli, 1989). Phenomenology is essentially "a reasoned inquiry which discovers the inherent essences of appearances" (Stewart & Mickunas, 1990, p. 3). "Appearance" in this context refers to everything of which the individual is conscious (Stewart & Mickunas, 1990).

The current research uses hermeneutic phenomenology as outlined by van Manen (1990). Hermeneutic phenomenology is descriptive, aiming to show things as they appear; and it is interpretive because it argues, "there are no such things as uninterpreted phenomena" (van Manen, 1990, p. 180).

Modern hermeneutics was a response to developments in classical philology, philosophy, jurisprudence and the needs of protestant reformers. It eventually became the province of philosophy (Mueller-Vollmer, 1985).

3.2.2 The evolution of the phenomenological movement

Spiegelberg (1982) in his historical introduction to this movement divides the development of phenomenology into three phases, which are the preparatory phase, secondly the German phase, and finally the French phase.

In the first phase, Brentano, a teacher of Husserl and the major figure of this phase, devised one of the fundamental models for phenomenological analysis (Spiegelberg, 1982). Brentano aimed to reform and restore a philosophy in the service of humankind. His contributions included the admission of experiences that had been overlooked in the science of the day, thus widening traditional empiricism and the development of a new descriptive psychology (Spiegelberg, 1982).

Brentano was interested in psychology, and was first concerned with finding a characteristic that separated psychological from physical phenomena. He first developed his doctrine of *intentionality* as the decisive part of psychological phenomena that separated it from physical phenomena. Brentano used the words *reference to a content* when discussing intentionality. This characteristic of psychological phenomena was an original thought of Brentano, and is stated by Spiegelberg (1982) to be the most important and the only lasting one for Brentano. Spiegelberg (1982) argues that the idea of reference toward an object was unique to Brentano who "uncovered for the first time a structure which was to become one of the basic concepts to all later phenomenological analysis" (p. 37).

Edmund Husserl founded the modern phenomenological movement. He belonged to the German phase. In common with Brentano, Husserl (1938/1996) had a strong commitment to scientific rigour, yet believed that science was degenerating and failing to deal with the deeper concerns of humankind. Husserl (1938/1996) considered "In all the sciences distress is felt, ultimately as a distress concerning method" (p. 10).

Husserl (1938/1996) believed that naturalism lead to problems with truth and validity. He considered naturalism to be a view of the world, as either physical or psychical, therefore able to be explored merely by the natural sciences. He considered this a narrow view, which allowed no room for ideal entities such as meaning. The value of natural science was accepted but Husserl believed that naturalism required supplementing in areas where inductive sciences were insufficient (Spiegelberg, 1982). In the Vienna lecture presented in 1935, Husserl (1938/1996) stated:

> But every where, in our time, the burning need for an understanding of the spirit announces itself; and the lack of clarity about the methodical and material relation between the natural sciences and the humanistic disciplines has become almost unbearable. (p. 12)

The vital notion that Husserl drew from Brentano was intentionality. He argued that intentionality was directed towards something. His term *intentional* "meant directedness towards an object" (Spiegelberg, 1982, p. 97). According to van Manen (1997), intentionality "indicates the inseparable connectedness of the human being in the world" (p. 181). Therefore, all thinking is thinking about something, and all actions are actions towards something.

Initially Husserl believed the roots of all knowledge were in the *things*, the *Sachen*, but increasingly he become convinced that the beginnings of all knowledge lie in the consciousness of the knowing subject to whom phenomena appear. Husserl's focus turned from the object to the subject, in order to discover the object sought by the subject. A new kind of reflection developed (Spiegelberg, 1982). Husserl outlined how this reflection could be achieved free from presuppositions in order to eliminate presuppositions not thoroughly examined. This process was to be achieved through phenomenological reduction. Reduction in this sense has a different meaning to that used in positivism. Reduction in Husserlian phenomenology refers to describing in a scientific manner as "the life of consciousness in its original encounter with the world" (Ray, 1985, p. 83). Husserl identified two stages of phenomenological reduction. The first was *eidetic reduction* or reduction from particular facts to general essences. The second step involved the suspension of all belief in the existence, which comes with every day life in order to study the essential structures as they appear. This does not mean that the belief is forgotten but rather that weight is not attached to this knowledge. This process was called *epoche* or *bracketing* (suspending one's presuppositions). Attention is then directed to what remains in terms of intuiting the essence of the phenomenon (Spiegelberg, 1982). Husserl (1996) argued that "a consistent epoche of the phenomenologist is required if he wishes to break through to his own consciousness as pure phenomenon or as the totality of his purely mental processes" (p. 17).

The purpose of reduction for Husserl was to return to immediate experience and so to purify consciousness from the "dross of the natural attitude" (Crotty, 1996, p. 59). What remains is the pure ego and what Husserl describes as *cogitationes*, that is, conscious acts or experiences, which can described at this point in a way that does not include the content of the external world. Husserl believed these *cogitationes* or cognitions formed a foundation for his rigorous science, termed transcendental phenomenology (Crotty, 1996).

A conflict arising from the use of bracketing relates to *intersubjectivity* (Cohen, 1987). Intersubjectivity refers to the idea that a number of subjectivities make up a common shared world of people, but when bracketing is carried out in a purist fashion belief in the existence of others is also suspended.

Another important concept explored by Husserl was *Liebenswelt* or "life-world." According to Spiegelberg (1982) life-world had a limited place in Husserl's later philosophy, and Husserl saw it primarily as one of two new avenues to transcendental phenomenology. Husserl considered the life-world was not easily accessed. Access would require some kind of first reduction to lead to another type of phenomenology (Spiegelberg, 1982). Dreyfus is cited by Magee (1987), to consider Husserl the culmination of the Cartesian tradition, which viewed humans as subjects in a world of objects. Dreyfus believed this view led thinkers like Heidegger to seeing the limits of that tradition and rebelling against it. Husserl (1996) believed that psychic life is accessible not just through one's personal experience but also through the experience of others. This knowledge of the realty of others as presented through human consciousness may confirm our own experiences or point out differences between individuals. Crotty (1996) considered that Husserl's legacy to the phenomenological movement was his continued assertion that access to reality was through consciousness, and idea of the unbreakable bonds between subject and object.

Heidegger was the second influential philosopher of the German phase. He was an established scholar when he met Husserl and became his assistant. While seeing the work of Husserl as the indispensable foundation of phenomenology, he claimed the right to develop his own perspective (Spiegelberg, 1982). Heidegger's work influenced the subsequent French phase of phenomenology, and some considered him an existentialist. He rejected this association. He focussed on *ontology*, or the study of Being, in contrast to Husserl's search for knowledge, and criticised Husserl's emphasis on description rather than understanding. Rather than seeing man as constituted by his consciousness as Husserl did, Heidegger considered consciousness an ability of humankind (Spiegelberg, 1982). Heidegger, however, did consider intentionality an essential theme for phenomenology, as have later phenomenologists.

For Heidegger, phenomenology is the method of uncovering that which is hidden, and the primary phenomenon that needs uncovering is Being. He believed himself the first thinker to have raised the question of Being, and proposed a new type of interpretation for this purpose. This led to the appearance of *hermeneutics* in Heidegger's phenomenology. Hermeneutics uses methods that go further than just description and "tries to uncover the hidden meanings" (Spiegelberg, 1982, p. 385). Heidegger's hermeneutical understanding, as explained by van Manen (1997), was "not aimed at re-experiencing others' experience but rather the power to grasp one's own possibilities for being in the world in certain ways" (p. 180).

Heidegger referred to a human being as a *Dasein* which translates to "being-there," and argued that Dasein "always understands itself in terms of its existence: to be itself or not itself" (Heidegger, 1962, p. 33). Dasein, as an entity, was argued by Heidegger has the choice to be itself or not. Dasein has either grown up into these possibilities (being or not being), got itself into them or has chosen them. This relationship to the world is verbalised in the term *being-in-the-world*, which according to Heidegger, is the basic structure of human being. Both the world and the being are what they are only in this relationship to each other. Dasein are thrown in to a world, which is threatening and uncertain and the inevitable end is death. This prospect fills individuals with dread, leading to anxiety. In defence against anxiety, truth is denied, and so existence becomes inauthentic. When functioning as authentic beings, individuals take responsibility for themselves, which leads to more openness to being in the world. This openness is not an either-or state, but can change depending on how the individual interprets their current circumstance (Spinelli, 1989).

Dasein and the world are complementary in the sense that how one is viewed determines the conception of the other. Inwood (1997) explicates Heidegger's notions of Dasein and the world. Dasein approaches the world with concern, is practical and has a spatial sense of the world. Dasein is aware of others and even when Dasein is alone, others are conspicuous by their absence and therefore Dasein is incomplete. In contrast to Husserl, preconceptions were considered to be part of being-in-the-world, so could legitimately be explored (Spiegelberg, 1982). Heidegger (1962) argued that any interpretation involves a *fore-having* (something we have in advance), *a foresight* (something we see in advance) and a *fore-conception* (something we grasp in advance). It is therefore impossible to bracket in the sense that Husserl proposed.

Mueller-Volmer (1986) argued that Heidegger restructured Husserl's phenomenological method to suit his purposes, and for him the phenomenological task is hermeneutic: that is, to interpret. Heidegger sees the individual's being as related to time. Whereas lived time includes past, present and future, one projects oneself towards the future (Mueller-Volmer, 1986). It is through understanding rather than knowledge that all the possibilities of life are disclosed. Understanding of Being, however, is never fully accessible for a number of reasons. Heidegger argues that understanding is embodied in skills. We dwell in our understanding as fish do in water. A third problem identified by Heidegger is that our understanding of Being is distorted in an attempt to ignore interpretative activity and the consequent unsettledness this brings (Dreyfus, 1991). Heidegger considers understanding as both existential and hermeneutic. Interpretation originates in understanding and is always derived from it. A notion of understanding also raised by Heidegger is that we can understand something only in relation to the whole of which it is part, and vice versa. This is referred to as the hermeneutic circle. Verbal statements are the forms that understanding takes in the human sciences, thus moving the analysis towards language and speech.

Philosophers such as Sartre and Merleau-Ponty developed Heidegger's work during the French phase, and it was here that existential phenomenology developed. Merleau-Ponty won prestige for his method. He saved phenomenology from becoming merely a tool of existentialism (Speigelberg, 1982). Merleau-Ponty also reinterpreted Husserl's phenomenology. For Merleau-Ponty, phenomenological description is primarily a protest against science. He disagreed with Husserl's notion of truth being found within the consciousness, believing instead that truth is found within the world, since it is in the world that one recognises oneself (Spiegelberg, 1982). Husserl's notion of reduction was also altered, and became in Merleau-Ponty's hands a means of "loosening our habitual ties with the world" (Speigelberg, 1982, p. 551). This change provides the greatest lesson: that complete reduction is impossible.

Dreyfus, as cited in Magee (1987), argued that there were two large gaps in Heidegger's text *Being and Time*. The first point he noted is that Heidegger never talked about the body, or even about skills and practices of the embodied being. These latter two cannot be considered in any concrete way without reference to the body. Heidigger spoke in an abstract way about notions of *ready-to-hand* and *unready-to-hand*, and used the metaphor of a hammer to illustrate these. Merleau-Ponty spoke of the body and the notion of the body-subject, and of the body as subjective experience rather than the notion of body as an object. This idea is central to his account of human existence (Matthews, 1996).

The second gap in the work of Heidegger identified by Dreyfus, as cited in Magee (1987), was the way in which he described perception. Magee (1987) argued that perception is spoken about as if it were staring at things. The way in which Merleau-Ponty speaks of perception as an embodied activity, whereby we move to understand things in the world, is more fitting for Heidegger's work (Magee, 1987).

A further influence on the methodology proposed for this research project was the work of Gadamer, which addressed the tasks of hermeneutics. Gadamer was a student of Heidegger and was influenced by his work. Mueller-Volmer (1985) stated that, while Heidegger fashioned hermeneutics into a philosophical tool for uncovering the ontological structure of human existence, Gadamer turned this around and took hermeneutics back to its origins. Gadamer maintained the historical nature of understanding itself, and argued that any interpreter is always guided by his or her own prejudices, which are part of one's historical existence. He did not perceive prejudices as some negative influence to be overcome in the quest for objective truth. Prejudice, according to Gadamer (1960/1998), referred to a judgment given before final examination of all defining elements of a situation. Gadamer considered prejudice to be a necessary condition for all human understanding (Mueller-Volmer, 1985) so the notion of bracketing and phenomenological reduction were rejected within Gadamer's hermeneutics, as they were by Heidegger.

A further contribution by Gadamer (1998) was the notion of horizons of meaning. These refer to the need for people seeking understanding to have a wide vision. Prejudices contribute to the individual's horizon that is constantly being formed. Fusion of horizons refers to the continuing fusion of the historical with the present. This process occurs through understanding. In hermeneutic inquiry there is ideally a fusion of the horizons of the interpreter and the text. The hermeneutic circle, a concept familiar from the work of Heidegger, is an important concept also for Gadamer. This dialectic process refers to the process of analysis where parts of the text are understood in relation to the whole text, with movement back and forth between individual texts and the whole text. As this process continues, the meaning of the whole text begins to emerge. As understanding of the whole text increases, examination of parts of the texts reveal a deeper layer of meaning which furthers the analysis and understanding of the whole. The hermeneutic circle therefore refers to a process occurring throughout data analysis, which alternates attention back and forth from the meaning of the smallest details to the larger units of data, thereby increasing understanding of the whole text.

All of the philosophers discussed have informed the Human Science approach of van Manen, which is phenomenological, hermeneutic and language oriented (van Manen, 1990). The current study aims to describe and understand the lived experience of the nurse when nursing suffering people via van Manen's approach, which values the meaning people ascribe to their existence and is concerned with the subjectivity of people's realities. This approach addresses the aesthetic and personal patterns of knowing.

3.3 Phenomenology as method for nursing research

Phenomenology seeks a deeper understanding of the everyday experiences of living. It asks what particular experiences are like for the individual. Van Manen (1990) seeks to understand the experience "from the inside" (p. 8) rather than gaining an intellectual understanding of the experience. Understanding of direct contact with the world involves the production of texts from the data and reflective writing. It is also hermeneutic because it interprets the texts in order to seek the meaning within them (van Manen, 1990).

3.3.1 Contributions from phenomenology

This chapter has outlined the modern history and development of phenomenology. The Human Science method described by van Manen draws from both German and French phenomenology, various philosophers, and from scholars of earlier times. The term Human Science derives from Dilthey, and according to van Manen (1990), is the title given to approaches to research that requires interpretation and understanding rather than observation and explanation.

Husserl's intentionality and life world inform this research approach. Attention is directed towards something that presents itself to consciousness in the life-world and for this study, it was the conscious experience of nurses caring for people who suffered. The process of eidetic reduction referred to by Husserl was implemented to grasp and describe the essences of the nurses' experience. Van Manen (1990) states that *essence* can be considered a linguistic construction describing the phenomenon which is the focus of the inquiry.

Heidegger's interest lay in discovering the nature of Being, or ontological questions of meaning, whereas Husserl focussed on epistemology, or what is known. For Heidegger, Dasein was always in the world and part of the world so bracketing was impossible. Van Manen suggests that need for awareness of existing beliefs, biases or assumptions held in order to prevent them influencing the interpretation of data. It is not possible however to

Van Manen's emphasis is on writing and the importance of the text. This writing occurs not just at the conclusion of analysis, but it is through writing and writing that the experience can be seen and shown. The Human Science approach advocated by van Manen (1990) was developed for research in education but has application for many fields. Van Manen (1990) argues its usefulness for nursing when describing a difference between nursing and medicine. Van Manen (1999) describes medicine as Gnostic practice. This form of practice aims to locate the disease and remove it, and tends to fragment the individual. Pathic practice seeks to reunite the patient with their body or with their world. Gnostic and pathic practices do not compete, but rather complement each other (van Manen, 1999). Van Manen argues, "Pathic questions cannot be answered by texts that primarily communicate cognitive meaning. And Gnostic insights cannot produce pathic experience" (p. 34). Given that nursing's focus in on care rather than cure and aims to assist clients as embodied beings to live in their world nursing questions are pathic questions interested in experience.

3.4 Conclusions from Chapter 3

This chapter describes phenomenology as basis for nursing research and contributions from the various phenomenologies to a Human Science approach identified. A qualitative research approach is argued to be more appropriate for this study. Phenomenology will best answer the question of what it is for the nurse to care for someone who is suffering. The next chapter describes the method drawn from the theory of phenomenology that underpins it.

Chapter 4 – Method: Researching the Phenomenon of Caring for People Who Suffer

4.1 Introduction to researching the phenomenon

The nature of a human science approach, the philosophy underpinning this approach, and its relevance to the research topic were discussed in the preceding chapter. The purpose of this chapter is, firstly, to describe the design and strategies used in the study. This includes the data collection, management and analysis of data, the writing process and ethical issues. Secondly, the context of the study, namely the provision of palliative care by community nurses in both urban and regional settings, is discussed. The participants are described and demographic details of each participant provided.

4.1.1 Research question and study aims

The study aimed to gain an accurate and authentic description of experience of nurses caring for people they believed were suffering. The nature of the research question suggested that it could best be answered by strategies informed by phenomenology. The question for the study therefore asks what is the nature of the phenomenon of caring for someone who suffers.

The study was informed by the Human Science approach described by van Manen (1990) and the method of analysis employed by Adams (1998). While the notion of lived experience cannot be grasped fully, since it requires reflection on experience, phenomenology aims to reshape lived experience into "a textual expression of its essence" (van Manen, 1997, p. 36). The experience of caring for people, who suffered, as described by the nurse participants in the study, was investigated in order to create a phenomenological description of the phenomenon under investigation.

The study aimed to:

- Explore the experiences of the nurses and their reflections on these to describe the phenomenon.
- Uncover the meaning of the experience of caring for people who are suffering for the nurses.
- Offer findings that will aid understanding of the experience of nurses caring for people who suffer. These findings will offer guidance for nursing practice, nursing education, and administrative support processes for nurses in clinical settings.

4.2 Design of study

The study is a qualitative study and was conducted using a hermeneutic phenomenological approach informed by van Manen (1990). This approach is influenced by the Dutch phenomenology of the Utrecht School and combines features of descriptive or Husserlian phenomenology and the interpretative phenomenology of Heidigger (Cohen & Omery, 1994). The preparation for the study, recruitment of participants, study process and ethical issues are described and discussed in the following section.

4.2.1 Preparatory phase

The first step of this approach, as described by van Manen (1990), involves personal reflection by the researcher on the experience of caring for people who are suffering. The purpose of this step is to orient to the phenomenon, formulate the question and explicate knowledge, preunderstandings, bias and assumptions held by the researcher. Van Manen (1990) argues that this step of explicating knowledge and preunderstandings is necessary, not with the intent to forget these preunderstandings and assumptions, but rather to hold them at bay, so preventing interference with the process of the investigation. This task involved reading accounts of suffering in the literature and reflecting on these and my past experiences as a nurse caring for people I believed were suffering.

Following this reflective process, I decided to explore the experiences of registered nurses who provided palliative care, since this group of nurses is exposed to suffering on a daily basis. The description of the caring for people who suffered required that the participants should be individuals who had experienced the phenomenon being explored. Therefore, the criteria for participation in the study were that participants would be providing palliative care, and had done so for a minimum of one year. The participants in a phenomenological study are chosen because of their personal knowledge of the experience being studied. A year of experience as a palliative care nurse was deemed necessary for the nurses to be able to provide the rich and thick description required to gain an insight into the experience as it was lived by the nurses. This description goes further than the surface of the phenomenon under investigation. It seeks to reveal a thorough understanding of the context and the "participants' motivations, interpretations and feelings about the situations relevant to the investigation" (Minichiello, Fulton, & Sullivan, 1999, p. 42).

4.2.2 Recruitment

The participants were invited to contribute to the study through a special interest group in palliative care nursing. I addressed the nurses attending the meeting of the special interest group, and presented my intended study. At this time, I issued an invitation to the members of the group to contribute to the study. This presentation was followed by a written invitation circulated to the members of the special interest group via their newsletter. I also approached an agency providing palliative care in the community to invite their palliative care nurses to participate in the study. The intention initially had been to focus on the experience of palliative care nurses, including community based nurses and nurses employed in hospice settings. There were, however, 12 community nurses who expressed interest in participating and only one nurse employed in a hospice. The decision was then made to focus on community nurses as they shared the same context of practice, had a particular perspective to share as community nurses, and indicated the most interest in the study.

The purposive sample, therefore, consisted of registered nurses who were providing, or had provided, palliative care in community contexts for a minimum period of 1 year. Two nurses who had resigned from palliative care positions within the past 6 months, sought to contribute in the study. These nurses were included although they did not meet the original criteria of currently providing palliative care. The rationale for including these nurses was the belief they could contribute a further dimension to the study. Their reasons for leaving palliative care would be helpful in determining factors that lead to palliative care services losing valuable experienced nursing staff.

The sample size was small for the following reasons: In qualitative research it is the events, incidents, and experiences rather than numbers of people that are typically the objects of purposeful sampling (Sandelowski, 1995). Holloway & Wheeler (1996) note that most often the sample in qualitative research consists of between 4 and 40 informants. Large numbers of participants are not required when the aim of the research method is to capture the essence of phenomenon rather than determine typical attitudes or behaviours so results are generalisable (Minichiello, Fulton, & Sullivan, 1999).

Those nurses interested in participating in the study were invited to telephone the researcher. When this first contact occurred by telephone, the study was described, questions or concerns addressed, and arrangements made for an interview. Although the original intent was to include 10 participants in the study, this number was increased to 12 participants, so ensuring that adequate data were collected should some participants withdraw from the study.

4.2.3 The context

The community nurses are described as being, or having been, domiciliary care nurses, generalist community nurses (GCNs) or clinical nurse consultants (CNCs). The domiciliary care nurses were those who had been employed by an organisation, which offered nursing care in the home. The GCNs were employed in community health centres and provided a more extensive service. These nurses undertook school screening and infant care services in the community. They also provided home nursing services, which included palliative care. The CNCs were employed in both domiciliary services and community health services. The CNCs did have a small client load, but for the most part offered consultancy and educational services to the domiciliary nurses and GCNs who were the primary nurses for the palliative care clients.

All of the nurses were based in offices situated either in hospital grounds or in a freestanding community health centre. Half of the participants were employed in the metropolitan area; the others employed in two regional centres. The team memberships supporting the nurses varied. In the community health centres the teams were multi disciplinary. The organisation providing domiciliary services employed nurses only, but had access to allied health professionals if these were needed for a particular purpose.

Whilst it is valuable in qualitative studies to observe the participants in their work place with the recipients of their care and other staff members, this was not possible in this instance. The nurses gave the care in the clients' homes, so they travelled from house to house during the day. Participants in regional communities travelled to other townships in the region to provide palliative care services. There were, however, some insights gained when carrying out interviews in the nurses' bases. The interviews took place at different times during the day. The number of staff actually in the centre varied according to the time of day. The busiest times were early in the morning and around lunchtime. This was an indication of how much contact the nurses would have with each other during the day. The centres were quiet in the later afternoons.

The term *client* is used in the study rather than *patient* to refer to the people nursed. The nurses generally referred to the people they saw in the community as clients, and I was informed by participants that client rather than patient was the accepted term for use in community services.

4.2.4 Consent and other ethical concerns

The participants were provided with information about the study via the newsletter of the special interest group in palliative care, and so had some knowledge before their first contact with me. Similarly, the CNCs employed by the domiciliary service were informed of the study at an agency meeting and provided with written information about the study.

Before commencement of the first interview, the participants received a copy of an information sheet giving details of the purpose and design of the study. The nurses then signed a consent form indicating their agreement to participate and their understanding of the terms of participation in the study (Appendix A). The nurses received assurance they could withdraw from the study at any time, their confidentiality would be maintained and their names would not be used. In order to maintain their anonymity the participants were asked if they wished to choose a pseudonym for themselves. Most chose a name they liked, others were happy for me to choose their name for the study. The nurses were also aware that the interviews would be audio taped.

While not exposed to the risks experienced by participants in clinical trials or experimental treatments the nurses in this study were at risk of emotional distress. This distress could be associated with recall of, and reflection on, experiences that were stressful and painful. It was planned that interviews would be terminated at the participant's request or they indicated they had difficulty in continuing the conversation. I allowed time for debriefing at the completion of each interview and refrained from asking insensitive or probing questions.

4.3 Participants in the study

This section describes the participant partners in the study and there were the researcher and 12 nurses providing palliative care in the community. These nurses were people who could provide accounts of the phenomenon being studied from years of practice as palliative care nurses.

4.3.1 The researcher

My interest in the topic has resulted from the personal distress of witnessing suffering. I initially pushed my concerns to the back of consciousness and chose clinical settings where exposure to another's suffering was reduced. While I was undertaking a course of study addressing religious and spiritual issues in health care, the topic of suffering was addressed. I was asked to reflect on a past clinical experience when I had nursed someone I believed was suffering. This exercise revealed to me how harrowing some of these past experiences had been. After sharing memories with other students in the class, it became apparent many of my classmates had similar responses to the witnessing of suffering and had never spoken of these before this class. I realised that the experience of nursing someone who was suffering was as painful to other nurses as it had been for me. This painful experience is something not usually discussed by nurses or addressed by nursing administration or educational services. I believed that nurses were expected to be in control at all times and have actually been discouraged from becoming emotionally involved with their patients. Nurses were expected to maintain an emotional distance from their patients or clients and were not encouraged to reflect on their own emotional response to the client or the circumstances.

I had not had clinical experience in providing palliative care, and so did not have preconceived ideas about this particular context of practice, but I wondered how nurses could care for their suffering clients day after day. Some of my most distressing experiences had occurred while working in a burns unit. My personal experience of suffering when seeing someone I cared about suffer was also limited until after I commenced this research project. It has been during this time that I have lost loved family members and seen people I love take on a carer's role.

My personal response to suffering had been a sense of helplessness and an inability to display empathy towards the patients at times. The patients probably interpreted this as indifference on my part, although this was far from the truth. I felt for these people but could not find a way to show this. There were times when I experienced a sense of failure, not from any lack of physical care given, but rather an inability to know how I could be present for the patient. I had never been taught, heard discussed, or understood how to be present for another until I studied mental health nursing.

I was familiar with the context of practice as a community setting for these participants, having been a generalist community nurse for a number of years with clinical experience in both regional and urban settings. I have also taught community nurses, which allowed insight into their experiences and required me to undertake further reading about, and study of, that context of practice.

This past clinical experience subsequently has influenced my choice of research topic. I wondered what the experience was like for nurses who were immersed in suffering daily, how they managed to continue to provide nursing care, and what helped or hindered them in this role. I believed a greater understanding of this experience of nurses would be of benefit for nursing practice, the education of nurses and administration of nursing services. It was possible that the care of the clients would be improved and nurses better prepared for caring both for clients and for themselves. The wellbeing of nursing staff could, and should, be partly the responsibility of administrators as a part of occupational health and safety responsibilities. Instituting processes and structures to address the problems identified from the accounts of the nurses could carry out this commitment to occupational health and safety.

4.3.2 The nurses

The choice of participants for a naturalistic enquiry is different from conventional sampling. It is based on informational rather than statistical considerations and aims to maximise information rather than facilitate generalisation (Lincoln & Guba, 1985). The method of choosing a sample in hermeneutic phenomenological research differs from other approaches. The researcher is interested in informants who can speak about the phenomenon, and the way in which they speak of it. The two criteria for participation in this study were that the participants must have provided palliative care for a minimum period of 1 year and if not currently practising in that field, must have done so within the past 6 months.

Whilst nurses in any context of care are exposed to human suffering at times, the care in many settings has positive results for the clients or patients. For example, for the majority of clients in a maternity unit the experience is one that leads to joy. The informants who participated in this study have most certainly witnessed great suffering and loss, since the outcome for their clients is the inexorable move towards a death that seemed to come too soon. There was also the suffering of those who loved them. These nurses could speak to the experience of what it is like to be immersed in a setting where there was tragedy and suffering for so many.

All of the participants were female and their ages ranged from 34 to 55 years. They had provided palliative care nursing services for periods of 3 to 15 years. Half of the participants lived and worked in metropolitan settings, while the other 6 were based in regional areas. Since all participants were female, feminine pronouns were used during the writing of the thesis.

Lynette

Lynette was a CNC in a Metropolitan area who had initially begun caring for dying clients as part of her role as a domiciliary nurse. Lynette had been employed as a CNC for approximately 8 years. During the period of time in which the interviews were carried out, her employing organisation was undergoing significant structural change.

The change was unsettling for this nurse. Lynette's care team consisted only of registered nurses, so she did not have access to a multidisciplinary team.

Lynette changed employers during the study but continued in the same role of providing some client care and supporting, and educating community nurses as the CNC in palliative care. In her new place of employment, Lynette was based in an office building near a suburban shopping centre and was part of a larger multidisciplinary team.

As the study participants were given the choice of where the interviews were to take place Lynette decided that the first interview would be in my home. Her stated reason for this was that she shared an office and there was no privacy at her place of work. The second interview and subsequent interviews took place in her office since she then had an office to herself.

The nature of suffering was the primary topic in the first interview, and Lynette recounted some of problems she experienced when trying to relieve the suffering of her clients. She also spoke of the effect the changing structure of her employing agency had upon her ability to provide care, and how she missed providing the nursing care directly to clients. Lynette became emotional when discussing this, and shed some tears, but recovered quickly and wished to continue with the interview. She did not carry a client load as a CNC, but assisted the primary nurses with care.

Lynette was more cheerful and hopeful about the future, due to the changes occurring in her organisation at the second interview. She now had an office to herself so had privacy when communicating with clients by telephone. After completion of the interview, she showed me around the office and introduced me to her fellow nurses who were in the centre at that time.

This hopefulness was not to last. Lynette had resigned after obtaining a position as a CNC in palliative care in another organisation. As Lynette did not inform me of this move when I contacted her, I sought confirmation that she was still interested in participating in the study.

The third and fourth interviews were held in her new office. Lynette spoke freely about her new role and was happy to be a part of a multidisciplinary team at last. She had noted the lack of this team support at her last place of employment in previous interviews. She stated that she still felt some loss of interest and joy in her work role as a CNC. Lynette described the changes she had implemented to assist the primary nurses providing palliative care. This feeling of flatness and lack of interest persisted in her final interview and Lynette wondered if it was time to say goodbye to palliative care nursing. She had experienced some health problems during the past few months and wondered if these were affecting her emotionally.

Melissa

Melissa was also a CNC in a metropolitan area. Her team was based in the grounds of a large teaching hospital. Melissa had initially been a hospital-based oncology nurse. She chose to become a community nurse and finally was promoted to the role of CNC for a team of registered nurses. This informant had access to people from other disciplines when needing their assistance. Melissa had a great deal of experience in oncology and palliative care, having practised in these areas for more than 10 years. She had postgraduate qualifications in oncology nursing, palliative care nursing and was just completing a Master's degree which investigated an aspect of symptom control in palliative care. Melissa stated she was fortunate as being one of few people happy in their role and her facial expression was consistent with this statement.

The interviews were all held at the premises where she was based. Melissa had been able to obtain access to an office in the building and the interviews took place there. There were no interruptions during the interviews, and since Melissa had carried out interviews for her Master's thesis, she was familiar with the process and what was required.

As with all participants, the first interview began with sharing of information about my nursing background and an introduction to the study and the signing of the consent form. The first interview addressed the nature of suffering as Melissa saw it. The second interview began with Melissa speaking of being tired, and she both looked and sounded tired. Her head and body drooped and she yawned at times during the interview. Melissa was about to take leave because of her fatigue.

Melissa returned from her leave before the third interview and was bubbly and enthusiastic after having a holiday. She stated that she was feeling enthusiastic and energetic after her vacation.

There was a longer time span between the third and fourth interview, as Melissa had taken recreation leave and some long service leave to finish her Master's thesis. The interviews were without interruption and uncomfortable silences.

Martha

This participant was one of the two who had resigned from a CNC position in palliative care within 6 months before the commencement of interviews, but still wished to participate in the study. Martha was currently developing a private practice providing complementary therapies for clients, and did not intend returning to a nursing position in the future. Martha was a staff member in a hospice before providing palliative care in the community. She was on call at night and provided care on weekends initially. Martha had first been employed by a Christian organisation as a palliative care nurse, but then successfully applied for a CNC position in an urban community health centre. Martha remained there until she decided to leave nursing. She had been a palliative care nurse for 12 years.

All the interviews were carried out in Martha's home as she had requested. The first interview took place in Martha's family room at a desk in an area set aside for working. She spoke of how she saw suffering, and her experiences in providing palliative care. Martha became emotional when speaking of how she came to leave palliative care nursing.

The second interview was shorter than the first, as Martha had other commitments for that day and seemed initially to be hurried and stressed.

Martha chose to sit outside, overlooking the back garden for the third interview. The final interview took place in the room she used for seeing her clients. Martha provided complementary therapies of various types for these clients. It seemed that Martha was almost showing me aspects of herself with the changes in the settings for the interview.

Robyn

Robyn was a CNC in a regional centre and employed by a community health service. This participant was one of a multidisciplinary team, and shared an office in a house close by the community centre in the town. Robyn had a postgraduate qualification in oncology and a Master's degree. She had initially been employed as a GCN and later applied for a position of CNC in palliative care and oncology. Her role currently encompassed provision of community care for clients in oncology and some clients receiving palliative care. She also supported the primary nurses providing community care through consultancy and education. Robyn had been in this role for 3 years but before then, she had been a GCN.

The first three interviews took place in her office in the community health centre. There were few people in the centre, but the first interview was interrupted by a telephone call from a client. I was struck by the tender tone of Robyn's voice when speaking to the client. This interruption did not affect the flow of the interview.

The second interview was also interrupted by a staff member seeking information from Robyn. Since Robyn was the only CNC employed to specifically provide palliative care she was called upon frequently for advice. She was also the contact person for oncology services. In the second interview, it became clear that Robyn was experiencing difficulty in her role. She spoke of personal family problems that demanded her attention, and how these had affected her. Robyn was a mother and a grandmother, so there were other family priorities for her.

At the time of the third interview, Robyn had reduced her workload from a fulltime to part-time load and was clearly experiencing problems in balancing the needs of her family and her work role. She spoke of how family problems and the worry of these had affected her ability to cope with the sorrow and suffering associated with her work. This interview was again held in her office.

Robyn subsequently took long service leave and resigned from her position as the CNC for palliative care. Robyn was employed by a nongovernmental agency as a health educator at the time of the last interview. Her appearance had undergone a change in this time. She had lost weight, and looked happier and healthier. This last interview took place in her new office. Robyn's position still related to cancer, but focused on prevention, and she had not lost interest in the area of palliative care. She thought she might return to palliative care in the future, but not as fulltime employee.

Beth

Beth had two part-time positions, one of which was as a community nurse providing palliative care in a regional area in evenings and on weekends. Beth was one of the nurses employed in an after hours service for clients receiving palliative care. She was on call at night and provided weekend services. Beth had completed her nursing education late in life after having raised a family. Beth had graduated from a Diploma program in Nursing.

Beth was isolated from her peers, in that she worked after hours and part-time. Her time spent in the community centre consisted of receiving a hand over of client information at the beginning of her shifts, and reporting back after completing her work. Beth had been providing palliative care for 6 years. Beth did not have a space of her own at the community centre, and opted to be interviewed in her home.

Beth cancelled the first interview, and a second appointment was made. This conversation took place in the family room of her home. There was a lengthy gap between the first and second interview, as Beth had taken leave from her place of work and was away on holiday for some weeks. Beth seemed comfortable and more at ease in this second interview which again was in her home.

In the third interview, Beth revealed her distress about an episode that had recently occurred. A member of a client's family threatened Beth with physical violence. This was the first time she had experienced such threats in her nursing role and was visibly distressed. Her distress was heightened by a perceived lack of support from her manager after reporting the incident.

The meetings with participants from regional areas were the most difficult to rearrange as travelling was required. The possibility of doing this depended on being able to travel on weekdays, and arranging an interview during normal working hours. Beth was interviewed on three occasions because of difficulties in arranging interviews.

Tanya

Tanya was a GCN based in a regional community health centre. She had been employed in the community for 4 years. Although she was a GCN, she had a particular interest in palliative care. This participant tended to carry a higher load of clients requiring palliation as the primary nurse than her peers do. Tanya was also interested in grief counselling and was currently enrolled in a diploma course on counselling.

Driving home after the first interview I felt distressed and wondered why. Tanya had spoken of the reason for her transfer from the hospital to the community. The transfer followed a disagreement with a doctor in the hospital over a patient's treatment. Tanya also told a harrowing story of another client recently referred to her. She believed this client had been poorly treated in the health care system. These events had clearly distressed this participant. Both these women Tanya spoke of were indigenous Australians. I had worked with indigenous health workers and indigenous communities for a number of years in the past. I have heard their stories of their treatment, and observed reactions to their presence in health care settings. Those stories distressed me at that time, and my feelings about situation of Aborigines in Australian society were reawakened by the content of Tanya's interview.

Tanya was based in a regional centre, and the first two interviews took place in the office of the CNC for palliative care. The third and fourth interviews took place in an interview room at the community centre.

Tanya focussed on the experience of caring for people who suffered, but she took a broader perspective than the nurses giving palliative care only did. She was employed as a GCN, so some clients she saw suffering were not palliative care clients. Instead, they were clients who experienced chronic illness. Tanya noted that these clients did not have the same access to adequate pain management as clients with a terminal cancer.

Marie

Marie was a CNC in the metropolitan region, and her office was situated in the grounds of a large teaching hospital. Marie had been providing palliative care for 7 years. She held postgraduate qualifications in palliative care and oncology.

This participant had first opted for the interviews to be conducted at my home. The interview was scheduled but Marie was delayed by heavy traffic. Since she was late and expected home earlier by her family the interview was cancelled. On the second occasion, she was also late and for the same reason. At the time she was able to participate in an interview the traffic was quite heavy. It was clear that interviews at my home were creating problems for Marie, so I suggested visiting her for future meetings.

The second interview was held at her place of employment. Marie had been seconded into the head office of her organisation. She was finalising a submission and seemed stressed. The interview was neither as long as I anticipated, nor as relaxed.

Our last two conversations took place in Marie's office at her home base. The tape recorder had malfunctioned in the third interview so some data were lost. I could recall what we had discussed, and so reviewed the content on tape with Marie.

She was calm and relaxed during the interviews and seemed at ease with her chosen area of practice.

Ellen

Ellen was a CNC in the metropolitan region and based in a hospital. She was a liaison nurse between the hospital and the community, covering both oncology and palliative care. She had been in this role for almost four years. At age 34, Ellen was the youngest participant in the study. Her areas of expertise were oncology and palliative care. She differed from the other informants in that her area of clinical expertise was in paediatrics. She held a postgraduate certificate in paediatric oncology.

Ellen requested that interviews take place in my home. She lived close to me, and it was convenient to call on her way home. The first three interviews proceeded without interruption, and Ellen spoke freely of her experiences. She was clearly shaken during the first interview, when describing her relationship with one client and her family. This situation had been so painful for Ellen that her distress at recalling this event was obvious. Her voice shook, her speech rate increased, and she acknowledged that recalling this situation was distressing for her.

The third interview took place just after Ellen commenced maternity leave and at this point she was less sure that she would return to her position in palliative care, as she had some concerns about being able to carry a load she considered required more than one nurse to fulfil.

The final interview took place following the birth of her child, and Ellen brought the baby with her to the interview. Ellen had made up her mind that she would not return to palliative care nursing in the near future, as she felt fulfilled in caring for her family. Ellen was now employed in a general hospital on a part-time basis. She spoke of the difference between her present position as a registered nurse in a paediatric setting, and her past position in paediatric oncology and palliative care. Ellen felt less burdened, but missed the emotional intensity of the palliative care practice.

Kirsten

Kirsten was a CNC based in a regional community health centre. She had been providing palliative nursing care for 10 years. Kirsten had a postgraduate qualification in palliative care. Before her appointment to the CNC position in the community, she had been employed in a community palliative care service. All interviews with Kirsten took place in her office. The value of Kirsten's experience to both community and inpatient settings became obvious when the first interview was terminated abruptly. She received a telephone call from the local hospital requesting her assistance with the family of one of her clients who had just been admitted to hospital.

The second interview was more relaxed and proceeded without interruption. The third interview took pace just after Christmas. Kirsten was very tired, and questioned how she could continue in the role without changes in relation to taking leave. She had been the sole provider of palliative care in the community over the Christmas break, as there were insufficient funds to employ relieving staff when permanent staff was on holiday. This period had been busy, and there were deaths that placed more strain on Kirsten's inner resources.

I returned for the final interview and found that Kirsten was ill and likely to be away from work for some time. I made the decision to omit the fourth interview for this participant, as there were difficulties in returning to this country centre because of my work and time constraints.

Sandra

Sandra practised in a role spanning that of a GCN and a palliative care nurse. Her week was divided between the two roles. She was based in a regional community health centre. Sandra had provided palliative care for about 15 years. Her role in palliative care was not formally recognised initially, as there was no specific service in this area when she began providing palliative care in the community. Sandra first set up the palliative care service in her community. She also provided care in the community in oncology as well as palliative care. Sandra had completed a postgraduate qualification in stomal therapy and palliative care, and qualifications in loss and grief counselling.

The first and second interviews took place in the office of the CNC palliative care and there were a number of distractions and interruptions, so an interview room was booked for the remaining interviews.

Sandra had forgotten our appointment for the final interview but came back to the community centre when telephoned by the centre receptionist. She was stressed and overwhelmed by her workload. Her fulltime fellow palliative care nurse was sick and there was no replacement, and Sandra's position in palliative care was only part-time. Sandra made the point that she had responsibilities to fulfil and clients that must be seen, so her working day would have extended to meet the client's needs. Although nurses were allowed to take time in lieu of working overtime, this was possible only when there were no clients to be seen and their work was up to date. A further problem was the expectation that this time in lieu be taken within a month of accrual; otherwise, it would lapse.

I could feel Sandra's anxiety during this interview, and felt guilty at the thought that I may be causing her further distress.

Alison

Alison was the second participant in the study who had recently resigned from her position as a CNC in palliative care. She had been employed in an urban area providing palliative care for 8 years. Alison had a postgraduate qualification in palliative care. She now held a position as a CNC in another specialty area of nursing, and had her own office in a facility that provided inpatient care and an outreach service for the specialty area in which she practised. Alison's office was the site for all four interviews.

Alison described her mother's dying and death in the first interview. Her voice shook, as the pain of that time was still with her. The first interview was interrupted by a telephone call and I turned off the tape. This call was short and did not affect the process of the interview. Alison told of how she came to palliative care, but stated that in hindsight it was probably to help her recover from what she perceived as poor care given to her mother as she was dying. Alison had returned to her country of birth to care for her mother when learning of her mother's diagnosis. The time spent with her mother had been a terribly painful experience for Alison, leaving her feeling a failure, and angry with doctors.

Each interview following was without interruption, as Alison told her stories of her experience and what had led up to her resignation from the palliative care service.

Lillian

Lillian was a community nurse practising exclusively in palliative care at the commencement of the study, but successfully applied for a position as a CNC in palliative care during the progress of the study. Lillian was the second youngest of the participants at age 38. She had provided palliative care for 4 years in a regional centre.

The first interview was scheduled to take place in Lillian's home while she was taking time in lieu for working excess hours in the community. I called at her home but did not receive a response and so left. When I contacted her regarding this appointment, Lillian explained she had fallen asleep and did not hear me knocking at her door. The interview was rescheduled and proceeded comfortably. At the end of the interview, Lillian's children arrived home from school and she introduced me to her two teenaged children.

Lillian was enrolled in a postgraduate course in oncology and was required to come to the city for on-campus instruction. I was able to interview her at this time, saving me a journey to the regional centre. This interview took place in a quiet corner of the staff cafeteria at a large teaching hospital where Lillian was accommodated. The interview was without interruption, and the audiotape clear despite the setting.

The third and fourth interviews were carried out in Lillian's office at her home base in the region. By the third interview, she was acting in the position of CNC waiting to see if she had been successful in her application for the vacant position of CNC palliative care. She discussed the changes this had brought about in her role. By the time of the fourth interview, Lillian had been appointed to the position of CNC in palliative care.

4.4 Data collection

Interviews are an essential part of data collection for many qualitative nursing studies, and were for this study. Sorrell and Redmond (1995) suggest that the interview approach be shaped by the specific research methodology. The interview process was planned to fit with a hermeneutic phenomenological approach.

4.4.1 The process

Hermeneutic phenomenology aims at gaining a deeper understanding of the nature or meaning of everyday life experiences through retrospective reflection on lived experience (van Manen, 1990). Munhall (1994) discussed the concept of intersubjectivity, which is defined as the verbal and nonverbal interplay between the subjective worlds of two people. Individuals do not know about another's subjective world unless told, and even then, one is not sure. In phenomenological research, the researcher is the unknower learning from the knower. The purpose of the phenomenological interview is to understand the shared meanings of subjective worlds by obtaining a clear and graphic description of the lived experience being investigated. The style and structure of interview must facilitate this process.

The interview process and the relationship between the interviewer and the participant influence the nature of the information gathered. Nondirective approaches coupled with careful posing of questions are suggested as ways to elicit rich data (Drew, 1993). Sorrell and Redmond (1995) suggest that interviews are participated in by the interviewer and the interviewee rather than being conducted. A conversational style was adopted for the interview to enhance the sense of participation for the nurses. The approach to interviewing involves active listening by the interviewer to the narratives of the participant. (Sorrell & Redmond, 1995) This encourages participation as the nurses feel they are really being heard.

4.4.2 The interviews

In this study, 10 of the participants were interviewed on four occasions and other two on three. The reasons for two of the participants being interviewed on only three occasions are discussed in the section describing the participants. Forty-six interviews provided events and experiences for analysis. Forty-six interviews were sufficient for the study as they provided adequate data for the study. Interviewing is time consuming, and restricted time and resources present difficulties for a single researcher involved in large numbers of long and complex interviews.

Data were collected through unstructured interviews, with neither question nor answer categories predetermined other than an initial request that the nurses talk about how they came to be palliative care nurses. Conversational interaction between interviewer and participant elicited information and each of these interviews were approximately ¾ to 1 hour in length. On the initial contact the first interviews were scheduled at a time and place determined by the participants as was each subsequent interview.

Each interview was audio taped and the audiotapes were transcribed. A copy was returned to the informants for their interest and as a record of the interview, if they requested this. Some participants requested the transcripts as a way of reviewing their practice. The second reason was to allow the participants to see their contribution to the study. There was no intent or request for participants to validate the data obtained.

As the interviews progressed, each taped interview was listened to immediately before the next interview. In this way noting some of the content discussed in the previous interview could link the interviews. I was able to clarify any information arising from the previous interview that was unclear to me.

Establishing rapport and careful framing of the opening question are critical for setting the tone of the interview and gathering the data required to answer the research question. Questioning style and the use of probes throughout the interviews assisted the participants to describe their experiences rather than interpreting them. Open questions and requests for examples or further information about issues raised by the nurses drew on the memories associated with these issues.

Drew (1993) wrote that the phenomenological researcher seeks descriptions that capture the experience of the participants, and this involves the concept of immediacy. This concept refers to phenomenology's concern with the concrete and the immediate. Immediacy is reflected in two ways in the interview process. The first of these ways relates to the interaction between the interviewer and the participant. Immediacy exists when the interviewer can engage with the participant. This engagement depends on how the interviewer is perceived by the informant. An interviewer perceived as non-judgmental, sensitive and ethical enables participants to share thoughts and feelings. I endeavoured to be such an interviewer.

Engagement was facilitated by sharing something of my past nursing experience and responding verbally and nonverbally to the nurses in a non-judgmental and sensitive fashion. Conducting the interviews in a setting where the participants felt comfortable also assisted in engaging the participants. Allowing the participant to chose the time and place of the interviews helped the participants to be comfortable and relaxed. I also needed to be sensitive to unexpected situations occurring on the day of interview. For example, on some occasions the nurse had admissions or other unexpected emergencies to attend. The time allocated for interview had to be reduced or changed. In community settings the nurses do not hand over to another nurse, but must complete their responsibilities for the day, even if the work day is extended to accommodate the client's needs.

The second aspect of immediacy was aided by the nature of the relationship between participant and researcher and the interviewing skills of the researcher. This second aspect affects the extent to which the participant is able to explore their experience of the phenomenon of concern. Counselling and communication skills obtained while undertaking a clinical master's program in mental health nursing assisted with establishing a relationship with the participants, and being able to actively listen and encourage open communication.

The data collected by interview was only one part of data that were collected. Field notes were maintained using the guidelines of Minichiello, Aroni, Timewell & Alexander (1995). These described each interview and its setting. Reflective notes on fieldwork experience and methodological issues were retained.

The conversation flowed well in all interviews. At the beginning of the interviews, the nurses sometimes wondered what they could talk about but after I commented on or clarified some aspect of the previous interview a conversation began. There seemed to come a point in the interview when there was a natural end to these conversations. The participants indicated they had nothing more to say. These endings felt comfortable to me being similar to the way the conversations end in normal daily life.

4.4.3 Data management

The guidelines set out by Minichiello et al. (1995) were used to manage the data, with modifications made as required. The information was organised by keeping a transcript file, personal file and an analytic file. The transcript file was used to store information on dates, times and place of interview and the typed transcript of the interview. The personal file consisted of a descriptive account of the interviews, reflective notes on the interviews and comments on the methodology. The analytic file was devoted to the examination of the research questions asked and the emerging ideas as the research progressed.

A further consideration of data management was the storage of information to ensure the confidentiality promised to the participants. The tapes, transcripts and any other confidential information were kept in a locked filing cabinet in my home office. Transcripts of the interviews and any other material will be retained in the locked filing cabinet for the required period and then destroyed.

4.5 Evaluation of research

The need to assure rigour and merit in qualitative research studies has been addressed by Burns (1989), Lincoln and Guba (1985), Guba & Lincoln (1989), Munhall (1994), and Sandelowski (1986, 1993). Sandelowski (1986) wrote that qualitative methods are frequently considered to fail to achieve the criteria of adequacy usually accepted in scientific research. The debate around the methodological rigour of qualitative research is argued to be further complicated by "...its diversity and the lack of consensus about the rules to which it ought to conform and whether it is comparable to quantitative research" (Sandelowski, 1986, p. 29). Sandelowski (1986) discussed the four factors identified by Guba and Lincoln (1989) as alternatives to the generally accepted criteria of rigour in quantitative research.

These factors or criteria are credibility, transferability, dependability and confirmability. They form the foundation for demonstrating trustworthiness and the decision trail in qualitative research. These alternatives have more recently been supported by Koch (1994).

Credibility reflects the extent to which the data are a true reflection of the participant's understanding of the phenomena under study. Credibility is established by ensuring that those participating in the research are identified and accurately described. Koch (1994) argues that credibility is enhanced when researchers describe and interpret their experience as researchers. In this study a field journal was used for this purpose. Other actions proposed by Guba and Lincoln (1989) taken in this study included prolonged involvement with the participants and peer debriefing. The interviews took place over a period of 12 months and consisted of a series of three or four interviews. Peer debriefing occurred through discussing the data analysis with my supervisors and presentation of my work to my fellow students. Ray (1994) described credibility as "a validating circle of inquiry" (p. 131) and commented that Buytendijk, a European phenomenologist, refers to credibility as *the phenomenological nod.* When the description and interpretation of the experience is recognised as an experience we have had or could have, we affirm this with a yes or nod. I experienced this phenomenological nod in the analysis and interpretation of the nurses' stories. A similar response was experienced by my peers when I have presented my work in progress.

The second criterion is transferability. This is dependent upon the degree of similarity between two contexts. Guba and Lincoln (1989) state that the original context must be described adequately thus enabling the readers to make a judgment of transferability. This judgment requires that the decision trail be fully documented. I have described the context of practice for the participants in the study.

Dependability is the third option. One of the ways in which a research study can be shown to be dependable is for its process to be audited by reviewing the documentation. A full description of the process with the method, theories underlying its choice and the analysis process are provided for this research undertaking. This meets the requirement for a decision trail which Koch (1994), states entails explicit discussion of choices made about method, theory and analysis throughout the study.

Sandelowski (1986) considers that a study and its findings can be audited when another researcher can clearly follow the decision trail used in the study. An additional test is that another researcher could arrive at the same or comparable conclusions given the same data, perspective and situation. Random selections of two transcripts of interviews were read by one of my supervisors and the thematic statements she identified were consistent with those identified by me for these portions of the transcripts. This result indicated some measure of dependability.

The final alternative is confirmability. Confirmability requires the data to be linked to their sources, thereby allowing the reader to confirm the conclusions and interpretation arising directly from them. Guba and Lincoln (1989) considered confirmability to be established with the achievement of credibility, transferability and dependability.

The decision trail for the study of the lived experience of the nurse caring for people who are suffering was maintained by keeping field notes providing the required information.

A full description of the process with the method, theories underlying its choice and the analysis process are provided for this research undertaking. This meets the requirement for a decision trail as described by Koch (1993).

Whilst there are no obvious benefits for the participant in the research, Hutchinson, Wilson, and Scodol Wilson (1994) suggest that participants can benefit in a number of ways from participating in research interviews. The participants in this study may have benefited from the opportunity to talk about their experience, and some participants expressed their enjoyment when listened to. The literature states that nurses often do not have the opportunity to talk about their experience with suffering, as friends and families find this distressing (Kahn & Steeves, 1994; Nagy, 1995). Other benefits for nurses noted by Hutchinson et al. (1994) are gaining a new perspective and a sense of empowerment after hearing themselves talk about their situation and telling their story sometimes for the first time.

4.6 Data analysis

Streubert and Carpenter (1995) argue that data analysis begins with data collection, because once the researcher begins listening to descriptions of the phenomenon being studied, analysis begins. After completing each interview, I began thinking about what had been said and what this might mean. I also transcribed some of the interviews and listened to the tapes to check those interviews transcribed for me. Analysis therefore began when reflecting on the interviews and during the transcription process. Any material so generated was recorded in field notes to assist with later analysis of the transcripts.

Phenomenological themes are considered by van Manen (1990) to be the structures of experience, so in analysing a phenomenon the themes or experiential structures are sought. This process was followed by further reflection and analysis to develop a hermeneutic description of what is to be caring for people who suffer.

4.6.1 The themes

The first stage of data analysis required the uncovering of thematic aspects. This involved listening to the tapes a number of times, and reading and rereading the transcripts to identify those statements or phases of the participants that provided some sense of the phenomenon. Hycner (1985) suggested the researcher must listen to the nonverbal and para-linguistic levels of communications, such as emphases, pauses and so forth to aid in this process. The process of data analysis outlined by van Manen (1990) guided the analysis for this study.

The thematic statements are drawn from the descriptions of the experience provided by the participants. In this study, the detailed approach described by van Manen was taken and each sentence or sentence cluster examined to determine what was revealed about the experience of caring for people who suffered. Streubert and Carpenter (1995) suggest that each expression be tested for the following two requirements:

- Containment of a moment of the experience that might eventually be a necessary constituent of the experience; and
- The possibility of abstraction and labelling of the moment without violating the formulation of the participant.

The next phase of composing linguistic transformations required the rewriting of the messages from the participants into thematic statements that aimed to provide an accurate interpretation of the participants meaning. Take, for example, Beth's statement:

> *You can't deal with all of life's issues and you can't fix people's lives. You can't. Right, there are lots of dynamics that have gone on through their lives with family members. I mean it's impossible to fix.*

This statement was transformed in the following way. The nurses accepted the impossibility of repairing long standing family relationship problems. It is at this point the essential themes will be distinguished from the incidental themes. Beth's message indicated acceptance of the impossibility of changing long-term family dynamics.

4.6.2 Developing the themes

The patterns of the themes began to emerge following reflection on the content of the thematic statements. As an example, it became apparent that a number of thematic statements alluded to what the nurses provided for their clients and the word *give* was used consistently by the participants. The chosen title for this theme was giving care.

Reflection on the themes identified indicated that each theme was essential for a full description of the phenomenon as revealed by the participants. This process is noted by van Manen (1990).

> In determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is. (p. 107)

4.6.3 Interpretive meaning of the themes

The final phase required questioning what it meant for the nurses to be caring for people who suffered. The themes describing the phenomenon were explored to determine what it meant for nurses to be *making the journey*, for example. The answer was found when asking what it is for nurses to in fall into the role, grasp opportunities, have a leaning for the field and to repair the past. For the nurses who had resigned from palliative care nursing, *leaving the field* and *living after leaving* provided a sense of what this meant for those participants. The description of "being" in *making the journey* was that of a sojourner. This process was repeated with every theme to determine the essence of each theme.

Findings

In summary, the description of the phenomenon of caring for people who are suffering is made up of the following findings.

These themes describe the phenomenon:

- Making the journey
- Knowing suffering
- Giving care
- Receiving back
- Keeping a balance

A hermeneutic description requires a further description revealing the nurses experience in caring for people who are suffering. Caring for people who are suffering is revealed through the essences of the phenomenon:

- Being a sojourner.
- Being initiated into the world of suffering.
- Being all they can.
- Being enhanced.
- Being mindful.

Finally, the phenomenon of caring for the suffering is presented as a mission of privilege and peril.

4.7 Conclusion to Method

This chapter presents an overview of the methods and strategies employed to complete the study in a manner consistent with the theory underpinning the approach. Whilst the process of data analysis and interpretation is described as if it occurred in a linear fashion, this was not the reality. The process of reflection, returning to the data, writing and rewriting was more of a spiral process, with meaning unfolding continually and throughout. The participants in the study and their context of practice are described, and information about the experience of the interviews provided. Criteria for assessing the quality of the study are presented with the strategies employed to assure quality in this study. Finally, an overview of the findings is presented.

Chapter 5 – Making the Journey

> *It was a journey that people were going on, and you learn to accompany them on that journey, I think. — Marie*

5.1 Introduction to Making the Journey

A nurse can be exposed to suffering in any context of practice. Palliative care, however, is an area of practice where nurses are constantly confronted with suffering. The nurses' decision to choose this context for practice was of interest to the researcher. Discovering how the participants' chose palliative care nursing could provide insights into the nature and qualities of the nurses and their past experiences leading them to this practice area. The study participants were first asked how they came to be practising palliative care nursing with the associated exposure to pain and suffering. Questioning why and how each participant came to enter this area of nursing also served to move them back in time so aiding their reflection on this experience. The nurses' accounts of their life as palliative care nurses reveal the beginning of their interest in alleviating suffering.

The nurses' stories of how they came to leave the palliative care setting indicated events in their personal and professional lives that contributed to their decision to leave palliative care and, in a couple of instances, nursing as a profession.

The messages from the nurses' accounts of their experiences in being in and leaving the context of palliative care informed the theme of *Making the journey*. There were six aspects of the theme providing a description of the experience for the participants. When telling how they came to palliative care the participants reflected on what had attracted them to the setting. Most who had left did so with regret. The aspects of the theme are:

- Falling into the role.
- Grasping opportunities.
- Having a leaning for the field.
- Repairing the past.
- Leaving the field.
- Living after leaving.

The aspects of the theme and the communications from the informants suggesting these aspects are discussed in this chapter. The aspects have been structured according to the way that events unfolded for the nurses in the study. Thematic statements were drawn from the accounts of the participants then clustered to identify the aspects of the theme. As these aspects were developed the meaning of the experience for the nurses emerged so revealing its essence.

The essence of the experience for the nurses can be described as *Being a sojourner*. This concept holds the meaning of this experience for the nurses. They visited the world of the suffering but were not permanent citizens of that world. They were purposeful visitors to this other world who could leave when they wished.

5.2 Falling into the role

The theme of falling into the role was developed from the descriptions and stories of the participants of how they came to be providing palliative care. While not actively seeking the opportunity to provide palliative care, some participants seemed to fall into this journey not really knowing where they would be taken. The requirements of their practice context, their personal circumstances when seeking a nursing position, or chance, was said to play a part in how they came to be there.

Before becoming community-based nurses, some participants were employed in hospices or hospitals; therefore descriptions and stories from these settings have been included. The different roles of the nurses help to explain the variations in how they were initially introduced to palliative care nursing.

5.2.1 Directed into the role

Falling into the role by some occurred through a directive or requirement of the employing agency. Some CNCs initially specialised in oncology, often in an inpatient facility. On moving to community nursing, they were required to provide nursing care in both palliation and oncology. Clients, recently diagnosed with cancer, were helped through the initial intensive treatment with symptom control, health education and support. These clients then moved on with their lives during remission. In contrast to their past role in oncology, the community role required the nurses to provide palliative care for the people who required this. The nurses knew there was a possibility that some clients, seen in their oncology practice, would return but this time for palliative nursing care. Palliative care became the larger part of their practice. As Melissa observed:

> *And my role, even though it started off as oncology, it got the tack on of palliative care and I guess really when it was even oncology in the community the majority of patients I saw were palliative care clients.*

Sandra had knowledge of palliative care prior to a community service being set up in her regional centre, so had been sought out by both nurses and clients for help and advice. The health service employing her was aware of her interest and knowledge, and so she was drawn into this role.

> *I was used as the resource person by the nurses as well as patients so I sort of got landed with all the oncology and palliative care and I felt very comfortable with that.*

Initial exposure for others was part of their roles as GCNs or domiciliary nurses. This was the case for Lillian who provided palliative care when running a private nursing service. She described her introduction to palliative care nursing.

> *That was my first introduction to palliative care. I did most of the administration but when I had terminally ill clients on the books I provided a lot of the nursing care.*

The CNCs in Palliative Care in the area provided education and training for nurses and other interested people and Lillian took advantage of this opportunity to learn more.

> *I actually got into the basic palliative care course that she [the CNC] ran at the time and got really interested in the concept of people dying at home.*

On selling her agency, Lillian applied for a position as a GCN. The provision of palliative care was part of her role and eventually she chose to practise exclusively in that field.

Marie was employed as a domiciliary nurse providing home nursing services. She did not choose oncology and palliative care but her employing organisation selected her to undertake training in oncology.

> *I was working for a district nursing service. Then the Oncology Nursing Certificate was being made available and it was suggested I might [do this course]. It wasn't that I elected to at the time.*

Whilst this was not an active choice for Marie, she was interested and eventually assumed the role of CNC in oncology and palliative care.

For Tanya neither community nor palliative care nursing was a first choice. For personal reasons she was transferred from her hospital-based position and the transfer was to the community. Tanya described the process.

> *There was someone with a bad back in the team so they exchanged us. And that is how I came to be in community health. I found the best job on earth and the best unit manager.*

Palliative care was part of her GCN role. Tanya explained this role.

> *The generalist nursing role in my area is that you do palliative care, school screening, and generalist duties. It's all encompassed.*

Tanya became committed to palliative care assuming a heavier caseload of palliative care clients than did her fellow community nurses. This was unusual for a GCN. Tanya expressed a desire to work exclusively in this field.

> *My heart lies in grief and loss counselling, support groups, palliative care-type work....I'm reaching an age where I'd just like to concentrate on those areas where my heart is and let some of the other stuff go.*

The assumption of a role in palliative care, while not actively chosen by all participants in the study, was the beginning of an interest that grew for them. Although the initial decision was made for them by others, it was the individual nurses who committed to and continued in this role. It was the individual nurses who sought later to practise exclusively in palliative care or, in the case of GCNs, assume a heavier caseload in this area. Robyn noted the contribution of the GCNs when discussing the allocation of palliative care clients to this group.

> *Some nurses really don't like palliation and don't do it very well, but others are just really good at it and you know they can get very heavy caseloads.*

The nurses who initially focussed on oncology accepted the addition of palliative care and all that the role entailed. It seemed that once exposed to the palliative care setting, these nurses became engaged and interested in the provision of care and the concept of palliation. It was as if there was something in the nurses that responded to the needs of people who were suffering; because of either their illness or that of someone they loved.

5.2.2 Falling by chance

Several of the nurses in the study were unsure of what had brought them to palliative care nursing. Chance seemed to play some part. For these participants there was a personal preference that determined their choice of employment or a chance meeting that piqued their interest in this area of nursing.

Alison noted this in her first interview.

> *It was partly by chance that it was palliative care because the place I went to was very close to where I lived.*

Alison sought to reduce travelling time, and had previously rejected another position because of the distance from her home and the travelling entailed.

Given that some of the participants in the study had worked in palliative care for many years, it was not always clear what brought them to the palliative care setting. Alison, for example, identified the element of chance but believed the nurse is not always conscious of what drew them to this setting. Alison reflected on this when thinking of her own situation.

> *I nursed my mother, who had died of cancer, and this was a very devastating experience and I certainly feel I needed to do palliative care to recover in a sense from that. But I didn't know all that at the time but I had an interest and it certainly would have been sparked off a lot by the fact of that experience with my mum.*

Martha had decided she wanted to resume her nursing career when she was 40, after some years of absence from nursing practice. She applied for a position at her local hospital and was surprised by the reception she received from the Director of Nursing.

> *The matron there was very hard. She looked at me and she looked at my work record, which of course was empty as far as the hospital system was concerned for so many years, and she said, "You haven't been doing much. Have you?"*

The Director of Nursing's response offended Martha. She considered child rearing, working through a marital problem and developing herself as a person to be quite significant. All of these things had been achievements in Martha's eyes. She was not offered employment at that hospital, but later realised this outcome was for the best.

> *I thought, "You don't know nothing, lady." It was like that cold hard approach to something that she had no idea about, so actually it was a good thing because I heard from a friend that the hospice was a good place to work. I really never thought about working with the dying.*

Neither Martha nor Alison had thought of being employed in palliative care service, but their initial choices were unsatisfactory for various reasons so both began practice as palliative care nurses.

Kirsten had a chance encounter with a visitor to the inpatient unit in which she was employed. This encounter brought the concept of palliative care to her attention. Her initial response to the idea was positive and she recalled the event.

> *I can remember I was working in the hospital and this woman came up to see this patient who was going home and I said to her, "Oh! What is happening here?" She said, "I'm the coordinator of the new palliative care service."… I said, "That sounds terrific," and I said, "What a wonderful idea."*

She was invited to visit the palliative care service and when the opportunity arose for employment in a palliative care setting she took it.

Ellen, a paediatric nurse, specialised in paediatric oncology. She had nursed in paediatric oncology units both in Australia and overseas. In contrast to the almost complete separation of palliative care from oncology in adult medicine, most paediatric oncologists continued to care for their child clients regardless of the prognosis. Ellen, therefore, learned about palliative care provided for children while employed in a paediatric oncology unit. Seeing the way community services in paediatric oncology and palliative care were provided sparked her interest.

> *And when I was at that hospital they had a home care nurse and so that's how I became interested in the role.*

Eventually Ellen was appointed as a CNC in paediatric oncology and palliative care. She could provide the link between the community and the hospital as a CNC in oncology and palliative care for children and their families.

Summary of falling into the role

Initially most of the participants could be considered to be directed to provide palliative care or have arrived there by chance. This view was misleading since once introduced to the practice of palliative care the nurses did not resist but actually embraced the role. Finally, these nurses had begun their journey of palliative care nursing.

5.3 Grasping opportunity

A number of participants identified opportunities for them in palliative care and oncology nursing. These included possibility of promotion to a CNC, access to further education, greater stimulation and a more rewarding practice. A role solely in palliative care allowed the nurses to focus on one clinical interest and develop a depth of knowledge in contrast to the shallower but broader knowledge base expected of them as GCNs. When the opportunity was presented the nurses accepted eagerly.

5.3.1 Getting to learn

A specialised setting provided the opportunity for further study and finding more stimulation in the work place. Most participants had opportunities for further study and gained formal post-registration qualifications in oncology and or palliative care while employed in the area. This qualification was usually a certificate in oncology nursing. There were opportunities to learn both informally and through formal programs of study.

Robyn identified the opportunity for career advancement as possibly being responsible for her decision to seek the CNC palliative care role.

> *I came into, I don't know, probably as a promotion. That's how I would have got into it I guess.*

Community health services are multidisciplinary and employ few nurses in contrast to inpatient settings, so opportunities for promotion, in either management or clinical practice, are limited for community nurses. The role of CNC in palliative care was one of few promotional opportunities for nurses.

Robyn also acknowledged the n…eed for more stimulation when speaking of how she came to be focussing exclusively on palliative care nursing.

> *I guess if I'm really honest I needed more stimulation when I was a generalist community nurse and the only course I could get into with the College of Nursing was the oncology certificate, so I went for it.*

Robyn's role as a GCN did not satisfy her need for expertise in a particular area. She expressed her frustration with the generalist role.

> *That was a frustration when I was a generalist, actually….I wanted to be good at something or know a lot about at least something.*

Lillian expressed a similar view finding the GCN role unsatisfying and perhaps requiring more than the nurse could provide. This participant was dissatisfied with her generalist role.

> *Like with generalist nursing you're kind of like a jack-of-all-trades and master of none and I really felt that I could do something here and just put those other things aside and not try to be the super nurse but just concentrate on one area.*

She had first practised as a GCN with a high care-load of clients requiring palliative care. She was interested in this area so took the opportunity to enrol in a post registration course in oncology. Lillian wanted to provide better care and additional knowledge of oncology would help.

> *I felt I needed to have an oncology background to provide better palliative care for my clients, having a better understanding of what they'd been through to get to palliative stage of their disease.*

Subsequently the creation of a new nursing position in palliative care for her region provided Lillian with the opportunity to apply for a CNC position.

Sandra felt the stress of trying to be too many things for too many people. She had a shared role in that for half the week she was a palliative care nurse and the other half a GCN. She was clear about her preference.

> *I find it much easier to be a palliative care nurse than I do a generalist community nurse but having to take this hat off tomorrow afternoon, albeit still carrying the phone, and attend to preschool screenings all Wednesday morning when I know that these people desperately need to be seen.*

Sandra shared the palliative care role with another nurse, but if that nurse was ill or taking leave, Sandra carried the full load of palliative care. This load included being on call at night and weekends. Sandra was also expected to meet the responsibilities of her generalist role.

Some participants in the study were drawn initially to oncology because of interest in, and curiosity about, cancer. Melissa was curious about oncology. It was a new field of study when she first became interested. She explored the options for formal study and applied to undertake a post-registration course focussing on oncology. She then practised in that field before becoming a community nurse.

The course in which she enrolled was offered in the United Kingdom. Melissa returned to practise in Australia after completing the course. Melissa satisfied her curiosity. She also found she liked this area of practice and enjoyed working with others in the field, and this was still the case.

> *I can say it was curiosity at first that got me in and then I just liked it.*

Robyn also expressed a curiosity or, as she phrased it, a fascination with the disease process, this being something else that drew her to studies in this area.

> *I thought, "Right, cancer fascinates me. It's always fascinated me. I'll learn, you know, a bit more about that."*

Almost all informants had a post registration qualification in oncology or palliative care, so opportunities to learn were valued and pursued where possible. The role was more interesting for these informants because they could focus at greater depth on one area of practice. Some of the nurses expressed a curiosity or wondering about the disease of cancer and what this meant for the patient or client.

5.3.2 Finding a caring practice setting

The philosophy of the practice setting, which allowed the nurses to practise in a way that was satisfying to them, was attractive for a number of the participants. The appealing dimensions of caring in palliative care nursing included the sense of importance placed on the spiritual dimension of care, the opportunity to provide holistic care, and the value placed on the human dimension to nursing care in contrast to an emphasis on technology.

One participant, a mature-aged nursing student, was dissatisfied with the hospital-based practice of her graduate program. Beth had cared for one of her children who had a chronic illness for many years before studying nursing. She had long experience as a carer of the varying quality of nursing care provided to patients. Beth believed that meeting the core needs of patients was devalued in comparison with the importance placed on technology. She sought a practice setting that would be satisfying to her by allowing her to provide the nursing care she believed was important. A palliative care service in the community could be that place.

> *I just thought I'd give it a go and just see if I could get in and see if it would be a more happy area or a more rewarding area to work in. And it turned out to be very much so.*

The opportunity to provide holistic care and to work in a context with a mission and recognition of the spiritual dimension of health and illness was noted as being important for other participants. It seemed for a number of participants they were on a mission, and the spiritual dimension was important to them. These nurses believed their Christian faith enabled them to consider the spirituality of clients. This spiritual dimension was important for Martha.

> *Being basically a Christian person, I felt, well, I could work in that way. It seemed really appealing to me to work with a spiritual dimension in nursing as well as the physical and so that attracted me.*

Ellen enjoyed the opportunity to provide holistic care, and spoke of the range of care she provided for her clients. She acknowledged that the nurses needed the technological knowledge of symptom control, knowledge of drugs and how to administer them, but this knowledge was only part of what was required.

> *You also have to look at the psychological needs of the family. You have to look at the practical needs. What equipment do we need? How do we get that equipment? Other things like that as well as knowing are the brothers and sisters being looked after? Is the cat being fed and all that? So I like the fact that this is, I suppose, it's holistic.*

Summary of grasping opportunity

The ability to look at the family as a whole and consider all their needs was important to these nurses, as their focus was not just the client but also the whole family. The area of palliative care provided the nurses with many opportunities for learning both formally and informally. The philosophical underpinnings of the practice area and the context enabled the nurses to practice in a satisfying way for them. Nurses providing palliative care only in the community seemed to have a level of autonomy that enabled them to give a quality of nursing care that was deeply satisfying for them.

5.4 Having a leaning for the field

Once the nurses experienced this area of nursing practice they discovered their attraction to, and ability in providing palliative care. Somehow, they seemed suited to this role. When reflecting on their choice of practice they could see something in themselves that enabled them to care for suffering human beings.

5.4.1 Knowing how

The nurses felt comfortable and familiar with the provision of palliative nursing care. The knowledge required seemed already to be there, and they felt as if they were in the right place for them to practise well. As Sandra observed:

> *I think there has just been something there from as far back as I remember.*

Martha experienced something similar. She felt able to provide palliative nursing care with ease and spoke of her perception of knowing what was required of her at the commencement of her employment in the field.

> *I sort of knew the job before I went into it. It was strange; it was almost like I had it inside me and I just pulled it out.*

The nurses felt they provided effective care because of this leaning towards the field. The work was satisfying for Lillian and she spoke of her enjoyment in providing palliative care.

> *I found I had a leaning towards it. I really enjoyed the work.*

Tanya did not always understand how or why but she believed that palliative care was something she did well.

> *Palliative care for me is something that I'm really good at. I can go in and connect with people in a way that – I'm probably understanding it more, but it's at a very intuitive level and at a compassionate but also probably at a psychological emotional [level].*

Kirsten was another who reflected on her feeling that she was meant to be in this field. She came relatively late in her working life to palliative care, but as she looked back she could recall something different about the way she had cared for dying patients.

> *I think there was always a leaning towards palliative care without knowing it was palliative care 'cause I mean palliative care in its structured form has only been around for about 12 to 14 years.*

Marie spoke of her comfort when around dying people and people who were afraid and suffering. A friend who was facing a frightening future valued this ability.

> *I remember a friend who was waiting for heart transplant saying that she found it easy to be with me because I didn't seem to be afraid of the suffering she was going through.*

Marie wondered if this ability to be with suffering people was a quality that came with her years of experience in palliative care. These nurses possessed a quality that enabled them to be with suffering people. They were able to be present in the face of suffering and death.

5.4.2 Doing the natural thing

A factor identified by these participants making this role easier for them was their attitude towards death and dying and where this should occur. All participants were committed to maintaining the client at home until their death if this was their wish. Death was perceived to be a natural part of life rather than something to be feared. Sandra commented on this view.

> *As far back as I remember, as a student nurse like I've been nursing what, 33 years, death has always seemed natural to me. I've never had a fear of death even as a young girl.*

Some participants discussed the view of death as a natural life process. Robyn recalled a conference presentation by a palliative care physician questioning the use of some medications during the last stage of life. The physician proposed that some of these medications might interfere with the dying process. Robyn reflected on this and found similarities to childbirth.

> *I couldn't help but think in the way he was talking, a little bit like what we've done with childbirth. Women, we sort of had them so they didn't feel anything and popped the baby out with an epidural you know, and whatever, and they didn't know anything.*

Dying at home was seen as something natural. Lillian equated dying at home to beginning life at home. She chose home births when bearing her children and saw it to be logical to also end one's days at home.

> *I got really interested in the concept of people dying at home in their own environment. I'd had a couple of babies at home and thought that was a very normal thing to do and I couldn't see why, at the other end of the spectrum, that dying at home, you know. I thought that was a good idea too.*

Marie told of a family who cared for their mother at home during the dying process. This participant was emotionally moved by the loving care given by the family, and it seemed that the dying and death was drawn into the fabric of their everyday life rather than being hidden and medicalised. Marie did not deny the value of an inpatient institution in some situations.

> *They all seemed to be taking it in turns so she was never alone which was lovely and bringing, I think, death back into society, do you know what I mean? It's a natural thing like at home, not locked away in a hospital, although that has its place too.*

This idea that the beginning and end to life's natural processes should occur outside the acute care settings where possible was extended to comparing the roles of nurses in assisting at birth and at death. Some of the nurses likened what they did to midwifery; only in palliative care they were helping and supporting at the end of life – a midwife for the leaving of the world. Martha made this comparison when describing her role in providing palliative care in the home.

> *We were literally accompanying people as they died and staying all night in their homes sometimes, and really doing that midwifing thing of being with them through the dying process so that they could manage.*

Marie was interested that a client's observation linked the notion of palliative care to being a midwife to the dying. The client's daughter was a registered nurse and during a discussion noted that she enjoyed providing palliative care but was now a midwife.

> *She said she enjoyed working with cancer patients but she was now a midwife and it was actually her father who raised, you know, one end to the other. It was interesting 'cause he was the patient there making that comment, and I just didn't say midwife to the dying. I thought, "I'll just leave that comment there."*

Summary of having a leaning for the field

Having embraced the field of palliative care, the nurses found they somehow knew what was needed in this role and performed with competence and tact. The aim of the nurses was for the death to occur at home with the client surrounded by family members if it was the wish of the client and their family. It seemed that to be able to do this was putting their beliefs about the nature of death as a natural phenomenon into practice. There was a sense that the nurses had found the place for which they were meant.

5.5 Repairing the past

Participants recalled experiences that they believed had led them to palliative care. They described situations where they considered that patients had suffered needlessly. The withholding of medication through ignorance of appropriate medications or dosages sometimes caused this suffering. There were also times when they believed people had given poor care. The nurses sought to do better than this with their commitment to palliative care.

5.5.1 Doing better

The nurses intended to improve the care given to people who were suffering. They sought knowledge of the disease processes and pain management techniques in order to provide better care. They strove to preserve the dignity and autonomy of clients wherever possible. The nurses had witnessed instances where they believed patients were poorly treated. Lynette chose oncology then palliative care because she had seen dying patients suffering terrible pain and thought there should be something better than that.

> *I guess I directed myself from that point on into oncology, to first of all discover the disease process that caused the pain and then from there onto hospice care where a solution could be found to the pain and the suffering that these people had.*

Lynette had provided palliative care in a hospice before assuming a role in the community as a palliative care nurse with the aim of improving the care of dying clients.

Sandra had also seen what she perceived as poor care and a lack of respect and concern for the dying in hospitals. This deeply offended and angered her.

> *I remember I always used to get angry with other nurses and other people who didn't have this respect and this thing about dignity for the dying.*

Sandra wanted this last stage of the life process to be one of a respectful caring for her clients.

Tanya recalled the inadequacies of the health care system in dealing with pain and suffering. She had almost determined to leave the nursing profession at one point in time.

> *I almost gave up nursing in the, probably the late 70s because it was just so hard and it was so cruel and people in pain.... It wasn't acknowledged. You were supposed to be stoic, and suffering then was dreadful, and I went and had the kids.*

Her circumstances required her to return to work some years later and she noticed a difference in how people were treated when in pain.

Some participants reported feeling distressed in the past when seeing people treated aggressively for cancer, which increased suffering without bringing about cure or remission. When Marie undertook the course in oncology she saw treatment she believed was ineffective and diminished the patient's quality of life.

> *The oncology course really drove me towards palliative care because I could see people were being treated beyond reason sort of thing, but things have changed. That was a while ago.*

Marie did recognise that people wanted treatment that was available so it was their choice. She spoke of her changing understanding of client's choices over time. Any treatment was a chance for life.

> *People, themselves, are wanting the treatment also and I understand that too. Perhaps I understand that better now than I did before.*

Lillian experienced a similar concern after observing the medical treatment of a patient whose prognosis was poor. This treatment significantly affected the patient's quality of life. Lillian was on a clinical placement required in the oncology course. She wondered how the nurses could continue to participate in this treatment.

> *She was very young and she was having chemo for breast cancer, and she had seven out of eleven nodes positive and she had radiotherapy and she had a really bad reaction to that. I wondered… how those nurses manage to go on giving those toxic drugs which they know will have a bad effect on her when her prognosis is not good.*

Lillian realised that the client had hope for a cure and would want to have the treatment but was still disturbed by seeing her suffering. She thought, however, that she would not be able to work in such a context and worried that her clients might sense her attitude. This thought concerned her greatly.

Those nurses who carried painful memories of instances in the past where they believed they had failed miserably in recognising and assisting peers or clients they believed were suffering. The most poignant recollection was that of Alison. Repairing the past for her was about personal healing. She was devastated by the experience of nursing her dying mother at home with little support from their family doctor or any other professional experienced in palliation. Alison was emotionally scarred by this experience and on reflection believed she needed to provide palliation to others in order to heal herself. She explained why she believed it to be healing.

> *Every time I could make someone comfortable or be there to listen…. Every time that happened I guess it was sort making me feel better about what I wasn't able to do for my mother.*

Summary of repairing the past

It seemed that while these nurses could not alleviate the suffering caused by aggressive treatments they could help prevent the suffering experienced by clients and their families in palliative care. The nurses also understood that what they saw as aggressive treatment damaging quality of life for possibly little gain was not always seen this way by patients. For those who had felt a personal failure in providing effective palliative care seemed to be healing and perhaps redemptive.

5.6 Leaving the field

Participants who left the journey to the world of suffering gave reasons for this choice which included wanting to leave the sadness behind, the demands of their families and changes in the workplace. While they may have been thinking about leaving, for each of the four an event provided the impetus. This event was traumatic for three of those leaving.

5.6.1 Having enough

Three of those four nurses who left the palliative care setting, had enough of misery, death and sadness. They could no longer bear the suffering they saw, and when some triggering event occurred, it provided them with the impetus to take some action. Alison expressed her feelings.

> *You seem to get more tuned into pain and you can cope with less of it as time goes on, or it doesn't seem to me I've got better at it. I think I am more affected by a person's pain than I ever was.*

Alison was becoming more sensitive to the suffering and pain of her clients and spoke of this with obvious feeling. She was constantly reminded of death and suffering by articles in magazines, books and television programs. She could not escape even when not at her work. The suffering she saw could not be kept out of her personal life.

> *You just get enough of it, because when you leave and there's something. It's all around you again. You go away from work and it's on the TV, every movie, every book and so I can go to those things a little bit differently and not feel, "Well I've had it all day, all week and here it is again." Well I just really got sick and tired.*

Robyn could no longer tolerate witnessing suffering and sadness.

> *I was starting to think, "I don't want to know about anyone else dying." You know, I've sort of had enough of that sad bit.*

Robyn attempted to cope with these feelings by dropping back to part-time employment. Then an event convinced her it was time to leave altogether.

Robyn had developed close relationships with some of her clients and their families. Robyn recognised how lonely women could become when dying of cancer and how the nurse became a part of their ever-diminishing social life. Robyn could see she shared much in common with these women. The unexpected death of one such client led to her decision to leave both palliative care and nursing. She was fond of this client and when the client died, the client's husband asked Robyn to come to the hospital.

> *I just found I started crying with him. He didn't realise but I'd lost control. Occasionally I'd shed tears but I knew I'd lost it [this time].*

Robyn understood that she would have to leave.

Martha decided it was time to focus on health and life rather than being around death and suffering. As Martha stated:

> *One of the reasons why I wanted to leave palliative care because I felt it was time to work with the living, not the dying.*

Martha was also angry. She believed that managers failed to care for the nurses despite the knowledge available for this.

> *They still have no idea that perhaps palliative care nurses in particular need to work a 3 or 4-day week in order to last the pace. They now have heaps of material from overseas that tells them how to work in palliative care best, you know, to prevent people from just exhausting themselves and the emotional effects and there's absolutely nothing that I know of that has been done. So that made me angry and sad.*

The participants who actually left the palliative care services were not the only ones who experienced the feeling of having had enough. Kirsten had worked during the Christmas break without her usual supports and there were a number of deaths during this time. She was very tired and felt exhausted.

> *It gets to you sometimes, you know, especially when you are so busy and tired. You just don't know where to go or what, and you know you keep on going.*

Kirsten went on to lament:

> *I don't want to finish work and I think this is what happens when people do change jobs. They get burnt out and the health services lose a lot of resource, a lot of knowledge and experience because they've got to start somebody again.*

Kirsten loved her work in palliative care but commented that she could not continue if she was no longer enthusiastic about seeing her clients.

> *I think that when the time comes for whatever reason that I don't look forward to going to work or I have a reluctance to go and visit somebody, that's the time I'll finish.*

Another participant had stayed in palliative care but moved to a different agency during the study. Lynette had been unhappy with the standard of care in her employing organisation and so decided to leave.

> *I think what I have had to learn is that good enough is the standard and it's not my standard so that is why I am leaving.*

This change of employer did not seem to help. In contrast to those who increasingly distressed by the suffering they saw, Lynette reported the opposite state of not feeling. She no longer felt or reacted to suffering as she had in the past and this was troubling and confusing for her.

> *I don't react to things and I don't know whether it's, like I've got a friend who is in haematology and she is just going up to the Gulf country, just leaving her hospital and her consultancy after ten years, and the interesting thing is that we both feel exactly the same way. We're both sitting here looking at life and thinking, "There's got to be something better than this," you know, why are we so flat? And are we depressed? Are we just permanently at low ebb? I mean, does nursing do this to you? Or, I mean she is not in palliative care. She was in haematology. Everyone dies in haematology. Lots of grief.*

Lynette had reached a point where she was unable to feel the sadness.

These nurses described their feeling states as ranging from acute sensitivity to suffering to numbness in Lynette's case. Their descriptions revealed that these nurses were suffering and this was unbearable.

5.6.2 Rejecting change

Organisational change was another reason given two nurses leaving palliative care. When the participants were accustomed to an organisational structure and the people with whom they worked, change was unwelcome. There was a point where willingness to adapt to constant change ceased. For Alison this change and her decreasing tolerance to witnessing pain and suffering led to her decision to leave.

> *That was another reason why it was time [to leave] because I didn't feel like making the big effort to change, to accept the change, and to find my slot in all of it.*

Change in an organisation led to disappointment. The failure of Martha's employing organisation to recognise the value of the new therapies she provided was deeply disappointing to her. This disappointment built up. A reduction in funding to the organisation meant that Martha could no longer provide services in alternative therapies to both the clients and their carers. Martha had invested time and money in learning techniques of therapies such as reflexology and shiatsu and believed that these therapies enabled her to provide better care to both client and carer.

Martha loved her work in palliative care nursing but felt disappointed and torn between her beliefs about health and healing, and those beliefs of her employing organisation. She described her feelings.

> *I feel as if I have been standing on two continents. One foot on each continent and one continent is called allopathic medicine, the medical model, that we have been brought up with in the past 50 years and the other continent is the one that's called natural medicine or complementary medicine.*

Trying to bring two belief systems together, which to Martha seemed to be moving further apart, was likened to *doing the splits* or *a sort of balancing act.* This situation had become untenable. Martha said goodbye to palliative care nursing, and to nursing.

There were also changes in staff that increased the distress of these two nurses. (Martha and Alison). The sadness of losing loved and trusted team members was particularly difficult for Alison who only felt comfortable working with people she knew. She was unwilling to expend the energy required to develop new relationships and contribute to team building.

> *I did get to know staff who I was very fond of, but it does get very sad when they move on. In fact I guess that was another thing for me.*

For the other participant experiencing a changing workplace structure, the staff resignations that had occurred delayed her leaving the setting. Martha felt the service was already in turmoil and she would be adding to this if she resigned when she first wanted to.

> *One of the reasons I put off saying I wanted to leave at the beginning of the year was because it was just like rats leaving a sinking ship. It felt really rude to say, "Well I'm leaving too."*

The distress these participants felt in terms of dealing with the pain and suffering they witnessed seemed to be compounded by organisational change. The familiar people and structures were vanishing just when these nurses needed them.

5.6.3 Needing to be for family

The nurses in the study spoke of the importance of their families and how they needed to consider family in their decisions about their career choices. The nurses who had left palliative care all spoke of the need to be available to their families. Their choice of palliative care nursing seemed to take something away from the family.

Family needs requiring the nurses' attention were a factor in their decisions to leave. Robyn spoke of her family problems. Being a nurse, Robyn was called upon for advice about health matters by family members. Robyn believed her own personal losses and grief compounded her distress and reaction to the suffering she saw in her professional role as a palliative care nurse.

> *My father's been, poor old darling, he [is] still alive but he sort of waxes and wanes, you know. The doctor didn't think he [would] last more than a couple of months and all this sort of thing. Even the baby I was looking after, they didn't think he was going to survive at birth, now he has and he's done extremely well, but I found it took me a long time to pick up after the threat to his life. That was my daughter's, that was the little bub I was looking after. I'd lost, a very close niece lost a baby last October. My son's marriage broke up. Did I tell you that? And that's been a constant source [of worry].*

Ellen was another who spoke of family needs influencing her decision to leave palliative care nursing. She took maternity leave for the birth of her second child. Her intention was to resume her role in palliative care but she no longer wished to do this when her child was born. Her mothering role and undertaking some part time nursing in a general hospital satisfied Ellen. She no longer had enough time or energy for palliative care and she explained her decision in the following way:

> *I don't want to go back to fulltime work and I'm getting enough from the children, you know.*

Although Ellen seemed ambivalent about leaving her position in palliative care, she also wanted to be able to watch her daughter grow and develop.

> *It will be sad but I'm happy with the decision.... I want to go to preschool and I want to go to swimming lessons and you know it is a lovely age. Oh! We've had some temper tantrums but she's really improved and she is just chat, chat, chat, chat, you know; and it's just nice to be there and see all the things she wants to do and just enjoy her at this age because it's amazing how quickly it goes.*

Alison's teenaged son was troubled during adolescence. While she tried to be available when he needed her, she recalled a time when she had a trying day at work. Her son needed her attention and Alison felt that she had not responded to him in the way that she would wish.

> *I couldn't respond. I couldn't be open to his needs at all. I was just totally immersed in my own world, you know, and that's happened a couple of times only but it really is total when it happens like that.*

These experiences left her with feelings of anger that her work affected the way she related to her family and felt cut off from their feelings at times. Alison felt unable to be the loving and supportive mother and wife that she wanted to be.

For Robyn and Alison the strength or capacity required to cope with the suffering and the other demands made upon them was no longer there. Robyn had new responsibilities to her family. Alison seemed to be unable to throw off the despair and suffering she was exposed to when at home with her family.

In contrast, Ellen's view was that she was giving and getting enough satisfaction from her children. She no longer needed the intensity and whatever else she received from her professional nursing practice in palliative care. These differences reflected the demands upon women at various stages in their lives. Ellen was the youngest of the participants with a young family. Alison's adolescent children needed her, Robyn was of an age when parents require more care, and her children needed help with their growing families.

Summary of leaving the field

Three of the nurses who chose to leave the palliative care setting seemed to be suffering themselves. They spoke of increased sensitivity to the suffering of others. The needs of their families came first. These participants were at different life stages but for each there were pressures to be more available for family and this was incompatible with their work role. Organisational changes also led to sadness for some. They were losing valued colleagues and no longer had the desire to develop new relationships at work.

5.7 Living with leaving

Leaving the field of palliative care affected the study participants in a number of ways. Preparing properly for leaving and looking forward to other possibilities were steps in the process. The participants spoke of what they did not miss. They felt relieved and free when no longer having to deal with some of the aspects of their work. Paradoxically, while there were expressions of relief, there was also regret about leaving and thoughts of returning at some time in the future. For one participant, leaving the field was experience as a loss and an occasion for grieving.

5.7.1 Preparing to go

The two nurses who left a palliative care service during the research process took extended leave with the intention to return. Robyn, while on long service leave, had time to think about her future. She did not plan to leave but the opportunity arrived to try something else. She realised she needed a break from palliative care and the chance to leave came unexpectedly.

> *It was purely accidental, you know, it was just sort of out of the blue. Sudden! A sudden thing. Whee! You know, here's a way out of the burden of it all.*

Robyn had realised that she was not coping with palliative care nursing. Whilst on leave she was able to look for other possibilities. She explained how she thought this had come about.

> *What happened was having enough time to read the papers and look at other jobs. Not really looking for a job but just sort of seeing what was offering and*

> *yeah, not sort of searching for a job by any means. I was just sort of thumbing through and thought, "Oh! That looks interesting." When I got the statement of duties I realised that it was prevention and upfront sort of stuff like, you know, encouraging early detection prevention and raising community awareness.*

Robyn realised this was the kind of activity that she most enjoyed, and her application for the position was successful. This was the beginning of a focus on prevention and a more positive role in health promotion.

Martha thought for some time about her resignation. It was a difficult decision to make after so much time spent in palliative care nursing.

> *I got the feeling at the beginning of last year that it was time for me to move on.... I needed to think about that and I pondered it for some months before I actually put it into action. But it became clear that I needed to take action so I put in my notice.*

Martha knew that this decision was not just about leaving her position but leaving both palliative care and nursing.

> *I was saying goodbye to palliative care as such and I was consciously winding down in all sorts of ways.*

Once Ellen decided to leave, it was important to ensure everything was left in order. Ellen had difficulty in directing energy to this task. She drove herself to complete all documentation, and doing all those things that enabled a proper handover of clients to another nurse.

> *I was tired and it was hard though, particularly in the last few weeks to sort of direct your energies when you feel you're not going to be there much longer.*

Once this was done, Ellen was satisfied.

Ellen felt close to some of her clients so needed to advise them she was leaving. She explained the reasons for this.

> *I was already thinking there are one or two families that perhaps I might ring and just say, "Look I've resigned" and it's almost wanting to say, "I won't be ringing you any more,"…. I don't want them to think I've abandoned them.*

These special families were not only current clients but included some who had already lost their child. Ellen followed up on these families because they had little social support. She also felt a bond and a responsibility because she was the one who had been with them through their loss and suffering.

For Ellen, as the sole paediatric community nurse in her organisation, careful preparation for the handover of care to another nurse was essential. This was not an issue for the other nurses as they worked with others who already knew the clients. Another difference between the nurses leaving the setting was their ages and future plans. Robyn and Martha were actually winding down and leaving nursing, not just palliative care. Ellen, being younger, was still seeing a future in palliative care at some point but her career was on hold.

5.7.2 Feeling free

All the participants who had resigned identified aspects of their role that they had experienced as burdensome. These aspects were a sense of responsibility for people even when they were not on duty, and responsibility for medications often prescribed in complex combinations.

Robyn noted that she had not realised the heaviness of her burden in palliative care nursing until she was released from it.

> *I wasn't aware of how heavy it weighed on me. Yeah, that's interesting isn't it? You kind of live in it. It's like the frog warming up slowly in the bowl. You don't kind of notice it happens…. I have noticed a difference.*

Robyn had been burdened by her work. She was carrying the sadness and worry into her own world. This meant she was never free. Robyn commented on the difference in her life since she had left the palliative care service.

> *It is lovely not to have the responsibility of people. I go home tonight and I don't worry about whether the family is okay, whether the person is alright. I don't have to think of that now and I like that. I've noticed a sort of burden lifts from your shoulders.*

The feeling of constantly being responsible for the clients may have related to the context of care being in the community. The nurse did not hand over to another nurse at the end of the day. The client, or family, relied on another nurse on-call who may not have been a part of the team but from an agency.

Ellen certainly noticed the difference when released from the responsibility of her role.

> *It is really nice to have a job where I can walk in at 2 o'clock and basically walk out the door at half past 10 and not have to worry about it, not to have to think "What am I going to do tomorrow, tomorrow's really a busy day I've got." I mean that's what good about it and so not to have to take home, I guess, a lot of baggage, a lot of extra worries, is good and that's what I need at the moment.*

Robyn and Ellen both spoke of worrying about their palliative care clients after hours and on the weekends. Both had given their home telephone numbers to certain clients, although there was an after hours service. These were clients experiencing a great deal of pain and suffering, were near death, or lacking in other social supports. Robyn worried about these clients and was concerned the nursing care might not meet the standard she expected.

> *You think, "Oh! I hope that girl who is on call tonight is sensitive" and, you know, hasn't had a bad fight with her husband [before leaving for work].*

The responsibility was felt to be greater because the clients being nursed were dying. This care might be the last thing the nurses could do for them. The family also leant on the nurses for support at this time. The nurses did not want carers or families left with bad memories of their loved one's dying that could have been avoided. Robyn explained this in the following way:

> *People depend on you and they hang on your every word.... When they are dying and their rellies, they elevate you.... So you can't make a mistake, or I can't. I mean you do it properly or you know they're dead tomorrow. You don't get a second crack at it.*

The responsibility for managing complex medication combinations safely and appropriately added to the heavy burden.

Release from exhausting work routines allowed time for other roles in their lives. For Martha this was having time to do many things, including being a grandmother to her first grandchild.

> *It's wonderful to have my autonomy and my freedom now when I can say "How many days have I worked this week? Is it time for me to have a day off?" Or plan my weeks, plan my days , so I actually fulfil all the other roles I want to fulfil like being a grandmother, making friends, or whatever.*

Another aspect of the role that was not missed was the horror of seeing and dressing the terrible physical damage wrought by cancer. Martha spoke of this experience and her reaction to it.

> *How do you still maintain the dignity of a person when the whole of their chest is a rotten mess and they can't bear to look at themselves...? They are living death.*

Martha also noted that she enjoyed being free of bureaucratic demands that took her away from what she saw as the real work of clients care.

> *I don't regret leaving a system where there is a lot of waste of time and energy by having to fulfil the bureaucratic demands of that system instead of getting on with the real care of people.*

In addition, she felt free of an organisation she saw as uncaring and unsupportive of staff. Martha harboured some bitterness about her experiences with the health care system and believed that the indifference of the system affected the health of the employees.

> *I was seeing other people, who were not able to even express as much as I did, who were leaving for one reason or another. Getting sick and leaving, so often getting sick and leaving, you know. And that sickened me in the sense that again there was this silent waste of human health because the system didn't acknowledge these people.*

Two of the nurses noted the changes in themselves that the lifting of the burden brought about. Alison was able to experience aspects of the world differently in terms of what she read and viewed on television. She could observe and read about sad things as part of a story line without feeling overwhelmed by suffering. Robyn noticed physical and lifestyle changes and others noticed these changes. She no longer needed to depend on food as she had in the past.

> *I don't eat the sort of food when I get home. I used to dive into food almost as a depression thing and I've stopped doing that 'cause I don't sort of need it now.*

It was obvious that Robyn had lost weight and her facial expression had altered after leaving palliative care nursing. Robyn looked happier and healthier.

Although there might have been a few regrets, the participants seemed to have another life that was freer, more joyful and less burdened. They were unaware of the extent of the burden carried in their role of a palliative care nurse until it was lifted.

5.7.3 Looking back with longing

Paradoxically, although the informants reported feeling freed from many things there was some regret about leaving.

Martha admitted feeling nostalgic about her time in palliative care nursing when meeting with other nurses who were practising, or had practised, in that area.

> *It even made me quite nostalgic. I thought, "Maybe I should go back to palliative care." I thought, "No, I made my decision. I will stick with it."*

Martha enjoyed the camaraderie of being with other palliative care nurses and the humour that often emerged in dark times but resisted the temptation to be drawn back.

Intense relationships with the clients and their families were noted as burdens by some of the participants, including Ellen, but there was also ambivalence about the loss of that intensity of interaction with clients. Ellen no longer experienced this intensity in her part time role in a hospital paediatric ward.

> *You don't get anywhere near the relationship with parents that, you know, I did before. I mean because I'm only there one or two days a week, and often those days are quite well-spaced, it's often not two days in a row.*

Ellen likened her current role to working in a day surgery. She enjoyed the depth of relationships experienced with her clients and their families in palliative care and felt that her role in a general ward was not serious nursing.

> *Whilst I do enjoy that work that I do sometimes I feel it's just sort of dabbling.*

Ellen also regretted leaving the clients to whom she had become close and sought news of them. She wished that she could have been part of the care team for those clients.

Robyn was relieved at no longer being in palliative care nursing but recognised there were aspects she would miss. The intensity of the experience of providing palliative care gave a fulfilment she knew she would not experience in her new position.

> *I'm not going to get that sort of fulfilment I guess out of this job because there's not so many issues involved is there? I mean you can only get that sort of satisfaction; fulfilment when you're really in it, up to your eyeballs really, can't you?*

Martha was another who looked back with mixed emotions and missed the special nature and depth of the relationship with her clients and their carers. Martha grieved the loss of intense relationships formed with clients after leaving palliative care nursing.

> *I think I grieved for the essential contact with human beings on a very special level that palliative care gives you.*

Martha also missed the contact with clients she saw as courageous and inspiring.

> *You meet so many varied and wonderful people in that job. That is the joy of it and the way in which human beings courageously and sometimes with very little knowledge and skill deal with their life situations. It's extremely inspiring and so I suppose I miss the opportunity that that gave me to meet so many people.*

For Martha there was an overwhelming grief that she believed affected her health. This physical effect on her body began in the last few weeks of working in palliative care and continued for a long time afterwards. Her commitment to this field of practice had been lengthy and strong. Martha, an articulate and sensitive woman, realised her health problem was related to grieving, and used the process of writing about it to help her overcome this response. Martha spoke of this experience. She still felt her grief in the retelling.

> *I had no where to take it. I had no one to share it with. I had no peer group to say, "Yes this is." I'm really feeling sad. Isn't it strange? Just talking to you about it, it brings up tears. It brings up a lot of sadness.*

Martha wished for an opportunity to share her feelings with others who had had similar experiences. In order to help herself she imagined rituals and ceremonies aimed at healing past hurts and grief, and imagined that it could be a ritual of letting the past go and embracing the future.

> *I was going through this process of letting go which I called the letting go of my palliative care work.*

Martha planned ways to find renewed joy and enthusiasm and working through these processes on her own helped her. She recognised her own feelings in the expressions of bitterness and sadness she heard from other nurses, and believed these feelings of nurses were not acknowledged or addressed by the health care system.

For the most part these nurses were still fascinated by palliative care and experienced the time spent as a palliative care nurse as a precious time. The experience of palliative care nursing would never fade into the past. The intensity of the emotional experience of being a nurse caring for suffering people seemed so powerful that this remained with the nurses and was the greatest loss for them.

5.7.4 Looking to the future

The participants sought new goals and different interests after leaving the journey. For some there was the opportunity to learn about other practice areas in nursing. Robyn had opted to leave nursing, so she was learning about a new field in health care. Martha also had determined to remove herself from the nursing role completely but, unlike Robyn, had to resist the temptation to return.

Martha particularly wanted to stay far away from a helping role and sought voluntary work. She ensured that she did not volunteer in areas that resembled nursing. She sought something new and different.

> *I do not need to do anything that is to do with caring for people, you know like reading to people or giving them meals on wheels.... I've spent my whole life doing that and I want to do something different so I chose plants and trees, tree planting.*

Robyn thought she would go back to practise in palliative care nursing, and still experienced the fascination she felt at the beginning of her journey. She acknowledged that she would need to make some changes to enable her to cope with the return in terms of perhaps working on a part-time basis.

> *I don't think it will ever fade into the past and I rather suspect that I'll probably go back to palliative care if I go back to nursing. I think that's probably what I'll do, I guess. I can be a bit more objective when I look back at it, but no, it's still an area that fascinates me.*

Ellen was much younger than Martha, Alison and Robyn. She planned to return to palliative care nursing at some future time when her responsibilities to her children allowed her to do this. She had the skills and the expertise to contribute more to this area and had enjoyed her time there.

> *I trained in paediatric oncology. That's where I've worked and that's where I've concentrated and I just feel there is more to learn. There's still more for me to do there in that area. I think I will try and go back on to the unit.*

Summary of living with leaving

The nurses thought about their leaving before they committed themselves. They were aware that it was time for them to go and prepared for this. The extent of how burdensome the role had become was revealed once they resigned. They moved on to other things. Moving on so not so easy for Martha whose grief affected her health. There was a determination in the nurses to find new ways to develop themselves in the world outside of palliative care with its intensity and fascination but also with its exposure to pain, suffering and tragedy. It seemed that some of the participants were still held in thrall of the almost dangerous emotional intensity of this context of nursing.

5.8 Summary and conclusions from Chapter 5

The chapter describes how the nurses came to be caring for people who were suffering in the context of palliative care and, for those who resigned from this role before the commencement or during the study, how they came to leave the journey.

5.8.1 Ways of making the journey

Making the journey was an exciting and intense process. It was also draining and life-changing for the participants. The theme, falling into the role, initially suggested that the nurses arrived by chance or direction from their employer. The opportunity for learning, promotion and a practice setting that afforded the opportunity to provide nursing care in a manner that satisfied them were also attractions. The major attraction was revealed in the theme of having a leaning for the field. Caring for people who suffered was something for which the participants had a talent that seemed to be innate. The nurses were attracted to and enjoyed providing palliative care and so were held to this context of care. The participants believed in the values and philosophy underpinning the service. Dying and death at home for the client, with people they loved, seemed natural and proper in contrast to dying amongst strangers in a hospital. The leaving of the journey was sad and associated with mixed emotions. The four nurses who had left the journey identified a number of reasons for this decision. Three had found witnessing suffering and experiencing grief and loss difficult to endure. Disappointment with, and changes in, the organisation were given as reasons. The nurses had no energy left to adapt to these changes. The participants also had changing responsibilities for their family members as they moved through their life stages.

In the aspects of the theme, living with leaving the nurses spoke of life after caring for people who suffered. Three participants who left the journey missed the intensity of the emotional relationships developed with some clients. There was ambivalence because, although they missed emotional involvement, the participants experienced a sense of relief and a lifting of a burden they had not realised had become so heavy.

The decision to leave was not taken lightly, and in living with leaving the nurses spoke of their preparations for this step. They realised that they had lost something valuable that perhaps they would never again experience. The intensity of the emotional ties with some clients was an unforgettable experience that was both draining and wonderful. The nurses who had left the journey were changed by the experience and carried the memories that for some led them to look back with longing.

5.8.2 Being a sojourner in another world

The hermeneutic experience for the participants is described as being a sojourner in another world. Each day the nurses journeyed to a parallel world of suffering. This was a confronting world where the nurses faced the suffering of others and the reality of their own vulnerability and mortality. This stay required them to be open to new experiences and learning.

The sojourner sometimes took wrong turnings but eventually found their destination of palliative care. Once there they were fascinated and sensed that this was where they were meant to be. They also experienced an autonomy that allowed them to practise in a manner that was satisfying for them. With the autonomy went responsibility that was ultimately a heavy burden.

New opportunities and new perspectives on life and death drew the sojourners. This was an emotional journey as the sojourners became attached to some of those they nursed. It could be a healing journey for some when they were able to alleviate the suffering of their clients or carers so making up for past failures.

Being a sojourner in the world of suffering required courage as this was a dangerous journey. The travellers witnessed suffering of many kinds and eventually the death of their clients. For some the witnessing of suffering was so overwhelming they also suffered and could not leave the suffering behind when returning to their own worlds of every day life. Their world was one where people made plans for the future in contrast to the other world of suffering and with its impermanence for their clients and those who loved them. The separation of the two worlds was essential because when the suffering started to seep into the nurses' everyday lives it became impossible for them to continue their sojourn. They could no longer visit the world of suffering perhaps because of some aspect of their own life was drawing them into this world as a citizen, or they were no longer able to maintain the boundaries between the two worlds. Leaving the journey was not without regret, grief and loss. Some who left the journey held on to the possibility of returning in the future.

Chapter 6 – Knowing Suffering

> *Suffering seems to be – it almost seems to be bigger than pain. It's wider than pain. — Kirsten*

6.1 Introduction to participants' perceptions of suffering

As the nurses in the study recounted their experiences of providing palliative nursing care in the community, they spoke about the nature and causes of suffering. Relevant incidents from their encounters with suffering people in their earlier nursing career combined with their experiences in palliative care contributed to their knowledge of suffering. The recollections translated into thematic statements that provide the basis for the theme of knowing suffering.

Over years of experience in palliation, the nurses had interacted with clients and their families, and from these interactions had formulated ideas about the nature and meaning of suffering. They became more aware of the signs of the client suffering, even when this suffering was not verbalised. The participants identified the actions, responses and experiences of the clients, their families and the health care providers that caused or increased suffering.

This chapter has been organised using the three aspects of the theme, *Knowing suffering* identified from the messaged derived from the communications of the participants. These three aspects are:

- Explaining suffering.
- Recognising suffering.
- Identifying the causes of suffering.

These aspects of the theme form the framework for the chapter. The aspects are first described and the messages from the nurses informing the understanding of the theme of knowing suffering is discussed.

After contemplating and interpreting the nurse's stories of their experiences know the world of suffering, the hermeneutic description *Being initiated* into the world of suffering was revealed as their lived experience. The nurses, as sojourners in the world of suffering, were then initiated into this world. They learned about the nature, meaning and causes of suffering primarily from those for whom they cared. This knowledge was not sought by many so was somehow mysterious and not readily shared.

6.2 Explaining suffering

The nurses reflected on their perceptions of the nature and purpose of suffering. Most nurses in the study had not really thought about suffering as a distinct concept and used the words *pain* or *pain* and *suffering* interchangeably. The use of the term *suffering* was novel to some of the nurses, but eventually most concluded that pain and suffering were different concepts that were linked in some way.

6.2.1 The nature of suffering

The study participants explored the concept of suffering as they viewed it. Kirsten noted the novelty of the term *suffering* for her. She found the word and the topic to be interesting and claimed that suffering was not a word she heard used often.

> *I just think that's a really interesting word to use 'cause it's not a word that's used very much.*

Some participants either had not distinguished between the concepts of pain and suffering, or considered there was no difference. Beth, for example, found difficulty in distinguishing between pain and suffering and believed there was none. She explained her thoughts.

> *I think suffering is pain whether it's emotional or physical so I make no delineation.... I just find it very hard to delineate between pain and suffering. I think whether it's emotional or physical it's all suffering.*

Other participants discussed differences between pain and suffering. Kirsten .considered suffering to differ from pain in terms of duration, and perhaps quality.

> *That's why I likened spiritual pain to be akin to suffering, but suffering seems to me to be a longer, more drawn out type of experience than perhaps pain.*

Suffering may have appeared to be long and drawn out to the sufferer and the nurses, as their perception of time was altered by the painful nature of the experience.

Kirsten had been in situations when the client's physical pain was so intense and unrelenting that it could only be described as suffering.

> *Well we couldn't move him [the client]…. He was just [in] that exquisite agony so I don't know, and suffering is – I think suffering is a harder word to define than pain, but we see it in different forms.*

The nurses identified causes of suffering other than physical pain. Although the two concepts were linked, pain did not necessarily lead to suffering, and one could suffer without being in physical pain. Lynette spoke of suffering unrelated to pain and gave an example of this.

> *I think their suffering occurs when they have unanswered questions or maybe they have never been told how to manage pain.*

The nurses believed suffering to be both physical and emotional. This concept of suffering was expanded to include spiritual suffering and social suffering. A strong link was identified between physical and emotional suffering by most participants. Suffering and pain were considered not only to be linked, but that each contributed to the development of the other. Melissa commented on the contribution of one form of suffering to another.

> *Sometimes you know their suffering is mental suffering. It's not just physical but it contributes to the physical or vice versa.*

Kirsten spoke of a client terminally ill with cancer who knew her condition would deteriorate. This client's suffering was generated by worry about how she would manage future suffering and about the fate of her beloved pet dogs if she could not remain at home. Her suffering related to fear of future pain. Kirsten could do little more than assist the client to remain at home for as long as possible.

> *They're the types of suffering sometimes you wish you had answers for but I mean after 10 years I know. I don't have the answers for, you know. I can just supply and provide meals on wheels, home help and all that kind of stuff.*

The nurses believed emotional suffering was as severe as the suffering of physical pain. Beth stated her belief about the equal intensity.

> *You know, emotional pain is just as intense as physical pain.*

Sandra considered physical symptoms were no longer the cause for most of the clients' suffering because of effective symptom control but there were other forms of suffering.

> *I think basically, because of modern day palliative care, that people don't have to suffer physical suffering so much. I really believe that. I really believe we now have fairly good symptom control, particularly around pain and nausea.... I really think the suffering is the emotional, spiritual, psychosocial suffering.*

People experienced emotional and spiritual suffering more often and these were the most difficult kinds of suffering to alleviate. Sandra commented on the difficulty for nurses of addressing these forms of suffering.

> *I really think the suffering is emotional, spiritual.... That's what people experience more, and that, of course, is what the nurses find hardest to deal with 'cause it can't be fixed by boosting up the syringe driver.*

For Robyn, the acute suffering experienced by people when they discovered their cancer had metastasised was emotional and spiritual. This suffering usually preceded that caused by physical pain.

> *I think it's very acute suffering if they find out they have metastasis and that's just a complete emotional, sometimes a spiritual shattering almost of people when they [find out]. I mean, you know they can put their faith that God's cured or whatever, or their doctor [cured them] and all that, and it can be a*

> *major change and a really acute emotional and spiritual suffering there. It's not usually physical at that point.*

A number of informants, among them Sandra, considered spiritual suffering to be experienced often by their clients when they were striving to accept impending death.

> *I think you see with a lot of people it's spiritual suffering, and some seem to deal with that better than others and I think that's in the process of coming to terms with the diagnosis, mortality, you know the whole dying process, and for some it's a struggle, and I guess in that sense I would see that they are suffering.*

Kirsten thought about how suffering was managed in the absence of pain. She recalled a client diagnosed with a cerebral tumour. While not causing physical pain, the tumour caused other symptoms that destroyed the client's quality of life. These included constant giddiness, nausea and weakness. The client asked about the possibility of being medicated to reduce her awareness and allow her to sleep away the little time she had left. This client did not consider her current experience as living. Kirsten consulted the doctor about the client's wish. Whilst travelling to meet him Kirsten was concerned about how she could justify sedation in the absence of physical pain.

> *When I was driving I thought, "Now if she was in physical pain, there would be no hesitation. We would put in morphine. She would be on PR Valium, all those things to stop this physical pain and the agitation and the restlessness." I thought, "Now she's not got the physical pain but she's got the spiritual pain, and here I am. I'm going to have to justify the use of or the beginning of sedation."*

Lillian believed the definition of suffering depended on the perception of the client. She thought that suffering occurred when something encroached on the person's body or mind that stopped them from doing what they could do normally but accepted it was what the client thought that mattered.

> *It's basically what the client says [it is].*

Some participants raised the notion of family suffering. This suffering differed from and exceeded the suffering of the individual client. Family suffering was unrelated to experiencing physical pain but instead related to the family watching a loved one having to endure pain and suffering, and in anticipation of losing that loved one.

Marie took a broad perspective of suffering and suggested a model of suffering which included the family.

> *I see suffering as an entity, and then there are parts of it that can be related to physical pain or yes if you were to draw a model of it. I'm not sure if you'd thought about actually making a model or even a molecule. I suppose you could actually have, you know, the patient at the centre, but then you've got the patient and the family as well and then sort of branching off from that various aspects and types of suffering.*

There was emotional pain for families when they could not be together at the end of the client's life. The coming together for support and the chance to say goodbye was important to the family but not always recognised as so by those outside of the experience.

> *I recall a gentleman who was not from Australia, and he was facing a terminal illness. He certainly didn't have many weeks left to live and I remember the family were desperately trying to get their younger daughter out from the overseas country, but there was a difficulty and as he already had family here, and the immigration people said no, he already had enough family looking after him here, and I felt sorry for them in that case.* – Marie

Families suffered vicariously, watching the person they love suffer and felt helpless when unable to reduce the suffering. Kirsten spoke of the family of a woman who could not be comforted or relieved of her pain and suffering. The client screamed in agony and this was unbearable for her husband and children.

> *The family would ring you up and say, "What can we do? Can you come?"*

The client was eventually admitted to hospital where intravenous sedation was administered. The family had been unable to say goodbye because of their mother's terrible suffering. They needed to come to terms with her sudden and terrible death.

> *After she died they took her from the hospital and brought her back home, and she was able to stay at home. They kept her home about a day or two… but they needed to do that to say their goodbyes.*

Ellen saw parents suffer as their children were subjected to painful medical procedures.

> *I mean, I've seen mothers upset, terrified, waiting outside treatment rooms for children. The child was having a lumbar puncture. The child strolls out like this, "Hey, that wasn't too bad. I had some gas and they told me a funny joke, Mum. I'm okay." I mean the mother is like white knuckled, you know, absolutely so distressed and stressed by it.*

Ellen was aware that the parents suffered much more than their children at times because they feared their children suffered and were helpless.

Since most of the nurses were, or had been before participating in the study, GCNs or domiciliary nurses, they were aware of the pain and suffering of clients with chronic illness. These clients did not usually have access to the specialised pain management services available to palliative care clients. Efforts to relieve pain and suffering were considered by some GPs to be relevant only to people in the process of dying. The participants saw this as an injustice for chronically ill people struggling with their pain and suffering. Tanya spoke of a number of clients in this situation and gave, as an example, one instance where she believed the client suffered bone pain related to deep invasive leg ulcers. Tanya thought that had cancer caused the pain the pain relief regime would have been different.

> *That pain left her demanding, stressed, difficult to go into. The staff found it hard to go and visit and be affirming and all of that because she just ranted and raved and was stressed and was self-centred and all that sort of thing. But to me she was where I would expect her to be given that. And if somebody*

> *would just go and say, "Sarcoma of the bones," we'd whip her out to the hospice, start a regime and deal with it.*

There was an attempt to clarify what was meant by suffering, differing views were expressed, but the focus was generally on the different forms of suffering. Emotional and spiritual suffering was more difficult for the health care team to address. The informants had strategies for most suffering with a physiological cause but not for the other forms of pain and suffering. The nurses believed the clients and the carers more commonly experienced emotional and spiritual suffering.

Some informants noted occasions where people suffered but this was not always seen and addressed. Chronic pain, unrelated to terminal illness and other uncomfortable symptoms, was not always viewed as being as serious and distressing for the clients.

6.2.2 The purpose of suffering

The participants in the study discussed possible reasons for, or purposes of, suffering. They spoke of how they understood the meaning and the purpose of suffering. Some nurses also reflected on the clients' perceptions of the meaning of their suffering.

A number of the nurses believed suffering to be a part of life and something endured by all people at times. Alison took this perspective. For Alison, suffering was an individual experience that happened to everyone in some form during his or her lifetime.

> *And you can't measure it and you can't compare it either, I don't think. And I think I'm a bit philosophical about it that. I think life is full of suffering now.*

Sandra also accepted that suffering was a part of life's journey, not just for a person dying but also for those who loved them. She believed that throughout life all human beings experience losses that cause emotional pain, and that is part of being alive.

> *Yes, there is a lot of suffering for lot of people, not just the client. I think the emotional suffering of coming to terms with letting go of a loved one, but I mean that's part of life's journey, all our life's journey.*

Other participants held the view that the suffering was the client's destiny. Kirsten attended church regularly but also accepted ideas from non-Christian beliefs as explanations for the death and suffering she saw. She accepted the idea that each individual had a destiny, and commented:

> *I like the North American Indian philosophy. They believe each of us, we have a wheel of life and some people have a large wheel and some people have a little wheel.*

Christianity influenced how some people saw the purpose of suffering. Punishment in retribution for past sins was one such purpose. Sandra believed she had seen instances where her clients took this perspective but the nurses generally did not.

> *They'll suffer in silence and they believe what has happened to them is because of things that have gone on or they've done in the past, and this is their retribution.*

The place of religion in finding a purpose or meaning in suffering was explored. Lillian had been a Catholic but now explored alternative faiths. She believed that, were she still a practising Catholic, she would find difficulty in justifying a purpose in suffering. This was particularly so for the young people she saw suffer and die.

> *You know, when I was a Catholic, suffering would be like doing your penance on earth or whatever they used to refer to it as, like if you do this on earth you can go straight to heaven or something.... Offer it up to the holy soul, that's it. I can just hear my father saying that.*

Lillian explored other faiths and the reasons they advanced for suffering.

> *Suffering can be like a karmic thing too, and whether they eventually die as a result of that suffering. Then I look at that and think, "Well they're obviously paying off some sort of karma for either you know, several past lives or whatever and I just think, "Well the next one's got to be better, you know, for them the next one will be better."*

It was important for Lillian to find meaning in the suffering that she saw, and to find something positive flowing from the suffering. She was not able to find justification in Christian beliefs.

Lynette was another participant who no longer believed in Christianity. She could see that suffering and death could be terrifying for individuals who did not have faith in their professed beliefs about religion. She recalled a client who experienced what Lynette believed to be great spiritual suffering. This client called out to Mary, the mother of Jesus, for help, but clearly was afraid of what she would face after death. Lynette considered suffering and death to be an enormous test of faith.

> *It's a test of your faith.... So something she had a peripheral belief in all her life was now being put to the test, and as far as she was concerned that was pretty terrifying.*

Participants thought about the value of suffering. Robyn recognised that some of her clients thought there was meaning and value in their suffering, but Robyn found that perspective hard to accept, and did not wish that experience of suffering for herself.

> *Some of the clients will think there's something useful in their suffering. I don't know whether there is. I don't think there is personally, but I don't tell them that. I don't know, perhaps it's just another life experience isn't it and your experiences, I don't know, they make the sum of you.... I'd prefer not to have it.*

This view was not something she discussed with her clients, but if they were suffering she would call upon their belief in an afterlife to comfort them.

Kirsten considered suffering enhanced some of her clients. This acceptance and transcendence of suffering most often occurred when the client had strong religious beliefs.

> *I think the ones with strong religious beliefs don't question. I think they're more accepting.... It's almost like well, this is what God has mapped out for me and, yes, I'll take this burden gladly, and I think those who do that, they*

> *do come to accept it and even become I think a little bit, what's the word, like they take their suffering on board and they are almost elevated by it.*

Other informants believed that some good could come from suffering. Alison, for example, thought personal growth possible, and the experience of suffering could aid people in knowing their limits and in working out strategies for dealing with life's hardships.

> *I don't think per se that suffering is good for you. I'm not that sort of person but in the end usually there are some good things that can come out of it.*

Lillian actively sought positive outcomes from the client's suffering. This positive outcome might take weeks or months but she believed it was always there.

> *You think, "Gosh! Isn't that amazing? Out of that person's pain and suffering this wonderful positive thing has emerged from that." And it's really interesting when relatives or family who are left behind can actually see that. When the spouses come to you later and say, "This happened as a result of that person's death. Isn't that wonderful?"*

There were times when an individual who had suffered a great loss could use their experience in a productive way to help others. Marie was touched when watching a television program. She saw the mother of a child she had nursed speak about palliative care. This mother had been impressive in the choices she had made for her child until the death, and was now using her experience to educate others. Marie recalled her reaction to the television program.

> *To see her speaking on this short program saying, "Well palliative care is care, not cure," and to speak favourably about the experiences I think was very good and lovely that she could do that, because it was obviously an emotional time for her, and me too, watching it on TV.*

Sandra did not see suffering ennobling people who had been unpleasant when they were well. She believed that very few people changed their character or behaviour when dying. She had nursed men who had been violent and abusive to their wives and did not see much change in the family relationships before the client's death.

> *Those women are usually still frightened of the men, and that they are not going to change. You know people basically die as they have lived. There's only a few that ever make dramatic changes; and I see a few of them that will sort of clear the air.*

Most participants had considered why some people suffered. The reasons advanced for suffering included the destiny of some or the fate of all human beings. The nurses did not identify retribution or punishment for past sins as a reason to suffer, other than Lillian who was interested in the nature of karma. They did, however, believe that some clients saw their suffering as retribution for their past sins.

Summary of explaining suffering

The participants identified what they believed were the various forms of suffering and realised that relief of some forms were beyond their ability. The nurses were aware of forms of suffering they might not have recognised before their sojourn in world of suffering.

Participants differed in how they saw the purpose of suffering. Religion beliefs were considered to sustain some clients but not all participants considered that religion would sustain them should they suffer. They were divided in their beliefs about whether something of value or meaning could be found in suffering, some seeing meaning in suffering while others considered suffering to be without benefit.

The nurses sought meaning or purpose for suffering but not all were successful. Perhaps finding a reason for some people's suffering served to explain why it could not happen to them. Suffering was then not an arbitrary mishap to which no one was immune.

6.3 Recognising suffering

The nurses recognised signs they believed indicated their clients were suffering. These participants discussed how they recognised suffering. The nurses heard the suffering in the client's voice when they questioned why this terrible thing had happened to them.

They found visual and behavioural indicators of suffering in their clients. Anger and aggression indicated that the client was suffering. At times, the nurses found the client's suffering to be obvious, whilst at other times they intuitively became aware of unexpressed suffering.

6.3.1 Hearing the words

Clients could sometimes articulate their suffering. Melissa spoke of a client she was currently seeing. This nurse found the client expressed his suffering clearly.

> *To me it was very obvious that that man was, you know, suffering, anguished suffering today as well as physically suffering. I think he just spoke what he felt.*

The nurses believed that the clients were suffering when they expressed a wish to die. Most informants had a story of clients attempting suicide, or actually completing the act. The clients sometimes expressed the wish for death on the nurses' first visits and believed the nurse could help with this. Melissa spoke of an incident where she had had to clarify her role for a client.

> *I met a man today for the first time, and he wants to die in a hurry, but I said to him that I can't help him with that, and I said that's out of my control, but I said what I can do for you is to relieve some of the symptoms that you've got.*

Robyn believed that unrelieved suffering led to clients wishing to die. This wish needed careful exploration, as there were times when the cause of the suffering could be identified and relieved. The client's suffering was often unrelated to physical symptoms. Robyn recalled a client who wanted death to come quickly because of his loneliness and not because of physical pain that could no longer be endured.

> *One guy was very lonely and.... He just wanted to die 'cause he, he was now isolated, he just couldn't get out of his house and whatever, and he was sort of locked in there and he just wished it would all hurry up, and it turned out he was terribly lonely.*

A number of the participants reported clients wishing for death to avoid going through the dying process alone. Marie spoke of a client who had killed himself. This man had cared for his wife through her final illness of cancer. He could not face this same experience alone when he was diagnosed with terminal cancer. Marie, in hindsight, commented on how his home environment reflected his life circumstances.

> *The first thing you noticed when you walked into his unit, it was very sparse of furniture and of course he was selling everything off because he wasn't going to be around. There was nobody there to leave it for and that was a big statement of what was happening in his life.*

Being left alone was unbearable for some clients who had nursed their partners with AIDS and then were left alone to die with the same illness. A couple of informants spoke of younger clients who found themselves in this situation. Melissa spoke of one client.

> *I just heard that he committed suicide. No he didn't have a carer, never formed another relationship and then was frightened to be by himself.*

Loss of independence, fear of loss of control and loss of a home were challenges for some clients. Marie told of a retired doctor who had always believed in euthanasia. When this client was faced with becoming dependant on others and having to leave her retirement unit, she decided that it was time to leave life.

> *She, as a medical person, discovered that you couldn't do a cut-down with only one hand. That was her explanation afterwards, so I think it was a good attempt but she wasn't able to carry through with it.... I think what she said was that she had a fall in her unit and she lay on the floor and thought "This must be the time. I can no longer get up and walk about. I think it's time I went" and then made the decision to try to bleed to death, I guess, but was unsuccessful and she didn't tell anyone for a day.*

The outcome was not as bad as the client feared. She had the means to pay a nurse to care for her so following negotiation with the management of the retirement village, she was able to stay in her unit.

Kirsten's client was not in physical pain but suffered the giddiness and nausea associated with brain tumours. The client was an artist and very creative, but was unable to do any of the things that she enjoyed and there was no relief for her symptoms.

> *She said, "I just do not want to continue this life as it is now." She said, "Because it's not my life anyway."*

The nurses did not always hear the suffering voice. Melissa advanced reasons for this. The nurses were tired or perhaps not ready to deal with others' suffering on that day. A suffering voice may not have been heard because the nurse cannot recognise or understand what was being communicated.

Martha recalled a client who had killed himself. The nurses found this client to be difficult to talk with and unreceptive to the nurses' suggestions. The staff had a team meeting after his death to determine whether they could have done something more to prevent this sad outcome.

> *We virtually came to the same conclusion, that he had been planning it probably for months, and he didn't want to die the slow death of cancer. He just wanted to shoot himself, and that was the way he planned it.*

The difficulty in communicating with this client may have been associated with his inability to express his feelings so his suffering voice was not heard.

6.3.2 Seeing the suffering body

The visual decay or distortion of the body distressed the nurses, and although some of the memories were of people they had nursed many years previously, they still had the power to disturb. Tanya referred to the power of seeing the damage to the body when discussing a situation that had caused her personal distress. A general debriefing for all staff that had cared for this client was required following her death. Tanya spoke at length about the client and her distress was obvious.

> *I think that it was so visual. My comment is it was the most visual cancer I have seen. I mean the counsellors don't normally see it. You know it's under a dressing. It's under the bedding. It's chemo in the veins. You don't often see your cancer. And all of a sudden, you have the most visual [cancer]. All the things that are normally repulsive, puking, coughing up, spitting and having to live with it on a minute-to-minute basis. You know! It was just enormous.*

Alison referred to the power of the sight of the suffering body. Her memories harked back to when she first provided palliative care in a hospice. It seemed for her that the visible bodily signs of suffering were the hardest to bear.

> *I'm a very visual person, and I'm affected a lot by pictures and I have this impression of a 7 o'clock start of going into a six bedded men's ward with these poor things propped up against the pillows waiting for breakfast.... So that's the hard thing for me is the suffering bit of it is a lot of what I see.*

The nurses did all in their power to fulfil the wish of clients to die at home. At times this was a hard and lonely task for family and the nurses. Melissa recalled nursing a man dying with a mutilating cancer. The client was cared for at home by his family and wished to die there. The memory of his physical decay still horrified Melissa.

> *I remember that he had a tumour that went from his back, literally his backside, right through under his scrotum and [it] just sort of ate him away internally, and we never fully controlled his pain.*

While this event that had occurred when Melissa first began providing palliative care many years before, it was a haunting memory that could still distress her.

Robyn spoke of the distress all staff felt when witnessing the suffering of a client. This client had radical surgery and suffered further pain from radiation therapy burns received after the surgery.

> *Oh! You know the poor kid couldn't swallow properly and oh! You know, she was just – it was so hard to get her comfortable. I mean, the poor thing, salivating.... You know we'd all end up in tears.*

Lynette’s story was of a malignant tumour that was disturbingly visible. The client was of another culture and her choices in care were disturbing for her primary nurse and the informant who was the CNC.

> *This client did not want the wound dressed and just let it ooze and she believed that was letting out the poison.*

Lynette was disturbed not just by the visual aspect of the tumour but also by the thought of what could occur.

> *She looked to me like as if she just moved her head a little bit sideways, the whole thing would fall off and just burst.... This tumour has totally displaced her eye, her mouth. It’s going to obstruct her trachea.*

All of the participants recounted a disturbing memory they carried which surfaced at times. Martha acknowledged that this visibility of suffering was something that all nurses had to face and accept as a part of their role.

> *Yeah. Rotting flesh is not nice. It’s cruel, cruel – a sort of distortion of the human being, I think, and it’s something we, as nurses, we just face it and take for granted that that’s our role to deal with rotting flesh.*

All participants had at least one story that still haunted them after many years. The visibility of the cancer and ravages of the body from the disease increased the sense of the suffering, made it more real, and impossible to ignore.

6.3.3 Exposed to the anger

The nurses were exposed to the anger and bitterness of some clients as an expression of their suffering. At times the family members of the clients expressed anger. The anger spilled out in all directions. Sometimes it was directed at the nurse or some other health professional. The nurses also witnessed anger directed at the carer by the dying client. The participants realised that the anger was often misdirected. It was really related to what had befallen them rather than actions of the person targeted.

Robyn spoke of situations where the clients expressed anger towards the doctor at his failure to cure them. They felt they had been misled and given false hope.

> *You're just sort of with them with their suffering, their disappointment, their devastation, their total devastation. [They say] that doctor thought he was going to cure me, or said he could cure me and it hasn't worked, and sometimes they are very angry towards the doctor, you know, that he has misled. He hasn't really.*

Most stories of angry clients were about men. The nurses understood how people could respond with anger, particularly younger men who had family responsibilities and more living to do. Sandra told of one man that she had nursed who was angry with everyone.

> *He was angry. Angry with the doctors, angry that he had cancer, angry with the world, you know. I mean he had a lot of living to do. He was only in his 40s and that sort of thing*

The anger could emerge when the client was in pain and pain relief was delayed. Beth experienced this one Saturday morning when visiting a client. The locale in which she worked had blind areas for mobile phones. It was the weekend when most people were on call. She was experiencing difficulty contacting a medical practitioner. The client's anger was directed towards his wife but the comments were about the health care system. Beth felt the inability to summon help added the difficulty of care giving.

> *I couldn't contact a GP. I couldn't contact any palliative care physician and I mean he was just getting angrier and angrier and, you know, talking about the bloody system and it's just an added difficulty.*

Wives often bore the brunt of their husband's anger about their diagnosis and what it meant for them. Tanya gave an example where the husband's anger was making it difficult for his carer to continue to care, although she wanted to give him the option of staying at home. In this instance, his unrelieved pain contributed to his distress, and Tanya was able to obtain medical help for pain relief.

> *He had a wonderful, wonderful caring wife who wanted to stay with him but the abuse was over the top.*

The nurses from regional areas spoke of their male clients somewhat differently to the urban informants, describing them as being of a more traditional Australian culture. This description reflected something of their response to their illness and loss of control. Loss of control may have meanings for these men that engendered fear and anxiety.

> *He was a real Aussie bloke, very tough, didn't want to accept his illness and was more or less taking out his anger and frustration on his poor wife who was quite distressed.*

The bitterness and anger of some clients at times spilled over into unacceptable behaviour. The nurses understood and generally accepted angry and irritable behaviour. The nurses found another element disturbing. Tanya spoke of a client that the nurses did not want to visit alone.

> *He was an angry bitter man.... He was very controlling; he was very lecherous but also not very nice to the nurses, lots of sexual overtones and that sort of thing.... And the stories he shared – like beating up on prostitutes in Malaysia when he was in the war and he was so proud of it.*

Some clients were angry with themselves. This anger occurred more often with female clients. Sandra spoke of one young client who was terminally ill. This woman and her husband had struggled to buy a home and provide a satisfying lifestyle for their children. Everything changed when she became ill. She could no longer work and needed a carer. The family lost their home, their semirural lifestyle and their pets. Sandra recollected the client's reaction to this change in circumstances.

> *She was very hard on herself, very hard on herself and became very angry with herself, because having her cancer meant that home and all that had to go.*

Female carers could be protective of their partners, and were more likely to be angry over matters relating to the client. Kirsten encountered the rage of a carer whose husband was close to death but she resisted him being given medication that would allow him to relax and sleep. The medication would also have made him unresponsive to his wife. Kirsten asked the carer to allow him to rest and gave the medication ordered by the client's doctor and that he wished to receive. The client died later that day and Kirsten returned to the house to face the reaction of his wife.

> *She went berserk. She just said…, "Oh, you're the one." She said, "You're the one; you're the one that did it." That's all she would say, "You're the one, you're the one," and she wouldn't look at me. She just took off.*

Summary of recognising suffering

Suffering was recognised in multiple ways. In most instances, the nurses could identify suffering by listening to the clients or carers. Perhaps there were times when the nurses missed the messages of suffering because of the client's difficulty in expressing this or because of the nurses' fatigue. The visual dimension of suffering however, was powerful and distressing for the participants, but accepted as part of their role and any disgust or horror disguised. Angry and aggressive responses were often hard to bear and seemed somewhat unjust but the nurses learned that these were indications of suffering and again controlled their reactions to the anger.

6.4 Causes of suffering

Participants identified factors that they believed caused suffering. The disease process was clearly the cause of some suffering. This suffering could be alleviated for the most people if their pain and other symptoms were well managed by pharmaceutical means. The nurses saw clients, carers and family endure other forms of suffering such as emotional or spiritual suffering. Suffering could arise from the disease, the effects of treatment, relationships with others and the despair of loss and grief.

6.4.1 Denying reality

Some of the clients could cope with their situation only through what was perceived as denial. Although this is a coping mechanism needed at times, continued denial led to refusal of treatment and inadequate symptom management that led to suffering.

Marie had been seeing an elderly client who refused care or treatment from the oncologist and the palliative care service. This woman had diabetes that she managed well but her cancer diagnosis seemed to be beyond her coping ability and she refused to consider options for treatment.

> *She's doing everything fine but this (diagnosis of cancer) has thrown her sideways and she just doesn't want to know about this at all.*

One of Lillian's clients was a young man in his 20s. Lillian was concerned about this man, as his denial was such that he could not acknowledge his diagnosis and impending death. She spoke sadly of how he looked for signs of improvement when his physical deterioration was obvious.

> *He couldn't believe that he was dying even though he was totally emaciated and had a colostomy and a nephrostomy tube, you know. He was just a walking skeleton and I took him to casualty one day because his nephroscopy tube had clogged up.... And he was sitting up on the trolley and he said to me "Oh! I forgot to weigh myself this morning, I'm sure I'm putting on weight," you know, and I thought "Oh, Goodness gracious."*

Lillian thought this young man was not ready to die and wondered if a lack of spiritual belief or a philosophy about what happens after death made the struggle more difficult for him.

Denial of the diagnosis and prognosis led to some clients to experience unnecessary pain. The nurses told of situations where their male clients had denied the presence of pain and this meant they must also reject pain medication. Kirsten recalled a client who refused to acknowledge his pain. This nurse believed that acknowledging pain meant he would have to face his worsening condition.

> *If you acknowledge the pain that means you have to admit that perhaps things are worse than you want, and maybe that may cause extra suffering so you don't admit to it.*

The nurses considered it was older men who frequently reacted in this way. These men would suffer in silence while it was clear to the nurses that they were in pain. Tanya spoke of such clients.

> *The generation we are dealing with is stoic, the stoic silent generation, and you go in and they're drawn, their lips are. And they're holding in the pain and they can barely move and they sit in that chair, you know, and they are not going to start the morphine 'cause: One, that says you've got cancer; two, it's facing the truth of the illness and; three, you might get addicted to it, which you won't where there is real pain.*

Tanya recalled a client who refused to have the nurses visit him or assist in any way. Finally, a crisis caused by his refusal to accept help and advice forced him to request assistance.

> *The denial made that year prior to his death very difficult because he wanted to do things his own way including control of the medications, especially the bowel ones, and he kept doing his own thing which resulted in horrendous constipation and complications.*

In an extreme case described by Marie, a client was diagnosed with advanced breast cancer. The client had not sought help and refused to acknowledge her problem or seek treatment. The situation was very painful for her family and attempts to broach the subject or suggest she discuss the problem with her family were met with hostility. This client had seen her mother die with breast cancer and seemed unable to accept she had same condition. For Marie, the strength of her denial seemed unbelievable.

> *Her mother had died of breast cancer, and she herself had found it on herself but didn't tell anybody about it, and it was even to the point of turning, shutting her husband away and then she was still playing tennis. I remember*

> *that, thinking she's playing tennis a week or two before she was admitted and very sick when she was admitted.*

There were times when the client accepted their impending death but the family could not. Ellen found herself in a situation where the mother of the client would not accept the deterioration in her daughter's condition. The parents were seeking rehabilitation when clearly the child needed palliation.

> *She could hardly manage a spoon [and the mother was saying], "Come on, come on," you know and all this absolute intent. "You've got to do this. You've got to try. You've got to do things better." And it was so frustrating because you could see that the child obviously wasn't capable of doing it, you know and I think the mother just found the slowness of her recovery very intensive.... she got to a point where she started to deteriorate again, and it was very hard to say to the mother, "Look, I think she's deteriorated,".... And at the time they asked for a referral to a rehabilitation team, which again the oncologist felt was inappropriate because she was not a rehab.*

People needed time to process the fact that they were going to die. Some individuals were not granted the time to accept their diagnosis and work through the issues gradually. One of Kirsten's clients suffered greatly as she went from diagnosis to death in the space of about two weeks. This client had been active in the community and functioning well almost until receiving the diagnosis of cancer. Kirsten found this situation to be the most difficult she had encountered as nothing relieved the client's suffering.

> *It was spiritual pain. She hadn't had any time to come to acknowledge or accept or whatever, even to get used to her diagnosis when she was dying. This was one of the hardest I think I can ever remember being in touch with, because that was utter helplessness, because there was nothing anyone could do for her.*

Denial made care giving difficult but the nurses accepted there was little they could do until the clients were ready to accept the their diagnosis and the need for help.

6.4.2 Effects of treatment

The client's treatment, or sometimes inadequate treatment, caused suffering. Mismanagement sometimes occurred when the client was admitted to a hospital ward where staff was unfamiliar with providing palliation. Kirsten recalled one client who was given analgesics in hospital, resulting in painful constipation. Aperients were necessary to counteract side effect of pain medication, so avoiding additional pain and suffering. Kirsten was amazed and outraged at what she deemed to be poor management.

> *He was constipated up to here, and they had given him, was it Thursday when he last [had his bowels opened]. This was now Monday and he hadn't had his bowels open. They had given him one Coloxyl with Senna tablet and one little micro enema but they were still giving him his 400mgs of morphine a day, so you know it just doesn't make sense.*

People could have a painful reaction to chemotherapy and Melissa saw a client who experienced such a reaction. Melissa suggested that the client needed to see her doctor.

> *She was covered in a rash all over her body and it was obviously a reaction from the chemo. It just did not agree with her.*

The client's family was angry with Melissa when she suggested the client might think about whether this treatment agreed with her and informed her she could choose to reject further chemotherapy. It transpired that the client had not wanted the treatment, but her family had persuaded her to accept it.

The nurses tried to minimise pain caused by treatment when they could. Ellen was the CNC for both oncology and palliative care based in a hospital. She would see clients at home and at the hospital outpatient clinic. Ellen would try to minimise the pain experienced by children during their treatment. She could do this for some children by taking blood via the central line instead of a hurtful fingerpick.

> *Sometimes you might take blood and so you open the central line, take blood, and then in fact they need chemo but you can't give chemo until you've got the results [from the blood tests] so you're opening the line twice sort of*

> *thing. Well you know, there's infection risks, there's all sorts of things but there are some children, a small number of children who… time after time [are] being traumatised by needle pricks and are not improving and things like that that we will say okay [to using the central line].*

This procedure was more time consuming and risky but less traumatic for those children, and their parents, who already had the burden of possible failure of treatment.

The nurses recognised when treatment caused more suffering and tried to prevent this. However, they were not always in control of the situation and found that clients could suffer, for example when admitted into a general hospital where staff was unfamiliar with palliative care.

6.4.3 Barring access to relief

Most of the nurses mentioned times when clients were denied access to appropriate care. The barriers to relief from suffering were erected by the GPs, the clients, their families, or the organisation of services. The participants identified some GPs being responsible for causing or failing to relieve suffering. Failure to refer to palliative care services was one cause of suffering leading to inadequate pain relief. The reasons for this failure varied. It seemed that some doctors denied the client's situation. Melissa was aware of a client in great pain whose cancer had metastasised to his bones. She tried to persuade him, in a subtle fashion, to request a referral to a palliative care physician. The client was unable to ask his doctor who was also his friend. Melissa felt distressed and helpless in this situation.

> *I had a doctor who wouldn't link a person into palliative care and he [the client] had cancer of the prostate with bony mets, and it was his friend and he played golf with him every Wednesday…. I sat by and watched this man bust his boiler in suffering.*

The issue of inadequate pain management was raised by most of the nurses. The nurses believed some GPs had an inadequate knowledge of pain management. Marie spoke of one of her clients being in pain, which could have been managed more effectively. It was difficult for the nurses to raise this issue with the doctors and the solution in Marie's case came from the oncologist.

> *I guess there was a way through that because in fact she went to see her oncologist but that was a month or two down the track and she did have more treatment which was helpful for her.*

Marie believed the client would have been spared suffering had the intervention occurred earlier.

Sandra was incensed by the failure of a GP to refer a client for palliative care. The client's niece was her carer, and had been for two years without being advised that assistance was available from the community health services. The pain medication suggested by her local doctor was woefully inadequate from Sandra's perspective. Sandra saw this as uncaring and ageist.

> *A lot of them don't have good concepts of proper pain control, 4-hourly medication, etc., and I think it's still with some, like this lady today, I think like it's, well she's old and she's going to die anyway thing. It doesn't really matter whether it's due to cancer or whatever. It certainly doesn't matter to me what the underlying cause is, but the woman's in pain and distressed.*

Sandra was clearly impatient and irritated with some of the local doctors but was usually unable to intercede for the clients. Sandra commented that advice from nurses was not acceptable to some of these local doctors.

> *A lot of it is that doctor-nurse thing too. They don't like to be told or be seen to be told.*

The nurses believed failure to refer to palliative care services or community nursing services increased the likelihood of more client and family suffering.

Lynette recalled trying to inform a GP about suitable pain medication with little success. She had sought advice from a palliative care physician who could have helped with the home management of the client had a referral been made.

> *I was getting the suggestions and feeding them to him. [the GP] He wasn't taking them from me at that stage. He has great respect for me. He just wanted to do it his own way.*

Lynette believed that some of the doctors had inadequate knowledge of pain management, but insisted on controlling the client's care. She recounted a story of one client who clearly suffered great pain. The doctor's approach to pain management concerned Lynette. She believed he was fearful of prescribing adequate sedation.

> *He doesn't do anything unless he's checked it a thousand times, and he doesn't do it from conviction you know. He's just scared to deal with drugs and terminal care.*

This nurse believed this doctor was afraid of being blamed for a client's death and she considered that there were legal constraints on doctors that led to ineffective pain management.

Inadequate monitoring of the client's medication by medical practitioner was another cause of suffering. Kirsten spoke of one of her palliative care clients being treated for another medical condition. On visiting the client, her attention was drawn to his symptoms and signs. This client was taking anticoagulant drugs and his clotting times were inadequately monitored.

> *He was really pushing it like and plus he, his stomach was bruised and he was talking about every time he knocked himself it would take about half an hour for it to stop bleeding, but the local doctor didn't want to hear of that. Then his little wife says, "And his blood's as thin as water."*

Because his GP was on holiday, Kirsten sought advice from a medical specialist at the local hospital. Kirsten stopped the anticoagulants for one week as advised by the hospital specialist. This nurse often had to find ways around barriers in the system to obtain help for her clients.

> *I don't hesitate [to go to specialists] any more. If I don't get satisfaction from a GP I go because I figure, "Well, that's what I can do." I might get my knuckles rapped over, but I haven't yet.*

Lynette believed that some GPs were reluctant to hand over or refer clients at any point, which infuriated her.

> *What they [GPs] have done over the past two years is find themselves private hospitals to put their patients into, continue looking after them [the patients] themselves so that they don't have them shunted off to a hospice where they will never see them again. And in fact the patients suffer because of that, because GPs hang on to them and don't even refer for a nursing service.*

A further cause of suffering identified by some participants was giving what the nurses perceived to be a false hope. Marie noted that when a client is desperate to live, they grasp at any chance, but then their hopes are dashed. This hope of cure prevents the client and family from focussing on what help palliation might provide. Marie recalled a client who offered hope of cure by surgery, but this offer came too late, leaving the client devastated.

> *Other things [cause suffering] like a specialist offering a person an operation but it was too late, a chance of an operation that might extend their life and at the same time the timing wasn't good.... I was feeling sad for that family that they were given false hope.*

A client of Lynette's was suffering, as were her family. Lynette attributed some of this suffering to the GP and the way he was approaching the medical care of the client.

> *The GP was obstructive right until the end, not in a nasty fashion, but in a gentle fashion by focussing on the technical side of things instead of the reality of the patient dying. He was always thinking of tests he could do that would bring hope to the family that this patient would go on.*

Martha's tale was of an elderly client and her husband who wished that she could die at home rather than be admitted to a hospice. Services were available to enable that to happen, but according to Martha, the GP tried to block that because he thought the client should be admitted for hospice care.

> *In most cases we knew we could make a difference for those people, that just the offering of around the clock nursing service could make a difference but in some cases that was blocked by the sometimes sheer bloody-mindedness of a doctor.*

Martha stood firm for her elderly client, allowing her to die at home.

The client, or their carers, could create barriers to care and relief of pain and suffering. Lack of trust in anyone other than his GP led to increased suffering for one of Kirsten's clients. This man did not seek help for the development of spinal cord compression because his doctor was away. By the time the problem was addressed it was too late for him.

> *He didn't want any medical input. He trusted one GP, and she was away on holidays and he developed, he had, he's got a slow growing tumour of his clavicle, 19 years since first diagnosed. [He] didn't let anybody know what was going on, and went from being mobile and active to a paraplegic in four days 'cause he's got spinal cord compression.*

The clients have many fears, one of which is fear of addiction to prescribed analgesia. Marie believed that the health care providers should understand and address these fears.

> *It can be very easy for a specialist to go into a situation and say this will help and that will help, but we have to understand that for the patient this is happening for the very first time in their lives, and there will be preconceived ideas about morphine and the fear of addiction so we need to be aware of that.*

Marie spoke of a client she believed was fearful of becoming addicted to his analgesic medication.

> *[He] was very cautious about anything he did or would prefer to wait for the doctor to say, "Yes it's okay to take that particular medication," or not I think. I had the feeling that he could have been more comfortable sooner.*

Clients feared that analgesia would lead to them losing control. This fear led to refusal of analgesia. Sandra told of one of her clients who resisted taking medication for his pain.

> *Pain issues were huge for him, but loss of control issues were the biggest issues, and that's why he didn't want to go onto pain control, because he was terrified that, you know, he wouldn't be able to get on the tractor or do this or do that.*

The loss of control and inability to function might also be seen as moving closer to death for this man.

Tanya identified the client's fear of symptoms as producing great suffering. Reducing the fear by alleviating symptoms relieved the suffering. Tanya gave as an example the story of her client with congestive cardiac failure who was having attacks of air hunger.

> *The heart starts to fail, the lungs fill with water and the breathlessness sets in. I've got an abstract theory that if we deal with the emotional anxiety and fears and terrors especially around breathlessness and air hunger. 'Cause it's just so awesome in the sense of suffocating or drowning. The energy that would go into these emotions actually is restored to the body which is why 10 minutes later with oxygen and Rivetil drops you've got a person who sits up.*

Religious beliefs held by clients could lead to suffering. Martha was distressed by the refusal of one client to take pain medication because she believed healing would occur if she truly had faith in God. Taking medication indicated a lack of faith.

> *She was going to do without drugs, you know and she was going to get over this cancer and it was going to be by faith. It was absolutely the most painful situation I visited I think. It was a deep, deep pain because she was in severe pain.*

Martha became so distressed by the situation that she hated to visit the home and needed time to strengthen her resolve before entering the house.

> *I would sit in the car for about 10 minutes before I went in there saying, "Dear God, how can I face this horrifying situation where she will not take any help at all?"*

It was ironic that both the nurse and the client sought help from God. Martha was distressed for the woman and her young daughter. Martha became aware the daughter was suffering too. She was angry about a faith that caused her mother such agony.

> *She was a young 15 year-old and the kid was going through hell because she couldn't believe this was right for her mother. She was losing her mother anyway, but the whole thing was she was angry. She was really angry that they had to have that sort of faith and what sort of faith was that, and where was God anyway?*

Kirsten recalled a carer who prevented the nurse giving her husband sedation. Kirsten spoke with the nurse.

> *She was going to give him Valium.... But the wife pulled the needle out, pulled the syringe before she could actually give it.*

Kirsten was astounded that the client's need and desire for medication ordered by his doctor was not met, and that a nurse had allowed that to happen. On her visit to the house later that day, Kirsten overruled the wife's objections and gave the sedation. Following the client's death, a friend of the family thanked her.

> *This friend of theirs who was a doctor and he came.... He said, "Thank you." I said, "Thank you for what?" He said, "For having the strength to go over her" [the carer]. He said, "Because she wouldn't allow the nurse this morning to give him adequate medication to settle him down but you had the strength to go over her."*

Carers were believed to cause suffering by insisting on being independent. Martha recalled a husband who had been giving all of the care to his wife, but eventually had to surrender and seek help.

> *She was shut away in this upstairs dark room, never getting very far out of bed. I think she went on to a commode and back into bed, in awful pain. [She] had been in pain for months, before we met her. [She had] a really smelly revolting tumour that he was dressing, very inadequately because he was too proud to have anyone in, and it was only by some really last minute intervention that we were asked to come in to help him because he was, he gave in at last, you know, to get help, and it meant that he'd blocked help for his wife by being that way.*

Lillian had received a referral from the local hospice to assess and advise on the care of an elderly woman who was experiencing unpleasant symptoms associated with her illness. The client's son-in-law was a doctor and had spoken about the situation to Lillian by telephone before the visit. This participant never learned why, but the woman's daughter was angry and misunderstood Lillian's purpose. Lillian felt unwelcome and unable to do what she had come for. She left concerned about the intended client's welfare.

> *The sad thing is the poor old lady is nauseated and she's going to die nauseated because nobody wants to help, you know. Like he [the son-in-law] hadn't done what I had suggested. I'd suggested the Stemetil suppositories. I also suggested Stemetil injections by the butterfly [needle] and the wife just spat the dummy about having an injection, and I couldn't explain to her that a butterfly was one injection.*

6.4.4 Family conflicts

Relationship problems for a couple or family sometimes resulted in suffering for the client, carer or other family members. Pre-existing family problems were exacerbated by illness and death.

The nurses endeavoured to enable family members to remember their loved one's death in a positive way. Disagreements between siblings about a parent's care sometimes distressed adult children. Martha told of a situation where the eldest sister took control of the mother's care. Her siblings felt they had restricted access to their mother as she was dying, and were not allowed to contribute to her care.

> *Even after the mother died some family members came to the hospice again to talk about the issues once more, and that was a whole lot of family suffering I feel.*

These family members had suffered during and after their mother's death, and perhaps would never come to terms with their loss.

The failure to heal breaches between family members caused suffering. Martha thought the following scenario was very sad.

> *I think [of] a daughter coming to see her dying mother, and there was obviously a relationship difficulty which had been in place, I guess, before the person got sick, and I think the daughter was hoping there would be some reconciliation and there wasn't. And I think the mother screamed at her to go.*

Lynette's tale was of revenge. She recalled a carer who had regaled the primary nurse and Lynette with stories of the terrible things her husband had done to her throughout their marriage. The nurses felt she monopolised the visits to her husband. The carer needed assistance but her problems were not ones the nurses could address. It was the way she administered the pain medication to her husband, however, that really disturbed the nurses.

> *She [his wife] wanted this man to experience the full pain of his death so she didn't give pain management. It was an extraordinary situation in that most people deal with pain and manage it 4-hourly with morphine but she decided when he was suffering and when he wasn't. And in fact that's what was happening it was a payback. He had put her through enormous suffering or she had chosen to suffer in her marriage with him.*

It seemed to Lynette the wife now had power and control and the client was at her mercy.

This change in power relationships did not apply to all carers who had been abused. Some carers, for example, were not free of abuse until the death of their husband. Sandra recalled such a situation.

> *There was horrendous abuse there, you know, physical, emotional, whatever else, who knows. He controlled her to the bitter end. He would not go to sleep unless she was there. Like there was no more [physical abuse]. He had no strength to physically do anything. Also there was abuse of alcohol, too, that she's had to put up with. She's had a hell of a life, a shit of a life, dreadful life.*

Sandra practiced in a smaller regional centre and perhaps knew more about a family's history than nurses based in the city would know.

Some spouses suffered because of the hostility from their children when they were unable to be the client's carer. When marriages had broken down but the couple stayed together, there were sometimes regrets and suffering for both when one was dying. Kirsten recalled such a couple. The husband regretted past decisions. He also suffered because he was unable to die at home. The marriage had been one in name only since the husand's affair with another woman 20 years previously. His wife could not bring herself to be a fulltime carer.

> *He suffered because he said he regretted not divorcing his wife 20 years ago, and having this other relationship with this woman.*

Kirsten believed his wife also suffered because their children were angry with her when she refused to take on the role of carer. The client came home for a few hours each day and his grown children would visit.

> *His wife was suffering, you know, she was on the outside. She was excluded, yet she was also expected to look after him and the family was very much down on her because she said, "I can't, I can't touch him. I won't be able to*

> *wash him you know," or, you know, have this personal intimacy with somebody that she hadn't had an intimacy for 20 odd years.*

Other carers tried to enable the client to remain at home to die following that kind of betrayal in their marriage, but this caring role was difficult. Beth had a client and carer in that situation.

> *That particular man had had a lover and had a child to that lover many years ago. There were a lot of dynamics there, but I know she felt she wasn't right to care for him.*

Beth visited the home late one evening to assist the client. She realised the client needed admission to the hospice, as he was near death and his wife was not coping. She was inebriated when Beth arrived at the home and Beth had great difficulty getting the client and carer to agree to his hospice admission.

> *By the time the man was transferred down the stairs and got into the ambulance, and I mean these ambulance officers were accosted by the wife. She was sort of giving them a cuddle and saying, "I'm not doing a dreadful thing am I?" And she was screaming and crying and carrying on.*

The carer was clearly torn between what she thought she was expected to do for husband and what she was actually able to do considering their relationship.

The nurses noted that the carer or other family members could suffer while the client was at peace. Melissa related the story of a carer who returned from interstate to care for her ex-husband after many years of separation. One son, who remained with his father, was hostile and unforgiving that the marriage had ended and blamed his mother.

> *The husband doesn't have any anxieties or suffering but the wife is suffering, or the ex-wife is suffering severely.... He's [the son] is making her life a misery at the moment, and really she didn't come back for him but he's not helping his father and she's here to help the father, and he's so angry.*

Martha found that to have happened in a family where one sibling took control of the mother's care when she was dying.

> *I can remember aspects of that patient's care, and interestingly enough the family was suffering, and the fact that they felt some of the members couldn't get to their mother or look after her the way they wished but when I ever saw her she appeared to be comfortable and at peace.*

The complexity of family relationships created suffering for all family members when someone was dying. These family problems were generally long standing and there was little the nurses could do to help other than to listen, offer respite care and avoid taking sides. The nurses could only stand by and watch these painful family conflicts played out.

6.4.5 Losing precious things

The nurses saw actual loss or the threat of loss as a cause of suffering for the clients or their families. The impending loss of life is a cause of suffering but there were a number of losses of earthly possessions or relationships causing suffering.

> *When people are dying and they know they are dying then they start grieving about the loss of things on this earth.* – Robyn

Lynette believed that nobody wants to die. This desire for life caused anguish and suffering which persisted despite analgesia.

> *I'm beginning to realise that people really don't want to die; doesn't matter how sensible, sane and educated they are, and how well you look after their pain, they just don't want to go. So if they don't want to go there can be an enormous amount of anguish.*

It seemed that Lynette had realised that the promise of an afterlife free of pain and suffering was not enough for people to accept death willingly.

The nurses believed a young person facing death suffered greatly since there was so much more they expected from life. Martha felt for the young person who would lose all their hopes and dreams for the future.

> *Their expectation is for a longer life and productivity, achievement, all that. That's no longer there. There aren't answers often as to, you know, why these things should happen.*

Robyn spoke of a client diagnosed with a terminal illness and saw the loss of future and the waste of talent as being one of a number of things that caused this client much suffering.

> *She was obviously suffering whole lots of things.... Just being so young, she was pulled out of her career and you know.... She had so much going for her.*

Some participants noted that it was an accumulation of losses for both client and carer that caused suffering. Sandra spoke of a young couple. The husband had been diagnosed with cancer and the losses cascaded for these two people.

> *He's had this diagnosis and had to leave work and next thing she's having to leave work to care for him and so you get enormous financial suffering and hardship and the whole psychosocial thing. They used to go and dance every Friday night at the club and they can no longer do that. That sort of, you know, readjustment does cause extreme suffering.*

Sandra had cared for a young woman diagnosed with an untreatable cancer. Both the woman and her husband needed to be employed to service the mortgage on their house and support their lifestyle. Once the client was unable to work and needed a carer the losses mounted.

> *The long and short of it was that the house had to be sold, you know, and massive life change for him and the children towards the end and that caused her enormous suffering.*

The loss of a life partner caused suffering. Many of the clients were older and retired. Robyn believed suffering could not be avoided for the client and their partner in these instances.

> *Often these people have been married 50 years or 30 years or something, and then you lose your partner. I mean it's a bit unrealistic to think you're not going to [suffer].*

Many of the older people had sustained a number of prior losses, which affected the ability of carers to take on the caring role. Robyn recalled a carer who was unable to cope. His dying wife was aware of his difficulties and requested admission to a hospice.

> *It was becoming too much for him, the losing her and having a burden of grief that wasn't really, well not, resolved. His son had committed suicide. It was all pretty sad stuff for him.*

A further unbearable loss for some clients was the loss of independence. Marie's client had attempted suicide when unable to manage by herself and fearing admission to a nursing home.

> *For that particular lady it was loss of independence, and that must have been devastating for her to perhaps realise she couldn't carry through, she didn't have the control that she always wanted for all things. Everything was disappearing away, was being taken away from her because of her weakness I suppose… [She] couldn't drive and couldn't even manage to take her own life.*

Kirsten mentioned loss of independence and privacy as a cause of suffering, and she provided an example from her practice. The client had suddenly become a paraplegic following compression of his spinal cord.

> *His suffering is really intense; he used the word exhausting. He was exhausted. This was about 10 days after we all started and the changes to adapt must be incredible, you know. One minute you're out striding the paddocks with your greyhounds and the next you're flat, well sitting in a*

> *chair with all these nurses lifting you.... And you've got all these people in your house that are virtual strangers doing all these private bodily functions such as enemas and all that sort of stuff.*

The losses described are major for individuals but Kirsten believed that the small losses accumulating before death occurs cause suffering. One of Kirsten's friends had recently died from cancer. Kirsten decided she would be a friend and allow another nurse to provide the palliative care. This participant could see all of her friend's small but cumulative losses adding up to a major loss for her.

> *Clothes were really important to her and handbags, leather handbags and leather shoes and everything. They were really important, that's what she was. That was part of who she was. She was dying. She was in a track suit you know and I can remember looking into her [wardrobe], and she had a sort of open wardrobe and I thought to acknowledge that you won't ever wear those cloths which were so important that aren't now.*

Kirsten thought people might be spared awareness of these successive minor though important losses. She believed that were she in her friend's situation, she would be aware of the small losses of things important to her.

The nurses believed the clients mourned many losses, as did their carers. These included loss of life, their future and the things that were precious to them. The changes in the bodily appearance and loss of function contributed to many of these losses.

Summary of the causes of suffering

The nurses considered that for the majority of their clients, physical pain and other symptoms could be controlled or diminished with the use of medications. There were however, many other causes of suffering. These ranged from inability of the client or their family to accept the prognosis, resulting in refusal to accept pain relief or nursing assistance. Denial of their diagnosis prevented the sufferer from moving on to grief and finally acceptance of their impending death. Other causes included treatments, poor management due to lack of knowledge and refusal of treatment because of fear of drug addiction or loss of control. The failure of GPs to adequately manage the pain, or refer to someone who could, and longstanding troubled interpersonal relationships were the most difficult causes of suffering to address.

6.5 Summary and conclusions from Chapter 6

This chapter describes the theme, knowing suffering, and how the participants came to know these things. The nurses explained their understanding of nature of suffering and their ideas of its meaning and purpose. The causes of suffering, as the nurses saw these, were also described. The essence of this experience of knowing suffering is revealed in being initiated into the world of suffering.

6.5.1 Ways of knowing suffering

The stories of the nurses' experiences provided an understanding of knowing the world of suffering for them. The participants observed the individuals and families they cared for and reflected on what they saw. The three aspects of the theme necessary to provide a complete description of knowing suffering were explaining suffering, recognising suffering and identifying the causes of suffering. In explaining suffering, the participants reflected on the many facets of suffering. The nurses attempted to define the experience of suffering but tended to focus more on the kinds of suffering they saw.

In discussion of the meaning and purpose of suffering, the nurses spoke of their beliefs about the meaning and purpose of suffering and gave examples. Two of the participants could see no value or meaning in suffering while others could see some meaning. It was important for the nurses to see something meaningful come from the suffering they saw.

Over time the nurses learned to recognise suffering and the second aspect of the theme addressed this. In recognising suffering the nurses described the ways in which they identified client suffering. The clients or carers were sometimes able to speak of their suffering but it seemed the nurses found most difficulty with clients who could not verbalise their suffering other than to scream and cry out in pain. The ravages of the disease or results of treatment changed the body and its functions. For embodied beings these changes led to other forms of suffering sometimes verbalised or indicated by the client's demeanour. Anger was another response to suffering. The participants were deeply affected by the visible signs of damage and decay of the body. They carried distressing memories of these bodily changes. The nurses realised that emotional and spiritual suffering were forms of suffering most difficult to alleviate and accepted the clients' and carers' anger to be expression of their suffering.

The third aspect of the theme described the causes of suffering. Causes of suffering, as the participants saw these, were identified. The causes of suffering were considered to arise not only from body but also emotionally and spiritually from the client's fear and grief. Relationships with others caused suffering. Ruptured family relationships existing over long periods of time were not amenable to change. The participants in the study patched over these ruptures where they could to help both clients and carers get through the suffering and dying. The failure of health care providers to refer client appropriately was also seen as a cause of unnecessary suffering. Carers and families suffered vicariously. The carers and families suffered when witnessing a loved one suffer or because of unresolved troubled relationships. They also suffered in anticipation of losing that person and their relationship with them.

6.5.2 Being initiated

Knowing suffering required the nurses to have experienced being part of the world of suffering. Their acquaintance with this world developed following their observations of, and interactions with their clients and the carers. The knowledge and understanding gained was not that taught in a classroom but came with experience. The nurses lived through this experience of knowing suffering as being initiated into the world of suffering.

The nurses came to the practice area almost as novices. They had been exposed to suffering before, as all nurses are, but in this setting they were steeped in suffering. Being initiated into suffering was an emotional experience and the nurses learned to stand by and watch the suffering. This witnessing of suffering, as it unfolded, required courage, endurance and acceptance from the nurses. With this acceptance came the ability to be sensitive to the feelings of others and aided the nurses in recognising suffering. Knowledge of human relationships revealed sources of suffering to them.

Some nurses sought meaning for the suffering others accepted it as a part of living. An inability to find meaning in the experience of suffering rendered the nurses less able to help those for whom they cared and more vulnerable to suffering themselves.

The nurses brought technical skills to the world of suffering but also an ability to manage their emotions and those of clients and families. This emotional management was difficult work requiring the nurses to suppress overt expression feelings of frustration, anger and revulsion and to avoid showing their sadness.

The nurses saw suffering they thought avoidable. This suffering could be caused by long standing relationships problems. They were particularly disillusioned and angry about suffering caused by heath care providers whose brief was supposedly to alleviate suffering and care for clients when cure was impossible.

There was no formal ritual or induction but these nurses were identifiable as a group acquainted with the world of suffering. They seemed to have a special knowledge and sensitivity to the suffering of others. Being initiated into the world of suffering could be empowering for the participants but it could also be confronting.

Chapter 7 – Giving Nursing Care

> *I think the main thing for me as a nurse when I'm in that situation is to try and be as much as I can for each person. —Marie*

7.1 Giving nursing care

When describing the process of caring for their clients the nurses spoke of their giving and what they gave to the clients and carers. Participants frequently used the word *give* and spoke of giving too much and too often. The actual concept of giving was hard to explain. The nurses recognised that giving encompassed more than clinical skills and information. These two elements alone were insufficient to provide the quality of care to which the nurses aspired. The intention of giving was to prevent or relieve pain and suffering. Giving referred to the skills, knowledge, power and tender care provided by the nurses. Melissa noted the difficulty in defining giving.

> *Giving is one of those words like knowledge that you can't define or have difficulty [with]. It's like trying to define nursing.*

The theme, *Giving nursing care* was drawn from the messages in the nurses' descriptions and revealed the aspects of the theme. These provide the framework of the chapter.

These aspects are:

- Bringing clinical skills and knowledge.
- Offering power to client and carer.
- Granting access to the sentient self.

The meaning of the experience of giving nursing care was interpreted to reveal the hermeneutic *Being all that they can*. The nurses endeavoured to give all that they could to relieve the suffering of the clients and their carers.

7.2 Bringing clinical skills and knowledge

The nurses identified the important skills and knowledge they brought to the nurse-client relationship in their efforts to reduce suffering and maintain the client at home. The skills and knowledge identified were firstly the ability to make accurate assessments of the client and carers' needs and of the home environment. They also required knowledge for effective and safe medication use, wound care, symptom relief, and sources of equipment and other supports required. Most of the nurses wished to initiate palliative care early in the progress of the illness to enable them to get to know clients, avoid crisis situations and enable the client to have the best quality of life possible.

7.2.1 Assessing the client and carer

The nurses spoke of the need for early assessment and interventions to reduce the possibility of clients being in crisis when first seen by the nurse. Delay in referral caused unnecessary suffering and made establishing a relationship more complicated. Assessment was the first step, which continued throughout the nurse-client relationship. Participants noted the importance of an accurate assessment of the clients and their carers.

Merely carrying out an assessment brought relief to the clients. Lynette spoke of the value of the assessment alone for relieving the client's fear and suffering. A full and accurate assessment by an experienced palliative care nurse inspired the client's confidence that their pain could be relieved.

> *The relief you see on a patient's face after an hour and a half assessment interview when you first meet them is absolutely astounding. You can see someone just physically melt in front of you with relief that there is someone who understands how to manage morphine and how to distinguish different pains.*

The nurses aimed for holistic assessments and sought to understand the client's knowledge, expectations and priorities.

They assessed the carers' ability to provide the care and availability of family and other supports. Knowing how individuals had handled past issues gave the nurses some understanding of the clients' or carers' current behaviours and responses to their illness or their caring role. Tanya spoke of an experience she had with a client who would not cooperate with the nurses and actually acted in ways that caused him more pain. This response created conflict in the home.

> *It was critical that he be quiet and he couldn't, and he got out in the garage and he built and he fixed and he sanded and whatever any of his family wanted. And you arrived there and he was grey with pain and sweat, swaying in the breeze, about to faint from hypertension and pain and what-not.*

Tanya learned that this man was focussed on doing things his way and being in control. This was how he had handled life. He could not tolerate being told what to do, or loss of control. The nurses and the carer ceased trying to tell him what he should or should not do, instead helping him do as he wished until he accepted the situation.

> *I guess maybe because we all stopped resisting each other he started to behave himself and the wife took over the tablets and the dosette box. That was a blessing because he was taking things all over the place.*

Using unhelpful coping mechanisms such as drinking alcohol was disastrous for carers, and created problems for all involved. Beth attended a client one evening and the carer was drunk. Beth knew she could not manage the care at this point.

> *The wife had been slowly getting herself drunk. I won't say inebriated, drunk, really out of it. I've sat quietly with the patient and convinced him that it might be best to go to hospital even though I knew he didn't really want to go.*

This couple had a difficult relationship for many years and although his wife had agreed to care for him, there was no change in how they related to each other and the way that his wife tried to cope with problems.

The physical environment of the home and its layout determined whether some clients could remain at home until death. The environment was assessed and, as with all assessment, was ongoing. As the client's disease trajectory changed, and with it, their mobility reappraisals were required. The change that the nurses dreaded was the onset of cerebral metastasis, because the care would become more difficult for the family. Remaining at home would be impossible. Kirsten had experienced this and she dreaded signs of cerebral metastases. Her assessment of the home in the changing care regime revealed new difficulties facing the family and the impossibility of the client remaining at home.

> *The house isn't designed for wheel chairs and toilet things and specially there are a lot of government houses that have small narrow hallways and you know that ultimately they're not going to be able to stay at home, so it's really hard looking at placement.*

The nurses observed for complications of the disease such as paraplegia related to pressure on the spinal cord. This condition is a palliative care emergency prevented by early diagnosis and treatment. Once it occurred, the condition was irreversible and again made care in the home difficult. Kirsten commented on the drastic changes to the client's life when quadriplegia occurred, and the need to carry out a total reassessment. She spoke of one of her clients who developed this complication and was sad for him.

The sadness was increased by the complication being preventable if caught early. This client trusted only his GP, who was on holidays, and did not seek assistance from the locum doctor.

Assessment was not always easy, particularly with male clients who were finding their illness, loss of independence and privacy difficult to cope with. Older men found it hard to admit to symptoms that might be construed as weakness. Beth gave an example.

> *He had been a very active sports person. His disease has made him very immobile. He had always been a very private person so trying to get any of his symptoms out of him was like trying to get blood out of a stone.*

When his wife expressed her concerns and revealed his symptoms to the nurse, the client became angry with her for discussing what he considered his private business.

The nurses also assessed the carers to ensure they could cope and received the support they needed to enable the client to remain at home as long as possible. Lillian made this point.

> *I'm not just looking after my client. I mean the client is my primary focus, but I have to look at the whole family as well.*

It was important to assess whether the carer was willing and able to provide what was needed to enable those clients who wished to die at home.

Carer assessment was also ongoing. Sometimes the carer was so tired the nurse doubted their ability to continue. The nurses would assess the situation in terms of the carer's needs and suggest how they could be supported. This was not always acceptable to the family because of past conflicts. Melissa told of one carer whose ex-husband asked to return to care for him following his diagnosis with terminal cancer. She came back to the marital home but was becoming increasingly exhausted. Melissa suggested that she might benefit from help but found the woman's son to be extremely antagonistic to this proposal.

> *We suggested that they have access to home care to do the housekeeping and things and the son said, "No, you got more money out of Dad years ago and we're not giving you another cent."*

The initial assessment of the client and their carer was important but did not allow for the identification of the deeper concerns that client and carer might have. The nurses needed time to develop a trusting relationship with the clients. Because the situation was also in flux with the progression from client palliation to death, the nurses needed to be attuned to subtle changes in both client and carer in order to make accurate assessments. This close attention to assessment was necessary to understand how the changes affected all parties.

7.2.2 Giving relief with medications

While the nurses acknowledged that there were times when medication failed, these were infrequent. All of the nurses had confidence in the use of medication for the relief of suffering caused by physical symptoms.

Kirsten was proud of her ability to manipulate medications in partnership with the doctor for the benefit of her clients. She recounted an example of this when a client wished to celebrate a last birthday and family gathering.

> *We manipulated her medications. It was really important to her because she was having family and everything coming from everywhere. They brought her 50th (birthday) forward by 4 months so it was a very important occasion for her and so through manipulating medications we were able to keep her there.*

The nurses believed that mostly they could access medication and get it to the clients quickly. This was possible when they had a good relationship with a doctor who trusted their knowledge and ability to access the client's situation. Thus was the nurse able to reduce the pain and suffering for the client promptly. Ellen was attached to an outpatient service in a public hospital so for her this was easily resolved.

> *I can write a script and I can take it around to the pharmacy and I can have it out to the patient's home like in the space of 2 hours.*

Kirsten was trusted by most GPs with whom she worked. Therefore she could assure her clients of rapid pharmaceutical relief. She recalled being telephoned by a desperate client.

> *I said, "Look I can get this medication ordered that will help you settle down and so that you will be settled and relaxed and be able to go off to sleep," and he said, "Do it, get that done," so I rang the doctor.*

Pain was not the only physical symptom that medication could alleviate. Some clients suffered with gastrointestinal symptoms such as indigestion or nausea. Melissa recalled a client for whom indigestion was the most troublesome symptom.

> *Once he starts on his pain medication and we reduce his indigestion then he will feel a lot better. He certainly won't be cured of his disease and he certainly won't be out playing golf, but he will feel less of a burden because with his pain easing. He will do more and so he'll participate more.*

Clients sometimes chose not to take the medications suggested, and reject the nurse's help to avoid being reminded of their illness. Failure to take aperients, for example, to address the side effects of pain medication led to further pain and suffering from constipation. Lillian described a situation where the client eventually required an unpleasant procedure to address this problem.

> *I kept saying to him, "But listen, if you would only let us come in more frequently and we can look at what is happening with your pain we could look at your morphia, we can look at your appearance then you don't need to have an enema you know." But he was saying, "No, I don't want nurses coming to visit me because they remind me I am sick."*

Fear and anxiety prevented the clients from resting and living as well as they might. Lynette recognised this in her practice. She believed that the disease process and some medications affected the client's ability to deal with their situation, and caused a level of fear never before experienced by the client. Lynette reflected on the difficulties experienced with one client, where the nurses became frustrated.

> *I guess we just got tired of her, and tired of the way she was handling things and in fact, she wasn't handling them. It was because she had some cerebral involvement, I'm sure, and that she wasn't herself, and the drugs she was on and her disease process were causing fear. She may never have had that sort of fear before.*

Lynette believed that the fear and distress experienced by the client could have been alleviated by further medication, but the attending doctor was inexperienced in palliative care and ignored the nurse's advice. This client was finally referred to a palliative care physician for symptom control after suffering excessively.

At times the clients experienced tension that affected their ability to rest. The nurses gave medication that could calm the client. Sandra recalled such a client.

> *We were really distressed that he would fall down, and he did fall on a many an occasion, plus these pains in his legs were driving him mad and it was just tension. He was really tense, and he really couldn't walk any more and the*

> *muscles were cramping and the whole bit. The Valium made a huge difference, yet it wasn't enough to zonk him out, but once he got that feeling of relaxation he actually relaxed more himself. Yes, he just needed that helping hand.*

These interventions benefited the carer as much as the client. In the situation related by Sandra, the carer was terrified her husband would fall and she did not have the strength to pick him up.

> *It gave a bit of peace for his wife who at least could curl up in her chair for a couple of hours.*

The nurses also saw clients who were not terminally ill but suffered anxiety and fear related to symptoms of long-term medical conditions. These symptoms terrified the clients but could be relieved. Tanya sought assistance from the palliative care physician in the following scenario, where the client suffered from an autoimmune disease and congestive cardiac failure. The nurse called the palliative care physician and arranged for him to do a home visit to assist with the client's air hunger and breathlessness.

> *He got lost. He rang me and he said, '"Can I miss her and go to my patients at the hospice?" I said, "No. She's really sick. She's having terrible air hunger attacks and she's very frightened and when she's having them she's absolutely terrified and panicky and it's been awesome." I wasn't there for any of those. That was hearing the client. So he came and he did it properly.*

Although dressings are not medication, they required knowledge of dressing types and useful medicinal applications. The nurses dressed the client's wounds with grace and care and tried to make them as comfortable as possible. Martha spoke of her approach in this aspect of care.

> *I usually do it with as much care and patience and love as I can bring to it and try to at the same time give that person a sense of their own normality in spite of it, you know, like encouraging them with talking about things or*

> *saying, you know, "What's most comfortable for you? Or would you like that a little higher?"*

The nurses experimented with dressings to ensure they stayed in place and to reduce odour or exudates. This required knowledge of dressing technology and good technique. This care was for the client's comfort but could also help the next nurse who had to do the dressing. Martha emphasised the important of this.

> *I always hoped that when I had done a dressing that the next person who had to do it would find it as I hoped to have found it, still intact and easy to manage.*

The nurses were confident in their knowledge of medications, and believed they knew more about this than some doctors they asked for prescriptions. This area of care presented few difficulties, and while it was a technical aspect of their care, they undertook this task in a way that focussed on the humanness of the client and their carer as well as the technical expertise. Symptom relief was a core component of the relief of suffering.

7.2.3 Enabling the client to stay at home

Giving clients their wish to die at home was an important aspect of the nurse's role. Informants considered that they palliated both client and carer to achieve this goal. When the nurse's relationship with the client and carer allowed, the nurses would try to find out what the client and carer wanted and determine how this could be achieved. Robyn spoke of this.

> *I like to find out where they want to die, whether they want to die in their own little bed at home or whether they want to be off in a hospital, an institution or whatever and you try and work that out. You try to enable the person to have their wishes, you know, so that's all part of it and that's what I aim for.*

All participants spoke of their desire to fulfil the client's wish to die at home and their sense of disappointment and sadness when they were unable to help them achieve their wish. Kirsten spoke of her feelings.

> *I find it hard when you can't give them what they want 'cause they don't ask for a lot. You know to be able to stay in your own home is not a lot. Is it really? When you think about it.*

The nurses recognised when the situation was too much for carers. Though they may wish to provide care at home they were not always capable. Sometimes solutions were found within the family. Beth recalled a client whose wife could not manage. Fortunately, he and his wife could travel to another part of the state to stay with his older sister, so enabling him to achieve his wish to die at home. This experience made a great impression on Beth. She compared the client's wife to his sister who assumed the carer role.

> *Well I don't like the word "cope." I don't use that word but she hadn't even been able to manage her own care during his dying process. He was staying with a very close sister and her husband, and the sister was absolutely incredible. Especially, you know, she was well into her 70s and she was just the most capable person I have ever met, and I mean she loved this young brother so much and was determined he would have his wish to die at home.*

While the nurses tried to maintain the client at home, sometimes they had to decide that the client and carer needed more support than was available in the home. Martha had faced that situation.

> *I might be the person coming in on the weekend and they are just on their last legs They really can't cope any longer, or something happened or it's just too much and you know very well that you have to be the bridge for that person to go to hospital.*

The nurses sought a hospice rather than a general hospital should the client be unable to remain at home. The nurses had links with a hospice and saw this as a gentler, caring facility than a public hospital.

Even though the nurses wished to enable people to die at home, there were times when the client chose admission to a hospice. One of Robyn's clients had opted for the hospice. Robyn believed the client had made this decision because she was not confident that her carer husband could manage if the client was no longer in control.

> *I think she just felt safer with nurses. If she wasn't going to be in control then the nurses would steer her through okay whereas the husband might not have. He'd lost a son and things like that, and he was sort of fairly emotional.*

A deliberate choice was sometimes made to spare the family, particularly children, from the memories of the dying. Marie nursed a young woman with a young family. She and her carers had decided that she would be admitted to the hospice rather than dying at home.

> *This lady didn't want to die at home because she didn't want her children to remember that. She wanted to go to hospital, and as far as the family was concerned that was, you know, a success story for them even though it was very sad.*

The nurses believed that success in enabling the client to die at home was important for most carers, giving them a sense of achievement in fulfilling this last wish of their family member. Beth recognised the effect on carers when they could carry this through. She told of how one carer kept her husband at home against great odds. Beth's first visit to this client was 36 hours before his death. He and his partner lived in a caravan park. The client had previously been in hospital and was now home on leave for a short period.

> *That lady was just the most outstanding carer. You know you would have thought she was working with syringe drivers all her life . Yes, she would see if she could cope.... Well when he died she was sad but you could see that she was – the fact that she'd cared for him as he wanted to be cared for at home. It had given her a sense of achievement. She was proud that she was able to fulfil his last wish to stay at home.*

Melissa spoke of the value for one carer of being able to take on that role. The client was diagnosed with ovarian cancer. She and her husband had just returned from Holland

and stated that, had they known what was ahead for them, they would have remained there and investigated euthanasia. This man cared for his wife at home until she died, and at the end was grateful for the time they had together. Melissa felt she had done something worthwhile in enabling this to occur.

> *The husband cared for the wife at home, and she developed a bowel obstruction and yet their relationship through that strengthened, and so that's what I mean by doing something. I mean, we didn't strengthen their relationship. They did that themselves and at the end of the day he thanked us for allowing him that opportunity.*

Although not all clients could remain at home and not all carers benefited from caring at home, the nurses saw a lot of love and care demonstrated by families who assumed a caring role.

Summary of bringing skills and knowledge

In bringing clinical skills and knowledge to the care of suffering people, the nurses needed to conduct ongoing assessment to decide strategies they might use and in a timely fashion note changes that could occur. These changes sometimes occurred rapidly and required immediate attention to avoid unnecessary pain and suffering. The nurses were proficient in their knowledge of medication use and ensured that their knowledge remained current.

The knowledge required was different from that of nurses in an inpatient setting; as these nurses in the community had to do all they could to provide the resources needed by the client and their family to enable their care at home. Some of these resources were physical, such as beds and equipment for lifting clients. There was also a need for technology such as syringe drivers that enabled clients or carers to deliver medications safely without the constant presence of the nurse.

The final element was the wisdom to know when to relinquish the attempt to keep the client in their home because of the inadequacy of available resources or the inability of the carer to continue with the care giving at home. Bringing clinical skills and knowledge was essential to giving nursing care.

7.3 Giving power to client and carer

The participants were experienced community nurses who knew when to hand power and control to the client and carer, because the relationship in the community context is more of a voluntary one on the part of the client. The nurses believed that their clients should manage their care as they wished rather than have choices imposed on them. The nurses gave this power, but in a way that did not compromise good practice and the safety of both nurse and client; and the information needed to make a decision freely had been provided. This approach required the nurses to accept the clients' and carers' decisions and give them all the support and control possible.

7.3.1 Giving acceptance

The nurses' acceptance of clients' choices was important. The view was that the nurse must accept the client's choice of treatment and care despite not agreeing with the choice. These clients were being cared for in their own homes, and were free to do as they pleased. Melissa recognised this, and believed it more practical to suggest what clients and carers might do rather than make demands that would not be met.

> *They'll do what they want to, because it's their domain, their castle, their whatever, but if you've negotiated something practical and you know in your heart of hearts they are not going to do it, then you say, "Do you think you could you manage to do it four times a day?"*

Martha emphasised the power held by clients when they were in their own homes compared to when they were hospitalised. Community nurses had to understand and accept that power.

> *I appreciated that when you're visiting people in their home the power is where it should be. They have the power to shut the door on you, to say, "No, I don't want you."*

The clients were aware of the irritation of some health care providers when they refused to undertake the suggested treatment. The nurses understood this and tried to be understanding and empathic rather than punitive and showing impatience. The nurses aimed to foster relationships with clients that made it possible to return and give more information about the possibilities for treatment in the future. This ensured that the client could change their mind when they had accepted their diagnosis. Marie spoke of her efforts to establish rapport with an elderly woman who had rejected the treatment suggested by her doctor for cancer.

> *She said, "I think the doctor was a bit cross with me"…. I just said to her, "Look I think it's a very hard decision to make. It must be really hard." I was hopefully being empathic with her then. Anyway, she gave me a cuddle when I left so that we parted good friends.*

The nurses tried not to show disapproval or irritation at the choices of their clients. The clients were given the information to make choices, and the nurses supported their choice. Lillian told of her support for a client's decision to move to another town despite her (Lillian's) misgivings.

> *I sort of really had this dreadful feeling that really she wasn't going to be any better off. In fact she was probably going to be worse off…. But how can you say that to someone when they've got their hopes and dreams set on living nearer the cancer centre? So we waved her goodbye with a kind of mixed feeling about whether it was a good idea or not.*

Melissa felt frustrated at times, but controlled her feelings and accepted the clients' choices.

> *Sometimes I will think, "Oh, wake up to yourself, you know, and I'll want to shake them and say, "Oh, can't you see?" but you know I don't do any of that, and that's their choice and that's how they want to play it and so I've got to let them run that race.*

The nurses also learned to accept the cultural differences of clients and their families to the culture of the health care system and they tried to accommodate these in their care giving. These differences related to information given to the client, the treatments chosen, the level of family support and the expression of grief and rituals following death.

The participants identified some of the cultural differences to which they must adjust. A directive from families of particular cultures not to speak of the terminal nature of the illness to the client was a problem for the nurse. The nurses would not raise the terminal nature of the illness with the clients if asked not to by the client's family. However, if they were expected to be evasive or directly lie when questioned by the client, the nurses were presented with an ethical dilemma. Kirsten understood this request of the families and recognised the importance of the fiction for the family that the illness was not going to be terminal.

> *Most of the time I tend to follow their direction because it is very important to them, you know, their tradition and their culture and they really do believe that if you tell the person they are dying they will die. They do believe it. They really do.*

The cultural requirements of some groups created problems for some participants, and also for hospital staff if admission to hospital was required. The expectation of the health care system generally was that people be stoic in the face of suffering and death. Sandra believed that refusal to speak of the diagnosis was the way some cultures dealt with the situation and that both family and client know the truth but choose not to discuss this. Sandra spoke of one such instance with the impending death of the family matriarch.

> *The time before last when I spoke to her she was fully aware of what was going on and she said her goodbyes. So she's happy, and yes there will be lots of drama and carry on but it will be okay.*

Robyn was both uncomfortable and unhappy at the thought of lying to a client when requested to do so by the family.

> *I'm very happy not to bring it up, and I can sit quite comfortably with that but if someone asks, start asking me questions, I'm not happy. Well I don't lie. I mean, I have to avoid it or you know, and I'm not happy.*

Melissa described how she handled such situations and suggested that often the client was aware of the diagnosis. While not directly confronting the family, Melissa attempted to provide the opportunity for a family discussion.

> *He, being the patient, asks me, the nurse, some question in front of the family which will then give away the fact that he knows or he asks me to tell him. And everyone holds their breath while I'm put on the spot…. I'll fish around a bit to find out what they think is happening and what that means to them. What would it mean if they had cancer and how do they feel now?*

The nurses were sometimes uncomfortable with clients' or carers' choices of alternative treatments and pain management. The nurses believed they were competent with medications, and were concerned when they thought the best medication was not available to the client. This difference was also something that the nurses had to accept. Lynette learned to accept the clients' choice in managing their treatment and death, although it was difficult initially. She realised that the service needed to conform to the client's plan. Lynette recalled a situation where the client rejected pain medication.

> *I felt quite comfortable when I was there. I didn't mind her not taking morphine. I didn't mind her being in pain if she chose to because she had her own ways of dealing with it, with her hypnotherapy and meditation.*

These nurses supported the client and their family in their use of other treatments despite their own lack of faith in these treatments or, in the case of Ellen, a concern for the child client's quality of life. Ellen commented with a sigh.

> *I don't particularly agree with the way they are giving him the treatment in that it's a lot of oral preparations, like he has tablets crushed and lots of foods and things that are quite unusual for a child of four, and they withhold. They won't let him have things that he asks for like lollies and biscuits and things like that, which is quite sad when you think that we're looking, or we think we are looking at quality of life. They also give him subcutaneous injections which we wouldn't be doing.*

Ellen could do little about the parents’ choice and remained supportive to the family.

The nurses accepted their clients’ choices and hid their frustration or anxiety about these. The maintenance of the nurse and client relationship was important to the future provision of help and support for clients and carers should they change their minds or the situation alter for them. It was difficult at times, especially when the nurses believed they could make life more comfortable for clients by reducing discomfort and pain. The ability to relieve pain and other symptoms with medication was a skill in which they took pride and believed they had much to give. This acceptance of the clients’ or carers’ choice was something the nurses learned and practised before it could be truly given.

7.3.2 Giving control

Giving control to clients was perceived as important. Loss of control has been identified as a cause of suffering for individuals. The nurses strove to allow the clients and their family control in a number of ways. Giving control required the nurses to relinquish their need to control everything.

The client’s right of control was demonstrated in how the nurses approached them in their homes. This involved never presuming a welcome, and always observing correct, formal procedure, even when the clients did not expect this once a relationship was established with the nurse. Kirsten referred to this careful observance of the rights of the client.

> *I just have a great awareness that this is their home and I will never just walk in.... They say, “Oh you always knock.” I said, “Yes I do.”*

Being allowed into someone’s home was considered not a right or expectation, but something the client allowed. For Martha, it took on the character of an honour.

> *When I was visiting each person in their home there was a sense of being highly honoured, a highly honoured guest in the home of somebody in their personal space as a community nurse.*

This concern for the client's right of control and power extended to where the nurses might park their car. The nurses would comply with requests, thereby understanding the client's right and need for privacy, as Marie's story showed.

> *People have actually requested that I park the car around the corner so nobody sees the home nursing service care.... It's telling the world that there's something not quiet right at home that somebody's not well, and that's an invasion of privacy.*

Some participants mentioned the need to relinquish their control in order to give control to the clients. Lillian reflected on her response to clients' rejection of her suggestions for helping them. She was aware that her feelings of regret or irritation related more to her needs rather than those of the client.

> *You just think to yourself, "Well if only they'd do this, I know that would be better," but you know it's just my stuff there. So it's a wishing or a wanting them to do something I know has worked perhaps for me in the past.... It's only hard because they won't do what you want.*

The underlying feelings of the client were important in the process of taking the control offered by the nurses. The clients lost hope and this hope needed to be restored before the client or their carer could assume some control. They could not hope for cure but the nurses tried to engender hope in achieving something of value to them.

> *It's the devastating hopelessness they come up against, and it's really trying to work them into some form of hope or control or something that they can get their hands onto. I guess that's the way I go with these people. — Robyn*

Giving information and teaching skills aided control and empowerment of the client. Melissa believed that giving the clients control over painful symptoms was a powerful way of enhancing mental control for them. She spoke of how she went about this in her management of a client who was having chemotherapy.

> *I taught him the importance of his drugs and how he could gain control of the situation by controlling the amount of pills he took, and regulating them and*

> *then reducing the symptoms which he successfully did for the third one (treatment) and to gain control mentally.*

Information had to be carefully presented at times, particularly when the nurse believed the client was not receiving the best medical care for the stage of their illness. Melissa was concerned about a client whose doctor would not refer him for palliative care which she believed that he now needed for his pain.

> *At different times I would put the information in very subtly to let him know that… the opportunity [for palliative care] was his if he would like.*

The nurses gave information while encouraging clients to choose their course of action based on accurate information. They did not always do that as Marie's story attests.

> *Sometimes it's a bit difficult to stand by and know that if they wanted to take more breakthrough morphine they could do that, but sometimes they choose not to. That's a bit hard but then to step back and understand that person. It's their right to make the choice.*

The nurses recognised the need for carers to have control, especially when the client was a dependent child. Giving information to the mother of a child-client would empower a mother to continue in her mothering role and participate in care giving. The nurses informed the parents how to care for the child, the problems that might arise and how to deal with these. Ellen gave an example of how she prepared the parents of a child with a brain tumour for care at home.

> *This child had a brain tumour so we were looking at probably headaches, nausea. Children with brain tumours don't get that much pain. Probably there could have been a possibility of fitting, things like that. We talked about what if he lost or when he lost consciousness. How would you deal with that? Things about fluid and hydration so the parents had an understanding.*

At times the carers, particularly the elderly, could not absorb the information because of their distress at seeing their partner suffer, and their worry about the future. The nurses needed to repeat information in a patient, understanding way. Melissa experienced this situation with an elderly carer who was devastated by her husband's diagnosis.

> *I suppose we go over the same ground all the time with her, not with him, but with her, and she is in an absolute dither.*

Giving the carer confidence increased the sense of control. The nurses taught the carers skills such as giving injections, and gave constant reassurance that they could manage the care. Reassurance was given if the carers were worried about the availability of nursing and medical services and advised them when to call for help. Beth told of such a situation.

> *I reassured them about the physician on call being, you know, [available], that we are able to disturb him anytime night or day and that's fine, and that if they have any problems even if they feel that they've just something that can be answered over the phone and when they say, "Well what's a problem that's bad enough to make us ring in?" and I said, "A problem that's stopping you from resting or that's stopping the patient from resting."*

The nurses showed the carer or family how to operate the equipment required to manage the client's symptoms. The equipment frequently included a syringe driver, which, after being loaded by the nurse, delivered regular doses of analgesic and other medications. Beth spoke of how quickly some families could manage this with confidence.

> *I tell people giving this it all looks new and foreign, but we'll start simply and in the end you'll be telling me what to do.*

For many families it was the first death in their home. Death normally occurs in hospital so families knew little of what to expect. The nurses empowered them by preparing them for the death of the client. They informed the carer or family about the dying process and what would follow the death. Helping the family to be with the client, giving information on the legal requirements following the death, and preparing them for the undertaker's arrival and the funeral was an important part of the nurse's role.

Ellen believed preparing the parents of dying children for what lay ahead was important to her role. Because Ellen practised in paediatrics she worked with the parents of dying children. She advised them on ways they might discuss the illness with their child, and how things might be with the dying child's siblings. Ellen prepared one family before the death of their child.

> *Getting them to think before the child has died what is important to them, but also warning them that often whilst, yes, that moment of death is terrible, the moment of handing that child over, the physical separation from the body is also very difficult.*

The nurses also prepared the family for the undertakers' use of a body bag. This was a shock for families. The nurses alerted the family to the reasons for the body bag, and that they could make an alternative arrangement in the case of children. Ellen recalled a family who had lost their daughter, and did not want her to leave their home in this way.

> *This family was concerned. They didn't want her in a body bag. Well most funeral directors don't put children in a body bag anyway, so making the family know that and saying to the parents did they want to accompany the child's body to the funeral directors. Would that make it easier?*

The nurses suggested how the carer or family might be with the dying client. When the client lingered on the edge of life, the nurses might suggest that they need permission from the family to go. The nurses believed permission was necessary, particularly when the client felt the family members needed them to stay. Kirsten spoke of a situation where she believed this to be happening.

> *She was just bringing him back all the time and I had to go in and I had to say that it would be alright if they talked to him but not to ask a question so he was allowed to go and not have to come back all the time. I said, "Just talk quietly and just say your very special messages and things."*

A GP had asked Robyn to visit one of his patients and her family, as he did not know how to help this family. Robyn talked with the stressed and grieving family about how they might be with the mother at this time.

> *I said, "Look, Mum is only going to be with us a few more hours, if that long, you know. Why don't you come and sit by her bed and talk to her? If you want to go in individually this may be the last time you can talk to Mum. Just think, are there things you want to say to your mum before she leaves you?" [The intention was] ...to get them to be able to be with her and to give them a sense of satisfaction and empowerment so that a year later they will look back and think, "I said everything I wanted to. Mum died peacefully and we were there."*

This giving of control seemed to relate to the care setting. The nurses saw this as part of philosophy of community nursing, and different from the hospital setting. Sandra described the difference between the two contexts of practice.

> *Well in the hospital it's still that thing, the nurse knows best. The patient just changes when you put them in a hospital bed. They lose their control; the nurses are in control. When they're in their own home they're in control. We're their guests, and so therefore they run their own show.*

All participants in the study took this view of the home setting being the province of the client, which clients should control. Other ways the nurses gave control were seeking client consent before calling the client's doctor on their behalf, and informing the clients of the content of conversations they had with the doctors or other health care workers regarding their care. The client and family were advised of options to deal with problems and encouraged to make their decisions based on that information. The nurses, insofar as they were able, allowed the client or their family to take control. Melissa outlined how she approached clients to address those problems of most concern for them and giving them some control.

> *One of the questions I usually ask the person is, as I did with this man today, "If I asked you what your biggest problem was what would you tell me?" and*

> *his was indigestion.... So I get them to prioritise for me, and sometimes what they prioritise I don't perceive as a problem. So it's good. I learned that from someone else and I always thought it was beneficial.*

At times the nurse assumed an advocacy role to enable the client and carer to control their situation. The nurses justified this advocacy role on grounds that they were always there. The role was even more important in community settings because the client generally saw only the primary nurses, CNCs and GPs. There was restricted involvement of other disciplines to be advocates.

Lillian saw her increased knowledge on completing an oncology course as an opportunity to advocate for clients. Her increased knowledge enabled her to educate community nurses on the sorts of things that could happen, and issues of which they should be aware when giving care and treatment in the community.

> *I'm planning on doing some sort of education fairly quickly for them so that if I'm not around they'll [the nurses] at least be aware of those things.... So consequently, I think the oncology patients hopefully will get better care because they've got someone who's kind of an advocate for them as well.*

The nurses also functioned as a client advocate with the doctors, to ensure their clients received medication for pain control. They sometimes had to deal with GPs who had little knowledge or understanding of medications for pain and other symptoms experienced by clients. GPs sometimes did not see the need for, or understand the role of palliative care. Melissa recounted her frustration at having to advocate for clients to get a referral for palliative care.

> *The badgering sometimes that I have to do to get a local doctor to understand that this person would be better if only we could get them seen by a palliative care doctor and have a little bit more insight into what is happening.*

The nurses had to stand their ground to ensure the client and the carers had access to some services. The inadequate pain management prescribed for one of her clients angered Tanya. Pain made him so irritable and angry that he lashed out at his caring wife. The GP had been approached but actually suggested that the pain medication be reduced. Tanya persisted and was able to gain a more successful outcome eventually.

> *We got a new rehab doctor up at the hospital. I pot lucked it and sent him up there for a second time.*

Martha recalled her first home death in the community, where the couple was in their 80s and the wife was dying with cancer. The client was dreading hospitalisation and her husband wanted to keep her at home.

> *She was dreading having to go to hospital. She was so dreading, having been in a hospital already and having bad experiences of hard, cold beds and none of her dainty things around, 'cause she was one of those pretty dainty ladies.*

This couple received little support from the doctor, who believed the client should be in hospital and was making demands about the care required. For example, he wanted the old gentleman to measure then give his dying wife hourly fluids through the night. The thought of this intervention was distressing to both client and carer. Martha saw a place for advocacy here.

> *As it turned out my role was to be advocate to that doctor because the old fellow couldn't bear to have another fight with the doctor.... He wasn't going to force his wife to drink because he probably knew she was dying and I just said to him, "Look. Don't worry about it. I will sort that out with the doctor tomorrow."*

While the nurses surrendered as much control as they could to the clients, they maintained self control and presented a calm demeanour to the clients and carers. The nurses must be seen as calm and controlled in order to support clients perhaps feeling out of control. Beth spoke of this calmness and control she maintained when unable to c contact any doctor to order medication for a distressed client who was in pain.

> *You sort of find yourself staying calm on top, but underneath you know you're sort of cursing because the doctor is not contactable, and I mean they could*

> *be just with their young child, you know, at soccer or somewhere like that, but just out of mobile or pager range.*

Giving control to the clients and their carers initially required the nurses to relinquish their need to be in control of all aspects of care. Informants recognised that the idea of control was an illusion, as people will do what they believe right or possible when in their own home. Clients and carers were empowered by having the knowledge and skills to manage all aspects of care for which they were able, although at times the nurses accepted that they needed to intervene with others on the client or carer's behalf. The nurses were committed to the philosophy of giving control to their clients and carers, having first provided them with the relevant information on which to make decisions.

7.3.3 Giving support

Participants spoke of the need to support clients and their carers. All participants in the study were committed to enabling the clients to die at home if that was their wish. Support for the carers was essential if the client was to stay at home. This support included maintaining regular contact with the carer, accessing other services that would make the task easier for the carer, and enabling the carer to have adequate rest and respite. The nurses assisted clients to obtain equipment, financial assistance when necessary, and the services of other health professionals or clergy. Some communities had a volunteer service to provide the carer with a few hours of respite. The nurses in one area obtained funding for a night nurse when the client required constant care. This strategy allowed the carer badly needed rest and sleep. The nurse arranged short periods of respite care in a hospice when she saw the carer really needed the break.

The nurses understood the difficulties experienced by families, and felt for them. Melissa had wondered about the benefits for a family caring for the client where there was little that could be done to relieve the client's pain. She felt deeply for the client and his family.

> *I can't see the positives for the wife in caring for him at home, you know, whereas I could for many other people.... But they had a very good relationship and she cared for beautifully but it must have been just agonising for her.*

At times, there was a conflict between the needs of client and carer. There was an expectation that the wives should be willing to care for their husbands if their wish was to die at home. The nurses considered each situation and supported a wife who did not feel able to care for her husband. Women, reluctant to commit to being a carer and enable their spouse to die at home, were sometimes pressured by family or hospital staff to do so. Sandra spoke of the reaction of hospital staff and family to a woman who would not agree to take her husband home to die.

> *So family and hospital staff [said], "What's wrong? Why shouldn't she [take him home]? What a terrible woman she is," but they don't look into the reasons why.*

Sandra was often aware that a wife had been abused or there were other problems in the marriage. She supported these women when they could not assume the role of carer.

While understanding the desire of a client to die at home, Sandra, for example, could also understand the wives' position when a marriage had broken down many years before. One woman refused to participate in the caring process that would enable her husband to die at home. While Sandra wanted her client to have his wish to stay in his home, she could also appreciate the stance taken by his wife.

> *I could also see her point of view. I mean she had not touched him, seen him, nothing. They'd had a strictly economic agreement and house sharing for 20-odd years and for her to do an intimate act of caring was totally repugnant to her and she couldn't do it.*

The nurses recognised that it was not helpful to the client or nurses if the carer was not committed to their decision to care. In these cases, no amount of support would enable the client to die in peace at home. Beth told of a harrowing experience where she had had to persuade the husband and carer that respite care was their best option. The carer was drunk and unable to manage the care of her husband.

> *He could have managed to die at home but with an unwilling carer, you know. There were lots of dynamics in that family, and I was aware of them*

> *and I knew she wasn't willing to take care of him, and I couldn't stay 24 hours a day.*

Melissa recalled a situation where the carer was very tired. The marriage had been over for some time, but when her ex-husband asked the carer to come and care for him at home, she returned from interstate for this purpose. It was a difficult situation for this woman as her son was hostile towards her for ending the marriage and leaving. Melissa was aware that this carer was very tired and needed a break, but had to navigate carefully.

> *I got him [the client] to tell me how tired his ex-wife was and that he thought he should give her a break – and so I mean that was a bit of conniving but it came from him.*

The nurse, in this case, was able to support the carer, and was pleased that the client opted for respite care to relieve the carer.

At times, the situation became even more dramatic, with a carer on the point of leaving. Robyn had to deal with these situations, and believed that they happened because of the protracted time of caring which the carer had not anticipated.

> *We've certainly had some not very happy situations, and I mean you tend to pop those people into the hospice for respite fairly regularly, because you know the carer is on the verge of leaving or whatever.*

This requirement of the spouse to allow the client to die at home was less of an expectation when a wife was dying, and it seemed in the case of older males there was a perception that the men were less able to provide care for their dying partner.

The nurses' stories of male carers were few, and the males who were able to take on a caring role to enable their wives to remain at home were generally younger men. While there were attempts to support the older men, the wives were often admitted to a hospice earlier than they needed to be. The nurses recognised when the situation was becoming too much for a carer, but sometimes the client made this decision before the nurses perceived it to be necessary. Robyn told of one woman who asked to be admitted to a hospice because she believed the whole process was too much for her husband.

> *She said, "I want to die in the hospice." She said, "I know it's altogether too much for Bob and I would feel insecure as well."*

Alison remembered, with much sadness, a client who had been admitted to a hospice. Alison had been her community nurse and visited her in the hospice. Alison thought that the client's pain was not managed well and the staff seemed to be unsympathetic. Alison felt terrible leaving her client there. She was saddened because the woman could have stayed at home longer if her carer was able to manage. It seemed that for some older men the caring role was just too difficult.

> *Her husband was a lovely man, but he was like a farmer and she, she could've stayed home so much longer, but he couldn't cope with anything practical in the way of the body, this poor guy.*

The nurse's support continued even when the client was admitted to hospital or the hospice. It was important to the nurses that relationships be nurtured and maintained, and the clients and their family appreciated this. Marie recounted an example.

> *I remember going there to visit him there one day, and the daughter thought that was reassuring that we'd talked about this in the home ...then they saw me come into the hospice and they thought... we really meant what we were talking about, that it was unified care for people.*

The support continued after the death of the client, and the carers were invited to participate in the aftercare. Melissa recalled a death where the children and grandchildren had shared the caring role. This care was continued after the death. Melissa described the scene.

> *One of the other daughters washed and you know, the grandson was the chief lifter and turner, and all the others brushed her hair and ironed the new nightie and creamed her body and put a little bit of lipstick on and did the*

> *face cream, and everybody had a job. I just sat there and said, "Oh! Let's do this," or "What about we do that," and they just did it all, and it was lovely.*

The nurses took responsibility for the aftercare of the family during the early stage of the bereavement, and routinely visited the carer while that was acceptable to the carer. The number of visits made to the family varied depending on how they were faring and whether the visits actually made a difference. Lillian noted the differing pattern in her bereavement visits.

> *It used to be two to three visits, but I mean I have people who I sometimes go to for 12 months depending on their circumstances if I feel they have a need for that. Then I have people, and I think you know after a couple of visits, I think, "Wow!" and then I might leave it for 6 months.... Sometimes you may stop not because they're resolved their grief, but you just feel like you're not getting anywhere anyway and really what are you achieving.*

Counselling was available for those who sought or might need this service. The offer needed to be made tactfully, as some people interpreted this service negatively. Robyn detailed her approach when offering access to counselling, making it seem almost part of the routine.

> *I don't ask for a yes or no because they'll always say no if you're suggesting a counsellor type person. They say, "Oh no, I don't need one of those," but what I say is," Look as part of our team one of our counsellors will contact you in the next few weeks and leave it sort of open."*

Summary of giving power

Giving power and control required the nurses to be committed to accepting a client's choice if this was an informed choice and there was no risk to others. The clients and carers needed the necessary information and their confidence boosted. They also needed preparation for what may lie ahead. Having hope for small goals to be achieved and the support of the nurses gave clients incentive to make decisions. Providing support could be difficult for the nurses, given the need to consider both client and carer. Clients and carers had individual feelings and needs, and differences sometimes resulted in conflict.

The nurses needed knowledge of human nature and experience to appreciate how the client and carer might see their situations. There was a need to refrain from blame where a carer could not carry out the client's wishes.

7.4 Giving access to the sentient self

Participants gave the clients and their carers access to themselves as feeling human beings. The nurses realised the importance of their presence to the clients, and listened when the clients and carers expressed their fears and sorrows. They became emotionally involved with the clients and their families, exposing themselves to suffering.

7.4.1 Giving time to listen

Part of giving related to giving time. There was a conscious effort to find the time to give clients all they needed. Giving time was especially noted in relation to talking and listening, but not when discussing the physical procedural aspects of the nursing role. Giving time for listening and talking somehow needed justification by the nurses. They found it difficult to articulate exactly what they meant by giving. The nurses did identify the importance of giving time for both listening and talking. Melissa spoke of listening as giving, and this needed time.

> *Listening is giving you know – giving of the time to listen. I could say," Okay, let's go. Time's up. I've got to go," but I don't if I perceive the need for the person to talk then I will give them that time.*

In giving time to listen, the nurses allowed clients and their carers to express their worries, and their emotional and spiritual suffering. Robyn noted the importance of addressing clients' need to express their feelings about their impending death, and things or relationships they would be losing. Grieving began when the clients and their families realised that death was inevitable. The nurse was one person who would allow them to talk about their feelings, and listening was helpful for their clients. Robyn spoke of the helpfulness of her listening to the client.

> *When people are dying and they know they're dying and they start grieving about the loss of things on this earth, I mean, you can see that as a natural*

> *process and talking about it. Often they simply talk about it, and that seems to be helpful to them.*

Sandra also noted the value of allowing people to talk, and the importance of giving time to listen as a means of reducing suffering.

> *I find that (talking) eases a lot of suffering, emotional, psychological suffering.*

One difficulty for clients or their carers was a sense of being alone or abnormal in their thoughts, and sometimes felt guilt about these thoughts. Sandra described a carer who wished that it was all over and the client was dead.

> *A lot of people do worry that they're thinking like no one else has ever thought, or a carer that, you know, she's wishing it was all over now, and nobody else has ever had that thought.*

Carers who wished that the end would come, or became frightened or unable to cope, needed to know that this happened to others. Alison told her response to client and carer worries. She tried not to appear overly concerned as they could interpret this concern as an indication of abnormality and feel more anxious.

> *You feel they are so vulnerable, that you want to save them, and yet you know that you don't help them. You're actually making them. You can make them feel more vulnerable by showing concern, as if it is something abnormal.*

The nurses listened to the carers' thoughts about how they might deal with issues associated with the dying and impending death. Finding the time for listening to the carers was often difficult. While the nurses might sense the distress of carers, it was not always explicitly revealed during the visit. Finding a space for the carer to express their feelings sometimes occurred on the way to the nurse's car or on the street, since some carers felt they should not burden the client or take up time allocated to the clients' needs. Kirsten spoke of this difficulty.

> *I'll say to them, "How are you feeling?" you know. "Oh not too bad, not too bad," says the man. The wife says, [she] talks about food and how much she is giving him and how much he is eating and what he is doing, and they'll push the people, you know, to get up and do their exercises and stuff like that. Then they [the wives] will walk you out to the car and burst into tears outside 'cause they can't talk about dying in front of the person.*

The nurses took another nurse with them when the carer really needed time to talk. They saw that their role was to palliate both client and carer. This enabled the carer to continue looking after the family member at home, so granting their wish to die where they preferred.

The requirement for a second nurse sometimes related to coping with a needy carer who was demanding and kept the nurse in the home for lengthy periods. Lillian visited a client with such a carer. This was difficult for the nurses, who believed that the carer had a mental health problem. This carer seemed unable to process information, and so needed endless repetition. The carer was also intense and took offence when the nurse intended none. The carer refusing care from other nurses exacerbated Lillian's difficulty.

> *She wouldn't allow any of the nurses in. She wouldn't accept any help, so we were kind of carrying the load, and she was sometimes very manic and sometimes very depressed.... I learnt very quickly that I wouldn't go there on my own, that I always took Jane with me because it was too stressful to try to cope with it on my own.*

In these situations, the nurses dreaded the home visits, and were pleased if someone else interrupted their visit so that they could leave. In this particular case of Lillian's, the GP asked whether he could be included in the debriefing at the community centre following the death of the client. It seemed that he had also found this situation difficult. His arrival at the home provided Lillian with a means of escape in the past.

> *A couple of times I left actually when someone else turned up, you know. The doctor arrived one night at quarter past six. I thought, "You beauty. I'm out*

> *of here. I can pass it all over to him now." I left him with a kind of stricken look on his face.*

Having two nurses attend the client also helped with difficulties in the client and carer's relationship. Sandra spoke of a couple whose long marriage had barely survived. Home visits were stressful for the two palliative care nurses in this service, until they began visiting the home together.

> *He's the one that's dying, and she's a very active doer, and you walk in there and you could cut the air with a knife and he won't talk in front of her and she won't talk in front of him. It's now very different but this was 9 months ago, so now when we go together I deal with the wife and Kirsten deals with the patient, and that works really well… I would walk around the garden, you know, with the wife so she could just vent all her spleen, and meanwhile he could do the same with Kirsten.*

The emphasis on giving time to listen reflected the nurses' need to justify time for this activity. Traditionally the emphasis has been on nurses doing more concrete tasks than the less obvious but essential task of listening to clients and their carers.

The nurses recognised the need for clients and their carers to express their feelings and concerns, and accordingly they allocated time. While the nurses felt competent about giving medications for the physical symptoms, medication did not help the emotional and spiritual suffering. It was this form of suffering that listening helped to address.

7.4.2 Giving permission to express emotions

The nurses noted that some clients could not easily speak of their suffering or show feelings by weeping. Some of the nurses identified giving permission to express emotions verbally or by weeping as an important nursing task. The nurses gave client's opportunities to express their pain and sorrow, and to weep if they wished. Giving opportunities for this expression of emotion was one of the most common tasks for palliative care nurses.

Marie spoke of allowing people to feel sad, and spoke of the sadness of a parent leaving behind young children. She tried to think of something tangible that the client might achieve to lessen their feelings of loss and helplessness. Marie encouraged the client to think about what they could leave for their children.

> *I think allowing them to feel sad for the situation they are in but to look at what they can leave – something tangible for the children [so] once they have gone, they feel there is something very special that they can do for the people they are leaving behind, and especially the children.*

Reasons were advanced to explain why people seemed reluctant to talk about their feelings. Marie noted that the structure of the health care system worked against the expression of emotions and feelings.

> *We really need to unmedicalise death and all those sorts of things and allow people to express how they feel, and I sometimes wonder the way health systems are set up, you know. There isn't a lot of room for people's feelings when they're seeing doctors. They're, "Oh I've got to do this," you know. Everything's sort of fairly structured. But I think it's changing. I hope it is, anyway.*

Sandra's story illustrated the difficulty that the health care system had with the expression of emotion of a carer. She was asked to come to the hospital to assist the staff with a carer from another culture who was hysterical and screaming at her husband's bedside. The woman had thrown herself upon her dying husband seeking some words of love and affirmation. Sandra told her story and was obviously amused by the discomfort of the hospital staff.

> *Of course hospital staff on wards hate uproar. [They were] saying we should do something and you know I said, "No." [They said,] "We should drag her off," but she needed to have tears and I said, "No, we just have to wait."*

Some informants likened the medicalisation of death to the medicalisation of birth. Informants made the connection between birth and death by seeing a link between the midwife who assisted with the ushering into life and the palliative care nurse who helped when the individual was leaving life. The nurses saw birth and death as natural events. Participants did all they could to enable death to occur where the client chose and with people whom the client loved. Martha noted that nurses always seemed to have a place at births and deaths.

> *Nurses can never actually get away from birth or death. There will always be a nurse at birthing and there will always be a nurse at death, [or] deathing. Everybody else, all the other roles, can sort of get away somehow, but nurses are always there.*

Marie recognised the link between birth and death while preparing a lecture on spirituality. She went to the art gallery to borrow slides of paintings to illustrate points. One painting showed someone in a bed surrounded by concerned people. She had thought it illustrated a deathbed scene, but it was otherwise.

> *I thought, "Oh! Look a death bed scene," and it wasn't. It was actually the birth of a baby, and really to look at it, it could be a similar thing and I thought, "Oh! Isn't that interesting?" You know, you start life, you end life, you know, in a similar sort of theme.*

Carers could deny clients the opportunity to speak their feelings. Ellen described her endeavour to enable a 14-year-old client to talk about her feelings. The client's mother discouraged this expression of feeling and emotion. The mother and carer of this girl seemed to deny the seriousness of the situation. The young client was pressured to do better and was accused of not trying hard enough by her parents. Ellen and the other team members knew she was a candidate for palliation rather than the rehabilitation the parents sought. Ellen offered the girl the opportunity to express her feelings:

> *I said to her, "What are the problems for you at the moment? What are the worst things?" And she had actually been incontinent for quite some time and that sort of thing. I thought that might be [an issue], and she just looked at me and she said, "My parents," and I said, "Do they nag you?" and she said, "Yes. They just [nag], you know, all the time." And I mean I was ready to burst into tears. She was so sad.*

For Ellen the outcome of this interaction was painful, as the mother interpreted her concern as dwelling on the illness. The mother forbade any discussion of the illness, considering that as discouraging her daughter from trying to recover. The parents not only refused to allow Ellen to see their daughter again but also complained formally to the service that employed Ellen. Remembering this experience during the interview still caused Ellen considerable distress. Ellen's distress was not only because she felt she wronged, but also because of the unnecessary suffering of her adolescent client.

Marie considered be able to give permission for clients to speak of their experience of their suffering was a strength of the nurse.

> *I think being able to say to a person how it must have been for them or, you know, in some way reflecting their sadness instead of bypassing that [sadness] by asking a question.*

Marie considered listening to the distress of another was so difficult for nurses that they sometimes avoided this discomfort and sense of helplessness. They would change the conversation to another topic rather than staying with the emotion of the client.

Sandra raised an important aspect of how she approached the experience of listening that could help other nurses when they heard an account of suffering and felt distressed.

> *I will sit and listen if it's their spiritual suffering, but it is their journey and I do tell them that, and I do give them permission to be or say whatever.*

Sandra could distinguish between the client's emotions and suffering and her feelings, which enabled her to allow the expression of suffering by her clients.

Anger was another emotion experienced by clients that is generally unacceptable and uncomfortable for others. Alison spoke of the need for clients to express anger at the diagnosis and their situation. She believed that dealing with anger was a large part of some clients coming to terms with a bad diagnosis.

> *I think you give them permission by just what you [say], how you are, and most people don't have to express it outright.... And if you give them the clues to actually talk about that [anger], I think that is very helpful because anger actually is not a really socially acceptable emotion.*

Alison recognised that many health professionals had difficulty dealing with the anger of others, and that it was helpful to themselves and the client if they could recognise that this anger was not directed at them personally.

The nurses recognised that not everyone wanted to speak of their feelings, and they respected the client's right not to speak. Some people did not wish to speak about dying or suffering at all. Marie gave an example. Her client was a man in his late 30s who lived with his mother, and did not want to discuss his illness at any time with the nurse.

> *When he realised he was very sick he actually rang and asked to be admitted to a hospice.... He didn't want to talk about it at all, and his wish was he didn't want his mother to come and see him at the hospice, and he just spoke with her on the phone.*

The client's mother understood his way of dealing with the situation and accepted his choice.

It seemed the nurses would never shatter even the most unrealistic hopes of their client, and therefore would not force a discussion of death and dying with a client whom they believed was in denial. Lillian spoke of one of her clients who could not accept that he was dying, and refused nursing care. His carer wife also adopted this strategy, so the nurses could not discuss whether the carer wished to maintain the client at home, or any other issue related to his dying and death. They also had to stand by and watch the carer and client struggle and pretend they were managing the situation, which continued until the client and his carer were in crisis.

> *Normally we would talk about those sort of things with our clients in preparation, but because they were in such denial and didn't want to know about us or even being there to shower him or anything else, there's no way you can come in with those sorts of conversations, you know. It's not appropriate.*

The nurses believed expression of feelings helped clients and family members during this important phase of life. The nurses provided opportunities for clients and carers to be heard, and recognised barriers to this communication that needed to be overcome.

Although the nurses believed there was value for the clients in being heard, participants would never confront a client or carer by initiating discussion about their prognosis and impending death. Allowing the suffering client to express emotions safely was a part of working with spiritual and emotional pain for these nurses.

7.4.3 Giving access after hours

Because the nurses were community based there was a need to make help accessible for their clients when they were not available. After hours services provided for clients were structured to suit the requirements of the service employing the nurses and the size of the organisation. One study participant provided palliative care during evenings, nights and weekends only. In another service, the two palliative care nurses in a regional community took turns being on call nights and weekends. They also provided care during normal working hours. In the larger centres and in the city, after hours services were well structured and the nurses participating in the study from the city were not required to provide palliative care after hours. The nurses ensured that clients and carers knew how to contact the services available to them at nights and weekends.

Some nurses gave clients permission to contact them after hours in certain circumstances. This was despite the availability of after hours' services. The circumstances identified were situations where they were particularly concerned for the client and their carer, when death was near or the client and their family had little other support. The depth of relationship they had developed with the client and their family was a factor. Ellen spoke of this.

> *I very much base that decision [to provide a home telephone number] on an individual basis, and again I think it depends a lot on my relationship with the parents.*

Ellen did question whether it was the right decision to give her home phone number to a client, in terms of fairness to other clients.

Lillian lived in a regional area and generally did not make herself accessible when off duty, unless there was no one available to handle the problem. Rarely did she make exceptions, speaking of one instance where she chose to visit a client while on vacation.

> *If I choose to bend the boundaries, that's up to me and I have done that. For instance last week I went out to the hospice… because one of my clients was dying and she [had] been admitted to the hospice whilst I've been on 3 weeks leave, and I knew she wouldn't be there when I went back to work…. I mean she was one of my clients who I've looked after for like 12 months.*

It was important to Lillian to see this client and say goodbye after developing a relationship with her over such a long period of nursing care.

A further concern related to the level of care available on weekends, with the reduction in staff numbers; or perhaps inexperienced nursing staff was providing care to especially vulnerable clients and families. Robyn spoke about her concerns for clients on weekends.

> *I find in oncology-palliative care I might give my phone number out to people that I think, for whatever [reason], I mean, I shouldn't sort of admit that perhaps the service falls down, but as I said, if I think an inexperienced nurse is on or the family particularly related to and trusted me and they're very fragile in the end if someone else comes in….*

Other nurses took a contrary position, being adamant they would not encourage this contact after hours, firstly because it did not seem fair to all clients; secondly because there were competent after hours services; and finally if they continued in this way the nurses could not survive. The choice to allow contact with clients after hours seemed almost disloyal to other nurses providing the after hours services.

Beth commented on her approach to preparing the clients for the care of other nurses.

> *I always make sure they feel really confident in the next person that's coming 'cause I really do feel confident in the coworkers and I think that's great. I mean, I think it would be awful if I didn't have the confidence, whether it was like personal envy or whether it was rational, but I am. I think we have a fantastic group of after hours palliative care nurses, and our daytime nurses are terrific.*

The choice to allow the client contact after hours rather than using the services was considered as giving too much by some participants, such as Melissa.

> *If I was out there all the time nursing these people at all God knows what hours, who would I select to nurse? What favoured or detrimental few would get me, and why shouldn't everybody have the opportunity?*

The difference was marked between the nurses from regional or rural locations and those from the city. Those nurses from regional areas saw their clients as they went about their daily lives on the street or in the supermarket. The nurses in one rural location were also on call after hours. The clients and family knew where they lived and how to contact them. Clients tended not to call unless the circumstances really warranted it. For the nurses it was not just the family members they came to know, but the household pets as well. Kirsten told the story of one client who lived alone and was fearful over how she might manage. The client asked what would happen if she got pain during the night and was by herself. After talking a number of issues through, Kirsten explained the preparations for this eventuality.

> *So she showed me where the keys are kept and I was introduced to the dogs so that in the middle of the night if I have to go out the dogs won't demolish me.*

The nurses in smaller communities also saw carers or close friends of clients in public places, and so were never off duty in one sense. Beth told of this situation and its effect on her when bumping into the best friend of a client to whom she had felt very close. Beth commented that people seemed to think anywhere was an appropriate place to chat when they wanted to talk about their grief or how their loved one died.

> *I bumped into that lady's, well one of her best friends, of all places in the ladies room of the shopping centre the other day, and I came out of the ladies room feeling as though I had emptied myself of more of what I had gone in there for – because that was very draining, because she was very intense and, you know, telling me she was never going to love or care for any one anymore because of the pain involved and this type of thing.*

There was one exception among informants from the city. This nurse worked solely with child clients and their families. Although cautious about giving her home number, Ellen did give it to families about whom she felt particularly concerned and whom she believed had little other support. Ellen recalled one situation when she had given her telephone number to a family and said they could telephone if they needed her. They called during the night to say the child had died.

> *I actually went out in the night. I had been very close to this family and I decided I would go though there was nothing practical that they needed me to do, but I went.*

Ellen would extend her normal role for a family to whom she felt close.

Kirsten cared for a client who had migrated from Spain. He wished to return to Spain to say his goodbyes, and Kirsten made all the preparations that she could to help with his care on this journey. The family said they would contact her if they needed advice while away and Kirsten expressed her surprise.

> *They said, "Oh we've got a telecard, Kirsten, so that we can ring you." I said, "From Spain?" They said, "Yes, yes, we will ring you and you will tell us what to do." I thought, "Oh! My gosh."*

It seemed that Kirsten was not just available after hours but also worldwide.

Some informants stated that, in general, clients only ever sought assistance after hours when this was necessary. These informants were primarily from regional areas and when their help was sought, it was given willingly. For the remainder of the informants, being available at all times for some clients was a dangerous choice for the nurse. This choice was thought to be disloyal to other nurses and unfair to other clients not offered this contact.

7.4.4 Giving emotionally

Accessibility did not just refer to physical presence, but also to emotional access. Most of the nurses discussed this aspect, and whilst these nurses believed they were expected not to become emotionally involved with their clients, completely distancing themselves was impossible. This feeling for others seemed a basic human response to distress and suffering. Each nurse expressed concern that emotional involvement could be considered unprofessional and contrary to what they were taught. As Martha stated:

> *One of the things I've noticed [is] that nurses really aren't allowed to have feelings. They're supposed to grin and bear it. The old concept is that you keep a very strong profile when you are at work, and you don't involve yourself in the emotions of other people even though it might be a devastating situation.*

Distancing was not possible for Martha, who became emotionally involved and almost dedicated to her clients. She spoke of her experience as a palliative care nurse and the emotional involvement with clients that she experienced.

> *You know there was plenty of emotional entanglement because it is a myth that you can go into a situation that is so loaded and not have your heart in it.*

Emotional detachment was also not an option for Lillian. She considered that giving the kind of care that she believed necessary required intimacy and emotional involvement.

> *I mean people who say, "Oh you've got to keep yourself detached," and you know, "You've got to have this kind of wall." It just doesn't work for me like that. It just doesn't gel with me.*

Lillian consciously chose to disclose something of herself in order to build rapport with her clients, and believed that this did not harm her. She felt that she had done the best job she could, and had there not been that emotional connection the dying and death may have been more miserable.

> *I've never regretted giving that bit of myself away and I do believe that I provide better care.*

The nurses noted that in some instances, they seemed drawn into the client's life, and clients sought to know about the nurse. The clients they cared for in the community were usually ill and forced to withdraw from many aspects of life. The nurse's visit could take on the guise of a social visit, particularly for women. They shared their lives with the nurses and asked the nurses to do the same. This involved, for example, asking the nurses personal questions about their life and family. Robyn spoke of this aspect of nursing her clients.

> *You sort of start getting to know the kids and the family and the husband.... And they in fact want to be part of your family too, I find. It's all very well sort of saying well you mustn't talk about your family but they ask you, "How many children have you got, Robyn?" You know, "What do they do?" and what are their names, where are they going? And you'll go and see them again and they'll ask, you know, "How's the baby going?" or whatever and they want to be part of that.*

Some study participants mentioned feeling part of the family. Ellen spoke of her distress on hearing that the cancer had returned in a child to whom she had become close. Her immediate response was to rush to the child, and her interaction with the father seemed to be almost that of family member or friend rather than nurse.

> *I walked out of the doctor's office, my eyes just filled with tears and I thought, "I've just got to go round and see him," and I was half way up to the ward and Dad came toward me. I was in the corridor and I just gave him a big hug and he almost was at the point of [saying], "Come on, don't you get upset."*

Lillian made it clear that this almost family relationship was temporary. The nurses did not replace any family member. The heightened emotion of the illness and impending death seemed almost to create an intimacy that would go as quickly as it had come about once the client had died and family life began to normalise.

> *If you don't have a good rapport with them [the family] you can sense that they are uncomfortable or whatever, so if you can just sort of breeze in and out and you almost do feel like part of the family, but I don't feel that ever displaces other family members. I mean, it's only a temporary thing.*

This rapport and emotional involvement did not occur with all clients. Some times the nurses' assistance was sought only to access the equipment required for the necessary care of the client at home or to organise or administer medication for symptom relief. This usually involved the nurse returning at intervals to load a syringe driver. The client or their carer could then safely administer the medication as needed. It seemed that this was experienced for some nurses as a rejection of what they had to offer. Beth seemed to experience refusal of her offer as a rejection or a failure of some kind. She was left, as she described it, feeling empty.

> *I went in on the Saturday morning to load a syringe driver and it was sort of, "Well you've loaded the syringe driver, get out." I sort of felt the person needed a bit of personal care but, "Oh no. We take care of that." So you could just do the purely mechanical things and then you had to go.*

The nurses believed they had something to offer their clients. They accepted that some people wanted less involvement no matter how much the nurse wished to give.

Some nurses had provided all of the direct care of clients before their promotion to CNC. They were now in their new role no longer the primary nurse, and did not develop the same relationship with the client and their family. This change seemed a loss for some nurses. Lynette saw her promotion as her taking a back seat in the provision of care, and instead she focussed on ensuring that the primary nurse provided appropriate care. In her consultancy role Lynette had no power to force them to do what she thought was best, but could only advise the primary nurse.

> *Not being fantastic, not being the one who was going to get all the accolades, not being the one who would even be noticed.... I've operated differently and since then I've been totally emotionally cut off.*

The change to a more removed role had been difficult for Lynette to accept. Martha likened the clinical consultant's role to providing palliative nursing care with tongs. Other nurses in the CNC role, while missing the role of the primary nurse, took a more positive view, believing that being a consultant enabled them to provide better palliative care for more clients through their consultant and educational role with the primary nurses. Melissa explained this in the following way:

> *I'm better at my job if I can teach more people to do things and then they can reach more people and so it goes on, and that's, you know, more power than me hanging on to all the knowledge, but it's also more satisfying as well.*

The development of an intense relationship with some of the clients and their carers had implications for the nurses following the client's death. The intensity of the relationship increased when home visits were frequent and the care complicated. Most of the nurses spoke of needing to say goodbye or somehow seek a sense of completion after the death of the client. For Martha, the writing of poetry and a journal for reflection were important. This activity enabled her to identify her emotional response to the death.

> *Quite often I would get out my sense of completion through poetry or writing, and that was an important part of my own growing I guess, and also an important part of my own stabilising processes, that I could put it out there and reflect on it and say, "This is it. This is what I experienced and it was beautiful or it was hard or it was whatever."*

If Beth felt that she needed a sense of closure she would attend the client's funeral, but this occurred infrequently. She did mention a situation where she felt the need to do something more, as her relationship with the client and her family was intense. Both the death and the funeral had occurred while Beth was on leave and unable to attend.

> *I did write a little note to the husband, just on a little notepaper, just saying how much, you know, I cared about his wife and how much I admired and how honoured I was to be part of the caring process because, you know, I sort of felt as though that [closure] hadn't been completed.*

Kirsten spoke of a client with whom she felt a special rapport. The client had died and the family had chosen a private funeral, so she was unable to attend. She had just heard about this before the interview, and spoke of having difficulty with not being able to participate in the funeral.

> *I'm not going to intrude with the family. I can't 'cause they have that right, but I'm also in limbo at the moment because I haven't. I won't be able to finish, put him there and move on, but I will. But it is hard at the moment.*

There seemed to be unwritten rules about attending funerals. Attendance was considered appropriate only when the nurses had a close relationship with the client and their carer. The nurses attended funerals for a number of reasons. Firstly they wished to achieve closure through the funeral ritual, secondly to show they cared for the client and their family, and finally to support the carer. Lillian believed attending the funeral gave her something to use on the bereavement visit that could help the carers.

> *One of the reasons I go to the funeral is because I think it's really important when I do my bereavement visits that I've got something that I can talk about to the family because sometimes it is hard. They are still grieving, and they find it difficult, and if you've been to the funeral it shows them that you are supportive. It shows them that you are interested enough, too, and respect them or whatever, and it's really important [for the family] to know that it went well.*

Lillian spoke of the anger of one carer at something that had occurred at her husband's funeral. Lillian had attended the funeral. She could give a more positive interpretation of the event and this interpretation mollified the carer, leaving her happier about her husband's farewell.

Participation in the funeral ritual of some clients was important for Alison, who attended funerals when she felt needed to attend for her and her client's family.

> *I feel very strongly about ritual and about saying goodbye, about doing things to make you feel right.*

All participants remembered clients and families with whom they had become emotionally involved. Their memories may have related to the nurse having a particular admiration for a family, and the kind of love and care that the nurses saw when the client was dying. Beth spoke of how the nurses needed to be aware of where they were in their own personal lives when witnessing a loving, caring family. Beth had provided palliative nursing care to such a family and found this family's love to be inspirational and rewarding. It contrasted with her strained home situation at the time. The comparison made her own situation more difficult, as the lack of loving concern confronted her in her own life.

> *It was just what you'd sort of call a wonderful situation in palliative care, even though some of the symptoms and some of the incidents weren't very pleasant , but then coming home to a house where there was, where there was nothing, where it was empty, That's hard. I knew then to call on friends. Not that I wanted to discuss where I've been or why but, you know, I'd contact a friend... so there was some contact and some warmth.*

Two nurses mentioned treasured legacies from these memorable clients. Melissa spoke with affection of an elderly client she had visited over a long period before his death.

> *He was a funny one, a really good cook, and I have the legacy of his baked cheesecake. He gave me the recipe.*

For Martha there were lilies that bloomed each year. The carer of a client who was special to her gave the bulbs to her.

> *John gave me a box full of November lilies to plant from Barbara's garden and a lovely indoor garden full of ferns, and I still have those, and every time I see those lilies, which I hadn't had in my garden before, and they multiply of course, I always think of her.*

Most nurses accepted that it was human to like some people more than others. It was therefore interesting to have only one of the participants comment on wondering about the reasons. Lillian had reflected on the nature of the nurse-client relationship after reading a paper about working with difficult clients, and she questioned whether nurses actually discriminated against them and gave less time and warmth. The article suggested that a close relationship between nurse and client was fostered when clients were grateful, compliant and accepting. Although Lillian could argue for a less negative view of the nurse's reaction to more difficult clients, the article made her pause.

> *I read that and I thought, "Oh hell!" I thought, "Gee! I feel like that's hitting a raw nerve somewhere."*

The nurses did become emotionally involved with some of their clients, and found that entirely distancing themselves from the client and their carer to be impossible given the intensity of relationships with some clients and their families. They believed that they had been taught that this involvement was inappropriate or even dangerous for them. Emotional involvement with some of the clients and their family led to feelings of grief at times. The nurses recognised their need for closure in some instances and developed strategies to achieve this closure.

All of the nurses recognised that rapport did not develop with every client and their family. They accepted that it was impossible not to like some people better than others. Only one informant thought more deeply about why some clients and their families were viewed more positively than others were by nurses and what this might mean for care giving.

Summary of granting access to sentient self

The nurses not only gave physical care but also allowed the clients and carers access in a way that affected them emotionally. They listened to stories of pain and anguish in order to ease the suffering and isolation of the client and their carers. There was an element of risk taking for some nurses who made themselves available to clients after working hours. Those nurses who chose to do this did so in what they considered special circumstances. Two of participants had no choice in this matter as they were on call some nights and weekends.

The nurses were also sensitive to those clients who could not speak of their feelings. Enduring the suffering in silence was a choice for some and the nurses accepted this without question.

Sharing something of the nurses' lives and feelings occurred when this was considered useful for them in developing a relationship with the client. The nurses gave something of themselves to the relationship and almost became part of the family for some clients. The nurses in the study recognised this was a temporary intimacy and that once the client died and the carer moved on with their lives this relationship would end.

7.5 Summary and conclusions from Chapter 7

The three aspects of theme, giving care, outlined the ways in which the nurses gave client care. This was lived by the nurses as being all that they could.

7.5.1 Ways of giving care

There were three aspects identified that described the theme of giving nursing care in the context of caring for people who suffered. The first of these was bringing clinical skills and knowledge to their practice. Here the nurses focused on assessment and intervention relating to the relief of physical symptoms of the illness and disease experienced by the client.

They drew on available resources to enable the client to die at home if that was the client's and their family's wish. Offering power to the client and carer exemplified the philosophical stance of their practice in the community, which accepted the right of their clients to be self-determining. They strove to provide the control and support that clients and carers needed in order to be as autonomous as possible. The final theme of granting access to the sentient self reflected the emotional responses and work that the nurses gave to the clinical setting. This was the most difficult in the sense that here the nurses had to confront the most difficult issue of spiritual and emotional suffering for which there was no magical pill or potion.

7.5.2 Being all that they could

When living with the giving of nursing care to people who were suffering, the nurses were being all that they could. To be all that they could required them not just to be clinically competent and ethical in their care giving but also to be empathic and generous in sharing something of themselves. This generosity exposed the nurses to the suffering of others in a way that could put them at risk of suffering.

In being all that they could the nurses needed to be competent in their clinical knowledge. This required them to be current in their knowledge of medications, dressings and the possible complications of the disease. They were observant noticing the nuances of the physical and emotional changes of both clients and carer.

Technical competence was only part of being all that they could. The nurses had to give up their own need for control to allow the clients and carers a measure of power. They also needed the wisdom to know when to intervene if the clients or their carers were no longer able to manage. This required acceptance of the clients' decisions though it may not be the nurses' choice. Wisdom was required in keeping faith with their values regarding some matters such as truth telling. The nurses found difficulty complying with a family's request that the client not be told they are dying.

In being all they could the nurses were generous in giving control to clients and carers through teaching and supporting the clients and carers to assume as much responsibility as was comfortable for them. The nurses were patient in teaching, repeating information, guiding and praising the carers in particular to build their confidence.

There were benefits for the nurses in being all that they could. They were able to give blessed relief from suffering and comfort and support the clients and their carers. They could also advocate for them when that was necessary.

Being all they could was risky for the nurses. They were taking chances with their hearts in becoming emotionally involved with the clients and some took more risks than others did. The nurses listened to the grief and sadness of their clients. They saw the tears and they sometimes cried. They allowed the clients access to them emotionally and the emotional connection was quite intense. The nurses sometimes almost felt a part of the client's family. This closeness led to grief for the nurses following these clients' deaths. With more experience, the nurses learned to protect themselves so were careful about retaining some boundaries.

The nurses were subject to a constant pressure of always striving to be and to do better in all aspects of giving care so they lived as being all that they could for their clients.

Chapter 8 – Receiving In Return

You also do it because you get something back, and so that's nice to know that you get something back. — Ellen

8.1 Receiving

The nurses not only gave to their clients and their families but also received in return. The positive affirmations of their help in relieving suffering encouraged the nurses to continue their caring role provides insight into the emotional experiences of the nurses caring in the context of suffering. Informants revealed the joys of their role. Participants felt rewarded and appreciated, and valued the opportunity for learning from this experience. The darker side of their work and unpleasant, painful emotions were discussed. This side was hidden from others. Overall, the positive experiences outweighed the more painful and traumatic.

The honest and rich accounts of their experiences demonstrated their ability to reflect on their practice and their relationships with clients, and enabled them to develop new understandings of themselves and others. The rawness of some emotions experienced by participants rang through the text. The nurses found ways to overcome the distress they experienced at times. The messages of the nurses informed the theme of *Receiving something in return*

The two aspects of the theme were identified as:

- Gifts given.
- Wounds sustained.

The chapter is organised around these two aspects of the theme. On development of the aspects of the theme the meaning of the experience of the nurses receiving something in return was revealed as *Being enhanced.* The nurses grew because of their experiences.

8.2 Gifts given

Caring for people who were suffering gave emotional rewards. The rewarding gifts included feelings of fulfilment and privilege. There was also a sense that the learning they gained had changed them, and added a dimension to them both as human beings and in their ability to practise nursing.

8.2.1 Feeling fulfilled

The participants experienced fulfilment when giving nursing care to their suffering clients. Fulfilment and joy were associated with giving effective palliative care and being useful. Relieving the clients' symptoms, for example, gave this feeling of satisfaction. The nurses also enjoyed seeing carers and families move on after their loss.

Others did not always perceive joy and fulfilment as possible. Ellen's clients were children. People could not understand how she could bear to work with children who may die. For Ellen, one of the rewarding and positive aspects of working with children was their higher survival rate compared to adults.

> *People always ask me, "How can you do this job and all those poor children dying?" and I think it's rewarding overall to the perspective that more of the paediatric patients survive long term than the adults, and people forget that.*

Lillian's daughter could not understand how she could do this work. Lillian saw her role as making what was inevitable for the client and their family less painful, and that was fulfilling.

> *She said, "Mum, I don't understand how you do your job." She said, "It must be so sad, so depressing." I said, "Well it isn't really, because for me I enjoy it, because I know that because I looked after that person their death was better. Their death wasn't as miserable."*

The ability to relieve pain and suffering was fulfilling and satisfying for all informants. Robyn commented on being able to relieve pain or other difficulties.

> *There's personal fulfilment for me in seeing those people who may present with pain and, you know, a whole lot of things going on for them [and] I can actually do something for them.*

Conversely, the nurses felt they had failed their clients when unable to reduce or eliminate the pain and discomfort. Robyn acknowledged this response when pain relief failed.

> *There are a few people who still have some pain, and I tend to view them as a bit of a failure, like you know, we've failed them. We haven't done what we intended to do with those folk. Yeah, I mean that becomes a bit of a failure to me personally when we have someone still in pain.*

Regardless of what other people thought of the palliative care nursing role, the nurses believed that for the most part they could assist clients to have some quality of life despite their impending death, and the nurses found this fulfilling.

8.2.2 Feeling rewarded

Informants spoke of feeling rewarded when they could bring about a positive change. They also experienced a sense of reward when they observed the client and their family resolve long-standing problems. Beth noted that while there were times when she had been distressed or afraid, overall she found this context of nursing to be rewarding.

> *I have had distressing moments but I don't find it [palliative care] depressing. I find it very enriching, and it's rewarding and it's just I love it.*

Alison acknowledged there were times when the situations she encountered with clients were problematic, but there were also warmth and other gains.

> *You just get sort of forced into situations you would avoid otherwise, I think. You know possibly that's a bit of an ongoing problem in terms of the effects or ways I think are negative.... But of course the other thing is the warmth and the wealth of what you get from the privileged position in the way of positives.*

For some participants the resolutions of the clients' personal conflicts and difficult family situations brought a reward. The nurses did not instigate these resolutions, but it was part of the human drama they saw. It was as if there needed to be a neat conclusion to the client's life to enable the nurses to experience a sense of personal merit. For example, Sandra felt rewarded when she saw people become peaceful when facing death or when family problems were resolved.

> *I find that sort of thing very rewarding, to see people make their peace with themselves and maybe with somebody they've wronged or, you know, family dynamics get sorted out.*

Another of the more rewarding aspects of the role for participants was the ability to stop or reduce the suffering, and to make the dying and death as easy as possible for the client and their family. This was important for Ellen, whose employing organisation focused on the care of children. Ellen was conscious of the parent's suffering when their child was dying.

> *If I can help make that death, I guess, managed in a way the parents want, in a way that's easier for the child, so that the child's comfortable, then that's my job satisfaction. That's my reward.*

The nurses spoke of their reward and joy when helping to bring about what they referred to as "a good death" for the clients and the family. Robyn was asked by GP to assist a family distressed by the impending death of their mother. Robyn suggested to them how they might be with and what they might say to their dying mother. She did not want them to remember the death with regret and disappointment.

> *All five of them were sitting around her bed when she breathed her last and they were holding hands, they were talking to her, and when she went they were almost elated. They were happy and because Mum had gone peacefully, they'd all been there, everything they wanted had kind of happened.*

Robyn made the point that achieving a peaceful death for the client was important to both her and the family. She endeavoured to help achieve a peaceful death for the clients and those who loved them, as dying is never repeated. Robyn expressed this idea:

> *It's all gone and it's all happened. I can't bring it back and say, "Let's have a second run with Mum," you know.*

The rewards came not just from the relief of pain and suffering, but also from the observation of love, caring and strength of both the clients and their carers as they struggled through the dying process. Beth identified the relief of suffering to be rewarding, but also found the witnessing of the love in families to be part of her reward, coupled with the fact that she was allowed into this process.

> *I think one of the most rewarding things is being able to stop the suffering, which in about 99% of cases we are able to do. But I think the most enriching, rewarding part of it is just witnessing the love and the caring and the stoicism of the carers and the patients, and the fact that they allow you as a stranger to go in.*

Melissa spoke of how rewarding it was see an old woman cared for by her daughters and grandchildren. The care was given with great love and generosity. Melissa described this as being a good death and explained what she meant by this.

> *A good one to me is where the family feels they have done well, and they had done well and they'd really, it was a united thing that they had all pulled for, for the grandmother or the mother, and she'd been just enjoying their company and being there.... She was on all the drugs but it was never a drama. It was just part and parcel of caring for her, so it was nice.*

Lynette described her view of "a good death":

> *A good death to me is, from a palliative care point of view, symptoms that are well managed, a patient who doesn't die in anguish, a patient who doesn't suffer spiritually, or physically, emotionally, a carer who's able to do the things necessary to keep that patient out of anguish, and a good death is probably no surprises, no drama or pain.*

Tanya mentioned "a good death" when relating the death of one of her clients. This man had been lovingly cared for by his partner. The couple lived in a caravan park. Tanya believed that the couple's ability to stay together and use all available supports for the carer helped with the carer's grieving. A good death for Tanya required that the carer be left without regrets about how things might or should have happened.

> *I think it was a good death, and she'll certainly come out of it better than some because she's got the network in place; she's prepared to use it and the things they both wanted in the midst of the chaos and pain, which was being there together, being there at the right moment, saying all that you want to say.*

The nurses were aware that some female carers were victims of domestic violence. The violence was not usually mentioned until after the offender had died, but the nurses would frequently sense that something was amiss. Sandra was pleased when these women begin to enjoy life again after the death of their husbands. She spoke of one woman who fulfilled her caring role despite the abuse of her husband over many years. Her husband's illness had progressed to the point where he was now dependent on her. Sandra spoke of how she perceived the changing situation. This nurse created a supportive environment that allowed the carer to share painful and humiliating features of her marriage.

> *I think she's got some control now for the first time in her life and she did share that with me that he no longer beats her up. She now, in actual fact, has the upper hand and yes she feels a lot freer, and I find with a lot of women, particularly women in those situations, they just blossom and they do start to blossom after the dreaded husband dies, you know.*

Seeing women who had depended on their husbands for everything, to the extent of never even having written a cheque, manage to take control things such as paying bills and even finding employment after the death of their husband, was rewarding to the nurses.

At times, it was the prevention of *futile* treatment that gave satisfaction to the nurses. The goal was nevertheless the prevention of suffering. The nurse would advocate for the family and prevent treatment that would have extended the client's life marginally without any improvement in quality. Alison spoke of her happiness where she could influence the outcome beneficially.

> *I just felt really happy about that, that I had been able to be there and to, you know, to be satisfied that he didn't suffer unnecessarily.*

Knowing that they had helped to bring about a peaceful death and the relief of pain and suffering for both client and family was rewarding for the nurses. Unrelieved pain and suffering were perceived as a failure of palliative care, so it seemed that "a good death" also reduced stress for the nurses.

8.2.3 Feeling appreciated

The nurses sought feedback from clients and carers about their experience of the nurse's care. It was important for participants to know they had made a difference to the clients' and carers' lives. For the most part, they felt welcomed and appreciated by the clients and their families, and this, too, was important.

Martha spoke of the early years of providing palliative care and how she had had to learn quickly. Although that was difficult, the role gave her great joy. Martha really enjoyed the fact that both the service and she were appreciated and valued.

> *I really loved the interaction with people and the fact that it was such an effective service, and people used to say to us, "Why didn't we know about you months ago? Why the hell didn't our doctor tell us that we could get this sort of help?"*

The carer's appreciation was sometimes unexpected. Beth had been honest with a carer about the client's prognosis. The man planned to return to his country of origin to see his mother before he died. Beth believed his expectations were unrealistic but nonetheless suggested he might talk to the palliative care physician. On leaving the house, Beth responded honestly to the carer's questions regarding his prognosis, informing his carer that travel was unlikely, as the end was nearer than he anticipated.

The carer appreciated this truthful assessment, and Beth was surprised at the response to potentially distressing information.

> *When I got to work this week there was a tin of chocolates sitting on there, and there was a lovely note in there just saying that somehow I had started her, that I had really helped her to accept and the time I spent out at the car with her. And I always remember because she was a well presented person, but because I didn't have a spare tissue in my pocket and she didn't have any tissues, she was wiping her eyes on the sleeve of her sloppy joe and things like that... I couldn't drive off and leave her in that state. That was my only contact with that person.*

Beth realised how powerful a nurse's intervention could be. The woman followed up with a telephone call to the community centre, expressing her appreciation of the care given to her by Beth.

Coming to know the clients well, and being welcomed and appreciated made the nurses feel helpful and useful, which was important. Ellen spoke of being appreciated by her clients and how she felt about this.

> *You get to know families on a very intimate basis and to be, I guess, taken in and welcomed in and, you know, I just feel useful and they will say to you, "It's really good. It's good to have you come here to the house."*

For Beth this welcoming appreciation was also valued. She spoke of how was established, she requested a space for herself in the home when visiting the client.

Beth was touched by the care the family took to have her space ready, and felt appreciated and honoured by this preparation for her visit.

> *But it sort of becomes a little place of honour as far as I'm concerned. They've cleared part of their dining table, part of their kitchen bench so you can work.*

Appreciation of the nurse's efforts took the form of positive feedback from clients and peers. The feedback gave these nurses a sense of accomplishment at providing palliative care. Lillian recounted how it had given her confidence in her clinical ability.

> *The feedback from both my colleagues and clients underlined that, you know, I felt that I was good at it.*

It was important for Ellen to hear that she had helped, and this made the distressing aspects of her nursing care bearable.

> *I feel I've helped people because families let me know that they feel I've helped them, you know, so that's always good but yes, you need to feel you have helped, however distressing it is.*

While the appreciation of clients was greatly valued by the nurses, it was accepted modestly. The care they gave was considered to be their duty, and just what the clients and carers should be given. As Robyn noted:

> *I've got some magnificent letters back from people, you know, about all the marvellous things I did or whatever but I mean I was just doing my duty. There was nothing marvellous about it, any nurse, you know, would do the same.*

Compliments were valued, but it seemed as if the nurses did not consider what they gave in care to be more than any other nurse would give.

Clients differed in their responses to hospital care and the care given by the community palliative care nurses. Melissa felt complimented by the appreciation of one client and his carer. This client had been angry with the staff during hospitalisation. Melissa experienced difficulty in persuading him to be readmitted for symptom control. She had intervened on his behalf to ensure he was admitted to the palliative care unit rather than the oncology ward where he had been before.

> *In the community he was good with us, but then we were in daily doing for him and, not that they aren't in the hospital doing for him daily either, but*

> *maybe we just had a different approach. But they [the client and carer] rang to thank us for all we had done, and I thought that was a great compliment.*

There were a small number of clients and their families who wanted no assistance from the nurses other than provision of equipment. Most informants had a story about a client who kept them at a distance or refused their help. Sometimes the nurse understood the reason for this preference or rejection. Lillian recalled a client who did not want the nurses there at all. This man had not accepted his diagnosis, and so considered he did not need nurses.

> *He wasn't dying, that's why they didn't want our help. He was going to get better.*

Ellen recognised that some parents of her child clients preferred to relate to their doctors. She accepted this philosophically.

> *If they have a problem they ring the doctor rather than me. The doctor deals with it, you know. They'll order them another script. They'll get something. ...You can only offer so much. You can't insist they take your help.*

Sandra was mystified by one of her clients. She felt she never knew this man during the time she visited him. He was always polite but gave nothing of himself to conversations with her. This client's response was neither acceptance nor rejection of her help, but instead was hard for Sandra to interpret.

> *You couldn't get anything out of that man. He would allow you to go there. He would listen to your information about pain control and certainly took it on board and relieved his physical suffering. He would smile at you sweetly and see you to the door. That was it.*

One nurse seemed to find the refusal of her offer of help more deeply. Beth felt that her nursing was incomplete when she could not provide the care she believed was needed. She had offered help before the client's death, but the family had declined this.

Beth returned after the death of the client and again her assistance was declined.

> *They wanted me to remove the syringe driver and they didn't want any sort of post death care given to the patient.... I drove away just sort of feeling, I don't know, as though I hadn't completed. Maybe I hadn't completed it for me.*

Beth reflected on her immediate response to the rejection of her services and owned the feelings as related to her need rather than that of the carers.

Giving care in the home and the approach taken by the nurses influenced the relationship between nurse and client compared with acute care settings. It was, perhaps, a more equal and tolerant relationship because the nurse more fully recognised the primacy of the client's wishes and their rights in decision making. The nurses enjoyed being valued and appreciated. They felt both touched and greatly complimented by the appreciation of the clients and their carers. While understanding why some clients or their family might decline help, for some participants it was hard to accept a refusal of all they had to give.

8.2.4 Feeling privileged

Informants felt a great sense of privilege in being allowed to share a profound experience with families. The nurse was the health professional most closely linked with the family. Other disciplines were called when necessary, but the nurse with the clients and families was in the centre of the dying process. Sandra spoke of this special relationship and her sense of privilege.

> *Nurses are in a very privileged position that the families and the client will talk often to the nurse where they won't talk to anyone else.*

Martha spoke of the privilege of being allowed to be a part of the most personal and private aspects of a person's life and death. This sense of privilege sounded almost to be a like an invisible aura around her as she travelled from client to client.

> *Generally speaking it is a great privilege to be in a position where you are the accepted person coming in the door to do something, sometimes very personal to that person's body or to that person's mind or spirit, to interact with them. And so there was always that sense of privilege driving around*

> *from one case to another and working on the home front rather than the hospital.*

Kirsten also noted this sense of privilege. At times clients or their carers confided deeply personal and private feelings and experiences. The nurse was then privy to feelings and experiences of the client that were perhaps never shared before.

> *There's one thing about palliative care, you are allowed that liberty of sometimes stepping over, people allow you to step over, or into, areas that they're had barriers up for many years. It doesn't happen a lot but just sometimes they open a door.*

Marie believed the sharing of the client's innermost feelings at times was reserved only for the nurse. The carer or family may not have been aware of the client's emotions or secrets from the past. Marie believed being the confidant and repository of the client's secret sorrow should be seen as a privilege.

> *If I wasn't a palliative care nurse, I wouldn't have palliative care patients. I wouldn't have that experience of meeting them at that level. Perhaps when patients, when people are sick, they may in fact share more with health professionals than their own family so I think we need to see that as a privilege as well.*

Ellen recounted an experience of caring for a dying child and her family. This family valued and appreciated Ellen's care and concern, and this care and concern was reciprocated. Ellen believed there were times when her clients' parents were concerned for her welfare, and this gave a sense of inclusion and privilege.

> *It was a terrible night, the night she died, in terms of the weather. It was pouring with rain. I didn't get there until about half past four in the afternoon and stayed til about seven, and they were concerned for me driving home and things like that and, you know, the minute I rang they said, " We knew it would be you. We knew you would ring," and just sort of made me feel part of it.*

There was intimacy and trust in this relationship, and the family knew that Ellen would be there for them when they needed her.

Martha referred to this intimacy when discussing how the nurses in her team always returned to see the family soon after the death of the client. Whilst the intent might have been to recover equipment, the visit often meant more to the nurse and the family.

> *It was to go back and just be with the family 'cause often we'd have been the only ones outside that family that would have been there or seen the death or had the lead up to it that the family knew. It was an intimacy that was born of being there and seeing the extraordinary courage and effort that people go to look after their loved ones, even when they feel absolutely forlorn and hopelessly inadequate.*

All informants spoke of feeling privileged when accepted into the family at this emotional time. The intimacy and trust that developed was an experience shared by few other health professionals. Informants believed they were privileged to witness the deeper emotions and feelings of individuals that most people kept hidden in everyday life.

8.2.4 Receiving wisdom

Participants all spoke of what they had learned from palliative care. The learning was both formal and informal. Most of the nurses had undertaken further studies in such areas as oncology, palliative care or counselling. They had attended workshops and conferences to increase their ability to practise using the latest knowledge. The informal learning was provided by other nurses and their clients. The participants valued all this learning highly.

Martha noted the value of other registered nurses as role models, and she admired the allied health workers who provided palliative care.

> *There were a lot of very caring other nurses there who were good examples and good models for me, nurses and other allied workers like pastoral care workers that I really admired.*

For Beth, the learning from nurses came before she commenced her nursing career. Beth had observed nurses caring for her son over many years, and recognised the caring attributes required of the professional nurse.

> *I can be there for people, and it's something that I've learned through life and just from my experience of nurses caring for my son you know. It wasn't only their nursing skills, it was the attitude they brought to the bed and they didn't have to be the best friends or close personal contacts. It was just their professional caring attitude that made the difference.*

Martha spoke also of learning from her clients, and of what she shared with them. This learning was so profound and so precious to her that she wished that she could share the knowledge with others, but there was no forum.

> *All the things that I learned were so precious. All the things I shared were so precious with other people, with other human beings, and often that was a one on one basis, and you had nowhere else you could take that knowledge or that extraordinary experience, of maybe an early morning death or sometimes that we were almost mystical. There was nowhere to share it.*

The learning that most of the nurses gained from their role seemed more than the usual understanding of the process of learning. For Melissa, the experience was so deep and powerful that she believed this had shaped her into the person she now was. This shaping for her was not just as a nurse but also as a human being.

> *I've learned through experience, and the experience has been the patients really, not so much from my colleagues but from what I have done in situations and how I have reacted and how I've learnt, you know, and changed. Yes, so whether they know it or not, I think they have fashioned me.*

Kirsten also spoke of how the experience had changed her, and this was a profound change in terms of what was important and valued in her life.

> *What I place importance upon is not what was important to me, you know, 10 years ago and the only things I find very important to me are family and friends now. Material stuff! No. It's simplified my thinking.*

Beth found caring for a young woman who was dying revealed the need to look at one's own life. This client's husband and young children rallied round her, and Beth could see the great love the family members felt for each other. Beth thought about the importance of loving relationships in life and reflected on her life own life as it was at this time.

> *I think it made me realise how important, you've got to sort of know where you are in your personal life there, because at that stage my home life was a bit strained, and when I was witnessing all this love it was so rewarding.*

For some informants the learning was not just about themselves but also the capabilities and potential for greatness of the human spirit. This was inspiring. Sandra told of learning about:

> *The strength, the courage [and] how people do come to deal with the death, the letting go.*

Sandra believed she learned much from her clients and their carers.

> *Oh, I love it. It's certainly not morbid for me. I mean, I just get heaps out of it, absolutely heaps out of it. It is a joy. You just learn so much from dying people, and the courage, resilience and whatever else that usually carers bring to it, you know, that source of strength.*

The learning was not recognised as such a deep personal changing process for all participants. Robyn considered that the palliative nursing care role added to her experience more as a nurse than as a human being learning about life did. She seemed unsure about exactly what change the experience brought, but thought it must improve her ability to provide palliative care.

> *Doing palliation with anyone certainly adds to your experience. Perhaps it makes you more competent; perhaps it makes me better when I see the next person. Well it must. I just know more about it.*

The experience sometimes changed the participants' views about how people should behave and how they should accept their dying. Lynette, for example, had felt irritated by a client who had difficulty accepting her impending death and was terrified. The client's fear was obvious despite her being a practising Christian. Lynette believed that faith should lessen the fear of death, but after reflecting on her response to this client, she felt she had learned something.

> *I think with this woman, what she brought home to me was that it is alright for us to say, "It's okay. You've got a strong faith, you believe in whatever it is you believe in, you know. It's going to be alright." She said, "Well how do you know? I'm the one that's going," and that you know is enormous. I mean, it's a test of your faith.*

This client had not accepted the assurances that the nurses tried to give her for the relief of her fear and spiritual suffering. Lynette could see how this client could feel this way.

The nurses in the study also received additional, formal education. Some had a post registration qualification in oncology and took advantage of opportunities to upgrade their knowledge of palliation. Others had a qualification in palliative care nursing and again kept up with changing practices and knowledge through continuing education. The qualifications held by the informants included postgraduate diplomas and studies at master's level.

The employing agencies sponsored some courses, but informants sought formal learning for aspects of care they considered necessary or helpful to their clients. Employers did not always provide these courses. Melissa, for example, attended counselling courses to learn skills in dealing with people and assisting her survival as a palliative care nurse. She believed her work experiences had taught her a great deal.

> *I learned a lot of skills, survival skills for me and skills in dealing with people. And I think the job has taught me that. The job, being experience, has*

> *taught me that [I needed these skills] because there was no [advice from the system]. I've gone to counselling courses and all those sort of things as sponsored off my own bat, as opposed to sponsored by the system I work in, to teach me these things.*

Melissa had survived many years of providing palliative care and still enjoyed her work. She believed herself one of a lucky minority who loved their work.

The journey through illness and death held intrinsic interest. Sandra liked to talk with the clients about their lives and their illness experience. Sandra found this as an opportunity to learn about the mystery of dying and how those dying and those losing them experienced this.

> *That process of people rapidly working through the head stuff to reach that point where they can let the person go or the dying person can let them go or whatever. I find the psychology, the dynamics, that process really fascinating.*

Summary of receiving rewards

Caring for people who suffered brought gifts for the nurses. The gifts included feeling privileged and rewarded. Some of the experiences affected them profoundly. The opportunity to learn was also a gift. This learning included knowledge for practice, self knowledge and learning about humankind at its best. The informants saw beauty and courage in the people they met and felt inspired by both clients and their carers. The nurses experienced joy in their caring, and there was a sense of wonder and mystery that held the nurses to their practice area. The nurses valued the appreciation and gratitude of the clients and carers expressed by clients and carers in return for all they gave. The joy, fulfilment, usefulness, learning and the appreciation of the clients and their carers were all treasured gifts received in return for what the nurses had given.

8.3 Sustaining wounds

Much of what the nurses experienced was seen as favourable, other experiences were distressing and painful. The emotional seesaw could move from fulfilment and joy to sadness, anger and helplessness. The nurses were wounded by their experience of caring for people who were suffering. These painful aspects of their role were recounted.

8.3.1 Feeling sad

Participants became emotionally involved with some clients and their families when providing palliative care. They experienced personal grief and sadness from the death of the client. They spoke of distressing emotions not often shared with others. Occasional sadness was common to all informants.

Participants identified situations that led to sadness. They developed a strong rapport with some clients. Witnessing the suffering and death of these clients caused them sadness, as Ellen noted.

> *Just some children and some families you get on with better. You have a better rapport with them, so therefore you feel their distress more.*

Most of the nurses spoke of grief they experienced when they developed a strong attachment. Martha became much attached to some of her clients and had to deal with her own grief when the clients died.

> *Some of them of course became very strong attachments, I suppose, and so that would be harder. Afterwards you would be like one of the grieving family saying goodbye. You had your own grief to deal with in that process and you know there was the odd one or two or perhaps more. I mean, I don't say that [about] every one of them. Some of them I couldn't bear going into. It was like really hard work going into that home.*

The death of children and young people caused the nurses greater sadness. The nurses saw these clients as deprived of their allotted span and still having much to do. The inevitability of older clients' death was easier to bear. Robyn spoke of her sadness for clients who struggled to live when unable to accept their impending death. She and other informants told of the intense suffering they had observed in younger people who desperately wished to live. Robyn's expressed her view.

> *Actually for the person who's dying I'm usually not sad any more because you know they've got this rotting body around them and who wants to stay with it providing, you know that they are happy to leave it, but I mean if they are struggling to stay there that's another thing.*

Robyn was very concerned for a young client she was currently seeing. This young man, in his 20s, was struggling with his diagnosis, and so denying his impending death. This situation was stressful for Robyn and she feared for him.

> *He doesn't want to die. No way, doesn't want to talk about it, you know. He just wipes it right off and you know it is just going to overtake him and he's not at peace about that at all. I don't know if that causes me suffering. It does cause me a form of anxiety. It is stressful when you know the poor little fellow is just struggling to keep going.*

The sadness at times seemed particularly related to the nurses believing that younger people had much more to achieve and would never experience fully what life had to offer. Robyn could see no justification or meaning in this.

> *I tend to feel sadder, you know when they are younger but I mean there is no justification. I mean, you are put on earth for a certain amount of years and he's obviously run his course, but it was in 28 years whereas you know most of us get a course of 80-odd.*

The sadness for the nurses increased when a number of deaths occurred at the same time, which multiplied the distress. Robyn spoke of her distress at a number of unexpected deaths. This distress was exacerbated by the suicide of a client.

> *I had a couple of unexpected deaths. They weren't even cancer deaths, just a couple of sad things, and then a client committed suicide and I just found that really distressed me. I mean it wasn't as though I could have done anything. I didn't have any guilt hang-ups or anything like that but I was just so sad and I can remember crying all the way home.*

The nurses were distressed when clients committed suicide of clients. They wondered if they had missed something or had not assessed the client's needs adequately. Alison had a client who committed suicide. Initially Alison believed she had done all she could for this gentleman. Later, when hearing a radio program about depression and suicide rates, particularly for men living alone, she wondered how she did not detect his intention.

> *I guess one wonders, because not long after that I heard a program on the radio about depression in the elderly and the rate of suicide, and particularly among men who lived on their own and I thought, " Oh gosh! How negligent could you be that I hadn't picked up any of those sorts of clues for him?"*

Alison commented on the experience:

> *Maybe I have a lesson to learn.*

One of Marie's clients attempted to commit suicide. Marie reflected on why suicide might be so disturbing for palliative care nurses since the clients were already dying, suicide hastened what was going to occur. It should not be so shocking. Marie speculated that the nurses' reaction might be tied with their desire to achieve the good death for their clients and their carers.

> *I'm only wondering if people working in palliative care, not that they have control over people's lives, but we look at the death being perhaps a good death and you know people in bed, comfortable, family around them, there is that scene, and this [suicide] is not the scene of that sort of death, I suppose.*

Some informants experienced more distress when the client or carer shared a feature in common with them. Examples include the sadness experienced by Beth for a mother on the loss of her child. Beth lost one of her children after many years of chronic illness and mentioned the effect of the death of a child days before the anniversary of her son's death.

> *I think because I'd lost a child myself and even though I'm very aware, and if I find anything I've gone through myself triggers little things I acknowledge them and say, "Well this is bringing up memories" but driving home at, oh,*

> *between 2 and 3 o'clock on New Year's Eve morning, the little girl was going to be nine the next day. [New Year's Day]. On the second, the next day, was my son's anniversary, and I think that is the most distressed I've ever felt at the death of one of our patients.*

Although Beth was aware of what was triggering her emotion, the awareness did not make the situation easier for her, and she had to manage this distress.

Lillian told of her sadness about a young woman with a poor prognosis following a diagnosis of breast cancer. She thought of her daughter and how this could be her in a short period. She compared her response to the death of a younger person in contrast to that of an older one.

> *I mean, my eldest daughter just turned 15 and I'm thinking, "Well that could be her in 5 years or 10 years" or whatever, you know. That's the reality of the situation.... When it's somebody young it is either you, or your friends, or your daughter and it just makes it, it brings it that little bit closer and it makes it more scary.*

Lillian recognised her fears about death and dying. Death seemed close at times when someone like her, or her loved ones, was dying.

The sadness experienced by the nurses stayed with them after they left the client's home. Robyn spoke of her experiences.

> *I often drive away from a client's place with tears running down my eyes because I am really distressed for them.*

The inability to maintain dying clients at home, if this was their wish, also saddened the informants. Part of community palliative care nurses' mission was to maintain clients at home when the client desired this. Kirsten spoke of a client who wished to remain at home but his circumstances prevented it. His wife could not assume the role of carer, and her needs and rights deserved equal consideration.

> *I find it's really hard when you can't give them what they want 'cause they don't ask for a lot. You know, to be able to stay home is not a lot is it really when you think about it.*

Kirsten was saddened when she could not help bring this client's wish to fruition.

The informants had to accept that they could not always help. No matter how hard the nurses might try, they could not make a perfect world. Sandra spoke of accepting that some situations were unchangeable.

> *I'm a very accepting person and very accepting of different situations in life, so I don't go out there with any illusions that everything is gonna be fixed up and made nice, you know.*

The home situations were not always ideal. The relationship between the client and their carer was sometimes hostile. The nurses tried to patch up the cracks and enable the client to remain at home. Robyn recognised the impossibility of solving such a long standing problem for a family.

> *If there's such a hateful relationship beforehand, I mean you can't really do much about it, and you try, well you know, you sort of palliate the both of them, really, to try and keep the carer in the home to care for the person who is dying so that they can stay at home, and you pull in a lot of backup.*

Sadness was very much a part of the participants' life, and that was a part of being a caring human being. There was sadness and mourning for the loss of clients with whom they had a special connection. The nurses were saddened by the premature loss of life for young people who had dreams and plans that would be unrealised. With the sadness came an acceptance of situations that they could not change.

8.3.2 Feeling alone

The nurses discussed their isolation. Community nurses often work alone. There was sometimes no one with whom to talk upon returning to the community health centre. This situation made it difficult for the nurses to debrief in the workplace. Debriefing was not readily available for most of the nurses. All participants discussed the problem of not having debriefing when needed. Formal debriefing was usually arranged for staff as a group when the care of a client had been especially harrowing for them.

Marie noted how the situation was different and difficult for community nurses. These nurses drive from home to home when seeing clients. If there was a disturbing incident, they had to make an extra effort to find someone to talk with.

> *Perhaps if you are working in a hospice or hospital situation you always have somebody around that you can debrief to, and that's not always available to a community nurse.*

Tanya recognised her need for debriefing at times but was reluctant to rely on peers even if they were available.

> *There isn't often a place for debriefing properly because you feel your peers have already been through enough that day, that in fact if there's a need for you to be debriefed at the end of a particular day, so you can't, sort of.*

Tanya felt that her fellow nurses had their own issues. She was reluctant to burden them further.

Debriefing was not always possible, particularly for nurses who worked on call evenings and nights. Beth spoke of how the nurses may have to carry distress throughout the night or all weekend after a disturbing event.

> *It makes all the difference if you can walk out there feeling as though you have offloaded, you know, because out there on your own isn't like working a shift in a hospital where everyone else was there with you while this was happening. Or if there's a critical incident there's usually three or four around the bed assisting, or you know people are immediately aware.*

Some of the nurses would contact the local hospice to find someone on duty and with whom they could talk. This contact was helpful when they needed someone to listen to them immediately, but was not always possible.

The nurses spoke of how they managed to move from one client to another without taking the sadness with them. They found refuge in the cars they drove. They sometimes shed tears and collected themselves before moving on to the next client. At times it was difficult for the nurse to move on to the next client when feeling distressed. Lillian acknowledged her need to discuss disturbing events before she could move on.

> *If I need to debrief I need to do it now, you know, I need to do it fairly quickly… virtually before I go on to my next client.*

Sandra acknowledged that while she did not consider her distress required her to seek debriefing, she was eager to talk over her clients with her fellow palliative care nurse. This sharing was a form of debriefing for her, which she acknowledged as something to which she looked forward.

> *Although I might say that I don't carry it, I still can't wait to report back to Kirsten, to share with her, you know, and even if it's just to say, " Yes, he is doing it hard. What do you think we should do?"*

Lynette illustrated the difficulty of accessing debriefing for the community nurse when it was desperately needed. She recalled visiting a young woman late one Friday afternoon. This dying client was soon to give birth. She was experiencing severe abdominal pain and Lynette was unsure if the pain related to her medical condition or the birth. Lynette needed other services to ensure that the client received appropriate care, but she had difficulty accessing necessary assistance for the client, much less debriefing for herself. Lynette was going out to dinner that night. She was late for the dinner and in great distress after just leaving work.

> *Like, the husband of the hostess met me at the door and I just started weeping straight away and said, "Oh! I've just had the most terrible experience," and he never talks. He just stood there with the shoulder. And I just wept. That was probably what I needed. I probably did debrief instantly with someone who wasn't going to judge me and who didn't know anything about the situation.*

Lynette felt embarrassed about even recollecting this experience, and thought that other guests might consider her insane. She had felt that admitting a need to debrief was judged by her peers or management as a weakness rather than a normal human need.

Some of the nurses had found their own way of debriefing and dealing with difficulties with management of clients or unresolved issues by arranging supervision by a more experienced practitioner. Beth paid someone for this supervision.

> *Yes I pay for it myself and she writes it down as supervision so I can claim it on tax, but I still pay. I mean, I only go and see her about every 3 months now, but she has always said, "If you have anything particularly hairy [call me]."*

Kirsten arranged supervision by one of the palliative care physicians from the hospice in her community.

> *I'm going to the hospice with the doctor and I saw her on Friday and that's just, oh yeah, I was there for 2 hours and [it was] just fantastic you know. That has been a life saver for me.*

Melissa felt she did not benefit from group debriefing sessions, and instead would talk with a few old and trusted friends with whom she had worked in the past.

> *I never talk work at home, but mainly to colleagues.*

The nurses rarely talked about their work at home, and so did not have that outlet. They emphasised they did not mention people's names or identify them in any way if they ever spoke of work at home. A few believed that, while their partners may be proud of them, they really understood little of their role and what it required of them. Ellen, for example, believed that while her husband did not really have an understanding of the true nature of her work, he was proud of her and tried to support her when she needed it.

> *He has some understanding of it and he'll often, I say often, but he's certainly, he's very proud of what I do. He thinks I do a very hard job but he doesn't ask the ins and outs of it.... He tries to support me when I'm sad.*

Beth believed her husband had no understanding of what her practice entailed, and it seemed as if there was no support for her in the home. From Beth's perspective her husband had no idea of the nature of her work.

> *You know my husband's got no idea of the intensity of the work that I do. I think that he thinks because I go to work fairly neat and I come home looking fairly neat, even though I often feel as though I want to have a shower and throw everything in the washing machine because it hasn't always been very clean and neat and tidy.*

Lillian sometimes longed to have someone in whom to confide. She was mother to two teenaged girls and did not feel that she could confide in them. She wished for an adult confidant.

> *I do have a partner that – he's not often home – so I don't have that adult to confide in, not that I would, you know. You are not supposed to talk about [your clients] but you know, sometimes it's good to have an adult to say to, "Oh! I've had a shit of a day today." You can say that to a teenager but they don't have the same understanding, you know. They haven't had the life experience to really know what this means.*

There were times when Lillian did need someone to show some interest or concern about her, especially after a sad and trying day. She described a situation where she could not contain herself, and demanded some attention.

> *Somewhere in the course of the evening I blurted out, "And nobody bothered to ask me how my day was, and the fact that I lost a 6-year old client is totally irrelevant, isn't it?" So I was obviously having a bitch about it. To think that, you know, like I'd come home and done all the usual things and hadn't said anything and perhaps I should have, but nobody bothered to say to me, "Well how was your day?"*

The nurses were sometimes burdened by a day's events, but simply went home and carried on without anyone showing interest or concern.

Alison was threatened with physical violence. She was visiting the client in his home when he became violent and went to strike her. She had been afraid and went home in great distress. The attack was unexpected. It came at the end of the day when there was no one at work with whom she could debrief. She had thought she could cope with her reaction, but then her teenaged daughter needed to ask her about something. Alison felt overwhelmed. Normally she was reluctant to talk with family about her work but on this occasion she could not control her emotions.

> *I just had to say to her, "Look, I'm really sorry." And then I just burst into tears and I told her what happened and she was actually wonderful, she really was. She just hugged me and cuddled me, and I really needed that.*

For Alison, comfort had come from an unexpected source and from someone whom she always tried to protect from the negative aspects of her work.

Most of the informants did not share their feelings of sadness with their husband or families. They shed their tears alone. Robyn was one. She spoke about what led to tears and sadness for her, and how she kept them hidden from her family.

> *It certainly does affect me emotionally when I've got a lot of sad things at home, then add to that a death or what I perceive as being sad, you know, something with my clients then that makes me more emotional or more tear sheddy as well. But no one would ever see any of this. No one would be aware of that, not even my husband or family.*

Robyn shed tears in private. If feeling tearful during the working day, Robyn would cry in the car where her clients or co-workers could not see her. The tears at home fell when she was in the shower.

Martha's partner was supportive, and had been from the beginning of her career in palliative care. Martha spoke lovingly of her family and their support when she returned to nursing fulltime after being at home and available to them in her early years of marriage. Her husband and three school-aged daughters helped with household tasks and encouraged her to take this challenge.

> *So all my jobs were allocated and I went out there free and got on with the nursing, which was terrific.*

Overall, there was a sense of isolation bordering on loneliness for most informants. Much of what they did and how they felt was hidden, and there was little opportunity to share emotion. Feelings of sadness were not what they wanted to bring to the lives of their family or friends. The absence of opportunities to debrief, the lack of appropriate supervision and their practice in the community contributed to feelings of being alone.

8.3.3 Getting tired

The nurses all spoke of the fatigue they experienced, which at times was overwhelming. One factor mentioned in relation to tiredness was when the nurses had been giving too much of themselves. Melissa spoke of this fatigue and its effect. It was obvious during the interview that Melissa was tired. She yawned frequently, and her fatigue was obvious to the interviewer via her posture and voice.

> *I'm dead in the head today. I'm tired and I can't think, you know, and that's a sign when I'm, you know, have a lot of new and heavy sort of problems to sort out. I get tired. I get mentally shut down.*

The tiredness was such that it was experienced as painful and dangerous. Martha spoke of tiredness and acknowledged it as something that all nurses experienced.

> *I would think that every nurse alive has experienced extreme tiredness and how very painful that can be, and how dangerous it can be.*

For Martha the fatigue was such that she almost had no other life outside work at times. She spoke of the effect on fatigue on her life.

> *Overtiredness is awful because your sense of perspective goes. You can't think straight and you become easily irritated. What else happens, you actually lose the ability to sleep*

Beth was employed part time by the palliative care service, worked evening shifts and was on call through the night. At times, she had no sleep throughout the night, and was delayed in the mornings providing a handover and writing her report. This was tiring. The fatigue made her obligation to a second, casual position sometimes impossible to meet.

> *You're up all night* and *then maybe at the centre until 11.30 and then you'd be back there about three in the afternoon to get the afternoon load for that evening. There were two nights when I didn't even see my bed. All I was getting was about 2 hours nap on this lounge.*

Fatigue was considered also to affect nurses' feelings about seeing clients and being able to listen effectively to clients or carers. Lillian spoke of a period of exhaustion when she did not feel like seeing clients.

> *If I had a choice of seeing a client or doing something else, I would have done something else.*

Whilst she felt that she performed appropriately and adequately in giving care, it seemed that she lacked her usual enthusiasm.

Kirsten believed that nurses working in such an emotionally draining environment needed more recreation breaks in order to cope with fatigue and avoid burnout. In addition to her standard Monday to Friday working week, Kirsten was often on call after hours, meaning she could not enjoy her leisure through being constantly alert for the phone. Kirsten wanted to change her situation, believing she could not continue in the same way.

> *I'm tired. I know I'm tired and that's what I'm saying. A month's holiday when you are working fulltime palliative care is not enough.*

Kirsten was negotiating for additional leave without pay, as she would rather not finish her working life or leave palliative care because of fatigue. The determination to gain additional leave was strengthened after the fatigue she experienced over a busy Christmas.

> *I didn't even go to church on Christmas day this year, which is really off. That says it, 'cause I just didn't have the energy.*

The need for frequent breaks was a common theme.

Christmas was often busy for the palliative care service. Staff applied to take leave, and because of funding shortages, was not replaced. Kirsten had found herself in this situation, the additional workload contributing to her fatigue.

Another factor was the driving required for nurses providing services in rural areas. These nurses sometimes drove an hour to visit a client. This added to their day's work and interfered with family life. Lillian raised this as an issue. For a mother raising two children, arriving late home of an evening was a problem.

> *So you get home late and everything is out of kilter, you know. Dinner is late, you're exhausted and you've just driven a few hundred kilometres and it all adds up.*

Excessive fatigue signalled to the nurses that they needed a vacation. The fatigue never seemed far away. Although a holiday helped, the nurses claimed to need frequent breaks because feeling of relaxation soon vanished on their return to work. Sandra spoke of this.

> *I just think you are stretched to the limit, so I sort of think, well I feel all nice and relaxed after a holiday, but it doesn't take long to feel in a state again. And I was dreaming about it last night, thinking, "How am I going to get all this done?"*

Lillian noted that her fatigue increased when she assumed the role of CNC, was carrying a large case load, had additional tasks in her personal life, and a very difficult carer to cope with. She had to seek assistance from her supervisor to enable her to continue.

> *I was tired, you know, I mean I think it was a combination of that plus, as I say, doing two jobs, feeling a great load and responsibility on my shoulders*

> *and plus, as I say, the few weeks before going home and not getting any rest, any reprieve, because I was doing all this other stuff.*

The fatigue experienced by all informants was almost numbing. In order to cope with tiredness the nurses had to recognise when remedial action was required, such as taking leave. They could do little about organisational factors, but they did try to alleviate as many of the pressures as possible.

8.3.4 Feeling threatened

The nurses were unaccustomed to hostility from clients or carers. When it happened they were distressed. Whilst they recognised that hostility was often misdirected anger, it was nevertheless hard to bear. Kirsten recounted a conversation with the palliative care social worker after an interaction with a hostile carer.

> *I said, "I haven't had misdirected anger for a long time." And she said, "No you haven't, have you?" She said, "You're used to accolades and warmth and all that."*

Kirsten recognised that her strategies for dealing with the overtly negative emotions of clients or carers had deteriorated through lack of practice. Most often, anger from the client or carer was assumed to be lashing out at the situation rather than a personal attack on the nurse.

Ellen recognised that anger was sometimes justified. It was not a response to any action of hers, but perhaps was anger towards the medical staff or the organisation.

> *I'm really on side with the family and I feel a lot of their anger is justified, but at the same time their anger is attacking the institution that I work for.... you understand possibly a little bit of why those rules are in place and you either feel constantly on defence, or you just sit there and take it. At the same time it's constant negatives and it's hard.*

Ellen tried to avoid feeling defensive. She felt empathy for her clients and chose to listen to their unhappiness even though this was difficult.

The threat of physical violence was very frightening for the nurses, who were frequently alone when making home visits. If there was an expectation of violence they visit with another nurse where there was a possibility of violence or could refuse to provide the service. The threat of violence was not, however, always predictable, and unlike the institutional setting there were not always other people around or an emergency bell.

Beth felt threatened by the son of a client who had died. Beth was washing and dressing the dead mother before the arrival of the undertaker. She had difficulty placing the client's dress over her head. This led to her bending the client's head somewhat awkwardly. The client's adult children were there and the sons had been drinking. The way Beth was handling his mother offended one of the inebriated sons.

> *He said if I did this to his mother, if I didn't do it the bloody way he said, he said he was going to knock my bloody block off. Just drunken rambles but you know he was towering over me.*

This was very frightening for Beth, and although she presented a calm face in the client's home, this was not how she felt. After leaving the house and getting into the car she could no longer keep up the façade.

> *I'd had to stay so calm despite the chaos in this room and I got into the car and I just started sobbing, and I thought, "How am I going to get this car from the client's home to mine?"*

Beth was shocked as she had never experienced violence before. It was late in the evening and she had no one with whom to talk about the event for over 24 hours. Her distress was intensified by the inadequate support when she reported the incident.

Alison, like Beth, was very frightened and distressed when a client unexpectedly turned on her.

> *I've never been so scared as I was on this occasion. I was visiting a man on his own and he turned on me. He got, he sort of got hysterical, and I was just waiting for the hit, which didn't come, fortunately, but I was so scared.*

What Alison found so frightening was not just the client's anger and threat but her response to the situation. It was as if she had never felt so powerless, lacking in control, small and helpless.

> *What is scary is not so much the anger but in this instance my helplessness as a smaller woman with less physical strength, and I suppose the conditioning as well that as a woman you are helpless. It struck me that I suddenly became this dithering female. It was a clear as anything and there was no part of me wanting to stand up to him and say, "Just stop this rubbish and calm down and let's talk about this." Looking at him, I couldn't because I thought that would be stupidity.*

The daughter of a client verbally abused Lillian. She had received a referral to visit the home with the intention of undertaking an assessment and assisting with the relief of the client's symptoms. The response of the client's daughter was unexpected. She misunderstood Lillian's role, implying that Lillian was going to force her mother into a hospice. In order to make her purpose clear, Lillian had asked whether she could sit, and she requested that the carer also sit so they could discuss and clarify the situation. Lillian sat but the carer refused and stood over Lillian. On Lillian telling the carer she felt threatened, the reply was as follows.

> *It was something like, she came back at me, "I don't care if you're feeling threatened, you know, you mean nothing. You're absolutely zero here."*

Lillian left the house feeling a mixture of emotions in response to an unexpected and inappropriate reception. She was further angered and confused because she had spoken with the carer's husband on the telephone about the purpose of the visit. He was a medical practitioner and had actually sought the home visit. During the verbal attack and intimidating posture of his wife, he said nothing in defence of Lillian.

> *I drove around and sat in the park and I thought, "Bloody hell!" I felt like I had been eaten up, chewed up, spat out, you name it. So I rang the hospice 'cause they had given me the referral.*

Lillian needed to speak with someone about this experience immediately, having found previously that if she did not deal with these emotions she could not go on to the next client or function properly for the rest of the day. She was able to gain some comfort when talking with the nurse from the hospice service.

The nurses generally felt appreciated by their clients and the carers. Verbal aggression was unsettling but the threat of physical violence was terrifying. They felt vulnerable when threatened. Community practice made them more vulnerable because there was rarely help at hand. The nurses experienced a sense of hurt, through perceiving themselves as well intentioned, and struggling with a difficult area of practice.

8.3.5 Taking on the suffering

Sometimes nurses took on or shared the suffering and grief experienced by the client or their families. Some informants reported suffering themselves or seeing other nurses deeply affected. Martha believed it was generally held that nurses were always composed and avoided emotional involvement or display. Martha believed the nurses' detachment was a myth and a burden for nurses, making them feel unprofessional when they experienced distress and sought assistance. Martha had left nursing in the 6 months before the beginning of the study.

> *A lot of mythology around nursing and particularly in the palliative care field and the lack of understanding are around the myth that nurses don't cry; that nurses cope no matter what; that they're seen to be always together; never vulnerable, you know, and to me that is a bed of suffering for nurses; that they're not given that human ability or human permission to be like other human beings wherever they are, whatever they're doing and to take time out every now and then to express their emotion in an appropriate way, in an appropriate place.*

Alison also had left palliative care 6 months before being interviewed. The suffering she witnessed became harder for her to bear, and her coping ability lessened with time.

> *I think that I am more affected now than I ever was by a person's pain in every sense of the word "pain," but even physical [pain], I can't stand*

> *physical pain. I can't stand witnessing any one in pain and I think it's got worse.*

Marie spoke of witnessing of suffering. She saw her response as a way of understanding and feeling for the client or carer.

> *You feel the pain as well and feeling the helplessness, but in fact you've got empathy then with the person because that's probably exactly how they feel as well.*

The suffering of those whose cancer recurred when they had believed they were cured caused Robyn the most distress.

> *I suffer most, really, I think when people have failed to be cured by their treatment, and they re-present months or perhaps a year or two down the track, and the doctors found metastases, and I see the anguish and disappointment.*

The informants were not always aware of the extent to which they were affected. Robyn commented on this in her second interview. She did not consider herself greatly affected, although she had left palliative care during the study.

> *I don't know whether I take suffering really heavily on board myself. I shed the tears and I think that resolves most of it. If there's too much happening at home and at work and I mean this would be geared with pressure and stressy things as well as deaths and whatever. I think it probably gets me almost into an anxiety state, which is manifested by waking up a bit earlier in the morning. I don't sleep as well.*

A number of the nurses had stories of others they saw who had been deeply affected by their work. Lynette recalled working with a primary nurse in her CNC role. She had been called to see a client who was refusing pain medication. This was difficult for the primary nurse less experienced than Lynette was. Whilst Lynette believed the nurse was suffering she also believed that nurses must learn to accept clients' choices.

> *The suffering of the nurse was worse because she can't see her way through it at the moment, and I think it will take a long time for her as an individual to grow up. It's a growing up process, being able to allow people to be responsible for their own pain and their choices.*

Marie was an experienced palliative care nurse, and reflected on her practice exploring her own emotional response to people and situations that caused her some concern or puzzlement. She had learned to be wary and to identify what was her sadness or tension, and what was emanating from the client or carer.

> *The other thing that I've found, I think, is that sometimes you're walking into a situation.... Sometimes their tension, sadness comes back on you.*

Kirsten noted that while she thought she did not take on suffering, on reflection the suffering crept into her life by stealth. She gave an example of the heaviness and suffering of her current work load.

> *Yeah, it's a suffering and I think you do take it on, as nurses you take it on. It's insidious. It's only when you stop sometimes and think about it, you know.... It's like this weekend another old man that I had. Oh! He wasn't old but he deteriorated really rapidly and he was admitted to the hospital. I had eight of them with cerebral metastases. Eight patients, and they're really hard and so he was admitted and he died on Saturday afternoon and his wife was found dead yesterday. And so we are having a double funeral on Thursday.*

Whereas Kirsten did not want to stop and think about the suffering, she could not help wondering whether she had done all that she could for the client's wife who died the day following the death of her husband. This reflection on the suffering she saw did affect her even though she tried to keep it at bay.

Alison spoke of the visual impression she had of suffering. The images of these people stayed in her mind as vividly as when she first saw them.

> *The hard thing for me is the suffering bit of it is a lot of what I see. It's an imprint, and I guess with my mum it was the same. I have this dreadful*

> *memory of how she looked, which is a shocking thing to look at, and I've had the experience with other people when I thought to myself, "How will I ever get used to looking at them."… It's a most strange thing – this thing of the pictures in my head.*

Alison's mother had died from cancer, and Alison had nursed her at home before choosing to work in palliative care. This had been a particularly painful time.

In Martha's view, it was impossible as a human being not to be devastated by witnessing the suffering of others.

> *I don't think there would be a human being in the world who doesn't writhe when they see someone else in pain. It's just part of the human condition that we actually transfer the pain somehow. We can't stand seeing other people in pain.*

The pain and suffering somehow were transferred to the observer, according to Martha's experience. Not to be affected by another's suffering was inhuman in her eyes.

It became apparent that no matter how the nurses tried to exclude their emotional response to the suffering, it would seep into their lives, and it was something of which they had to be aware and acknowledge in order to survive. The feeling they had for the other was a mark of their humanness.

8.3.6 Feeling helpless

The nurses could not always improve the client's situation. These occasions brought feelings of helplessness and frustration. Beth spoke of her frustration and helplessness when unable to contact a doctor to prescribe pain medication. She provided palliative care after hours and on weekends, and these were the most difficult times for contacting the client's doctor.

> *You know, I'll be getting medication but of course I have to get a doctor's order so they're [the carer] looking at you to get this doctor's order, and to stop, well to stop the suffering of the patient, plus their anguish of watching this patient suffer and then you're on the phone for an hour or so, you know,*

> *and paging and phoning and trying every which way just to get hold of a doctor to get an order.*

Lillian recounted a similar story where she had been unable to obtain the medication for a client because of difficulties obtaining a prescription and accessing a pharmacy. The client lived in a small community some distance from her home base, so she was unable to return until the next afternoon. Lillian was distressed that the client had not been relieved of the pain earlier.

> *I could have had that man out of pain and sedated totally the night before, and I didn't get back to him until the next afternoon at 3 o'clock, so I was feeling bad that it hadn't happened the night before.*

Melissa could never forget a client she had when she first began in palliative care. The client's symptoms could not be relieved despite many measures. The admiration she felt for the client and his carer made the situation even worse for her when failing to relieve his suffering.

> *I think there was a helplessness there, you know, and a frustration. Far be it from saying that he was a nice man, because you would do the same for some one who wasn't nice either. But he was a nice man, and therefore it made it even more difficult to watch the family [and] stand by and feel helpless and know there was nothing we could do.*

The inability to improve the situation for the client or relieve their pain and suffering led to feelings of helplessness and failure both personally and in relation to the palliative care service. Robyn felt this way when unable to relieve pain.

> *That becomes a bit of a failure to me personally when we have someone still in pain.*

Beth reflected on a situation where her client's symptoms could not be controlled. She was concerned also about the attitude of the client's doctor.

> *One of the deaths was one of those; I suppose, I've had two or three in 6 years, where symptom control could not be obtained. It was just horrendous and this man was only 49 with two young children, 16 and 18-year old daughters, a young wife. He fought his illness all the way, wasn't going to give in to it. He was going to win, and he was under a doctor that doesn't allow people to say when, you know. If this doctor had his way you'd have a blood transfusion as you die.*

The doctor's failure to understand that sometimes treatment and refusal to admit defeat caused additional suffering worsened the situation for Beth as the nurse.

The nurses were relieved when the struggle was over for clients who had suffered much indignity and pain. Lillian spoke of the death of a client to whom she had felt close and had known before his illness.

> *You know they are going to die, and they know they're going to die. Quite often it's a relief for me as well, not just for the family, but it's like you don't want to see them suffering. I was so glad when Jack died, you know. I thought, "He's unconscious." I was so glad when he died, and the same with the other chap. I just think, "Wow! That's great. I'm glad they died. They're not here any more to put up with this crap."*

Alison felt helpless and a failure when first told by a client that death was preferable to their current state of being. It was more difficult for her when she was striving to do her best for the client.

> *I think it's always hard the first time when they say, "I'd just like to be dead." It sounds a terrible thing...and you're doing your best. You feel a real failure when they do that.*

The nurses did not believe in active euthanasia, and considered that clients expressed wish to die when a problem causing the suffering had not been recognised and addressed adequately. Alison was one spoke of this.

> *I'm very much against active euthanasia, because mostly when people talk about it there is something you can do to improve the situation and they're not always saying that they would actually like to be dead, I don't believe.*

The client's unrelieved suffering was distressing for the family and the nurses. Witnesses to this suffering also suffered and felt helpless.

8.3.7 Reliving one's own past suffering

Some participants found that witnessing suffering and dying in the clinical area compounded their personal feelings of grief and loss. This response may have related to an event from the distant past, or something more recent. Palliative nursing care became more stressful and difficult after the death of one of their family members. The suffering and dying that they were confronted with in the clinical area reawakened and increase their own, personal grief and loss.

Robyn found herself unable to continue palliative nursing, leaving before the completion of the study. Losses and illness in her own family affected her ability to provide care in the way she believed.

> *Two years ago I would have said, "Oh no! My family doesn't affect what I do at work," but this year, or in the past 12 months, it has been affected. You know it affects me, as I said I'm probably weepier now, and I find that almost, I have trouble concentrating and things like that, and I've not had that before and I think that's sort of outside family things.*

Marie raised the possibility of past suffering being recalled. She was a highly experienced palliative care nurse who felt better able to deal with the resurrection of her own grief, because of her past experience.

> *It's not that the pain would be any less. It's just that maybe you can recognise it and deal with it a bit more. I'm not sure I know what I mean, just in terms of your own grief for things that have happened in your own life. These things continue on through your life. The pain doesn't get any less but maybe you've worked out strategies and maybe you're recognising things more quickly because you've been there before.*

Marie knew how one's own past suffering could be revived by witnessing suffering of others in the present.

Melissa was aware of how a nurse's personal grief can affect their work. Melissa was an experienced CNC working with primary care nurses. She acknowledged her responsibility to the less experienced nurses, trying always to recognise when they were having difficulties, and endeavouring to support them. Melissa noticed the effect on one primary nurse following the death of her father.

> *One of the nurses lost her father about 8 weeks ago and she is finding hard going.*

Martha spoke of caring for a client who reminded her of her own mother. The resemblance was heightened by other circumstances. The client's daughter returned from another country to see her dying mother, which echoed Martha's own experience with the death of her own mother.

> *I made great friends with her daughter who came over from America and that was another thing. I suppose I identified with the daughter because I had my own mother in another country dying, and I knew what it was like to be in another country when your mother is dying and not knowing what is going on from one month to the next and not knowing when to go home and if you should stay a little longer, and will she die this time.*

The death of her mother was a painful memory for Alison and coloured her response to GPs she encountered in her palliative care practice. Alison had sought the truth about her mother's diagnosis, but the family doctor who had actually delivered Alison lied to her mother. Alison told her mother what the oncologist had said when asked.

> *I just blurted out that the doctor has said there was nothing he could do to cure her and it was terrible. It was just dreadful because from then she turned away from me and it was like I'd produced the death sentence for her.*

On the family doctor's next visit Alison asked the doctor to support her. His response was to inform her mother that her symptoms result from slight anaemia. The doctor's behaviour on this occasion was like rubbing salt in Alison's wounds.

> *And I felt it even further. It made me look like some kind of ogre that just wanted to tell her bad things.*

Alison's experience as a palliative care nurse was healing in many ways, but still retrieved some of the old pain and grief. Alison's voice quavered in the telling of her experience when caring for her mother.

The nurses recounted stories of past grief and how the impact of their own grief or that of other nurses had affected them in how they worked. Recalling their pain was helpful as long as it was recognised and owned by them. There was a sense that past wounds enabled the nurses to be more helpful to others in their care.

8.3.8 Facing vulnerability

Participants recognised their own vulnerability to misfortune, and how it could cause them to suffer similarly to the clients or their families. They identified circumstances that exposed their personal vulnerability. Marie noted that perhaps this was even more of an issue for community nurses because they function mostly alone in their work role.

> *In the hospital situation perhaps sometimes we can hide behind other issues without having to confront painful issues with patients. Perhaps we can get busy with other things, drugs or whatever, or hide away doing charts. I don't mean hide away, but yes, I just wonder.*

Kirsten emphasised how the sense of vulnerability related to the life situation of the nurses. Their age and family circumstances determined how much they related to the client's situation.

> *I think that where you're at in your own life, you know, if you've got women that are in a very similar time frame as what you are, and I can think of a lot of young ones, palliative care nurses who are looking after young women*

> *with children the same age. You tend to relate very closely to those that are in the same time frame as you are.*

Informants who were parents found the suffering and death of children close to the age of their own children to be especially traumatic. Lillian experienced this after seeing a very young woman with breast cancer.

> *I mean my eldest daughter has just turned 15 and I'm thinking, "Well that could be her in 5 years." You know, I mean it's just 10 years or whatever. That's the reality of the situation.*

Marie recalled a mother caring for her 7-year old daughter who was dying. Marie was amazed at how the mother gave her child the happiest time possible and how well the child's symptoms were managed. Despite the good aspects of the experience, caring in this situation was sadder for Marie because of her life stage in child rearing at that time.

> *It was a very good experience, although very sad of course, because the little girl died some time, probably a couple of months down the track, and you know having children the same age at that time, I found that very traumatic in its way for me, I guess.*

Robyn spoke of the similarity of herself to a group of clients for whom she cared and liked. These women had not survived, and the trauma of their deaths contributed to Robyn's decision to leave palliative care before the study was completed.

> *We had a few women sort of my age group and younger than me, like you know, 40s and 50-year old women who I'd got very close to who were having aggressive treatment, you know, aiming for a plateau at least and who died. They didn't survive and I found that fairly hard to handle. They were women like me, you know.*

The nurses had to face their own mortality and that of those whom they loved. Terrible events happened to people just like them, and although all nurses face death and suffering in their work, it is not usually so frequent and overwhelming.

8.3.9 Feeling angry

Participants spoke of when they had felt angry with clients or their carers. Anger had to be contained, as befits the professional nurse. For some, anger was difficult to acknowledge, with it implying a lack of self control. Beth spoke of being supervised, and on her recounting the situation that had caused her distress and her emotional response, was challenged by her supervisor.

> *When people do something a little unkind to me I sort of think, well, it must have been my fault and she'll say to you, "Yeah where's the anger? For heaven's sake, Beth, anger's OK. You know you can be angry at the person. You can tell me you're angry with them." I think the first time I told her, I said, "I got bloody angry," and she started patting me on the back and she said, "Thank God we've got to the honesty stage."*

Lynette reflected on a situation where she felt angry and impatient with a client. She was surprised by her reaction and that of the other nurses to this client, whom they were unable to help despite the medications. All of the measures were in place for this client to die with minimal suffering, but the client was unable to gain peace of mind, and her obvious distress was increasing the suffering for her family.

> *All we wanted was for this woman to pull herself together, which is not a nice way for nurses to feel.... I found it interesting, looking at myself and hearing myself saying this because I'm the last person to say, "Pull yourself together," but that's exactly what you felt like doing. You felt like shaking this woman and saying, "For goodness sake, you're 65, 70 years old. You've led a wonderful life. All your family is here. It's time to go."*

Anything that caused unnecessary suffering for clients aroused the nurses' feelings of anger. Martha identified herself as a Christian, and was angry about the suffering experienced by one of her clients. This client and her husband were part of a Christian group who believed that the illness could be healed by faith, and refused medication. This included any medication for pain. The client's doctor also belonged to this religious group and prescribed accordingly.

> *It was like a massive gut wrenching situation and absolutely nothing we could do about it, not a bloody thing. She died in dreadful pain.... It was really horrible and I know Jesus refused to have vinegar at the cross or whatever it was, but they were not Jesus, you know. Who did they think they were? It was, it was anger. It was the pain of frustration and anger and sadness, a whole combination of things.*

Robyn became angry about smoking, for example rather than with individuals.

> *I don't look for someone to blame, although do get annoyed with cigarettes you know, but that tends to be your older people.... You know men dying in their 40s from CA of the lung that upsets me; I feel it's a jolly waster.*

The decision of a client to take their life aroused strong emotions in the nurse, anger being one of these emotions Martha spoke of her anger with a client who took his life. She had found the client difficult to help because he ignored her or other helpers' suggestions.

> *His son and his wife hardly ever left his side, so he must have got them out of the room in the time for him to shoot himself, and I was so angry with him too because she had just done everything for him, and tried so hard to deal with him so well, and that was the reward she got. It was this horrible revolting death in the bathroom, her bathroom.*

Participants who received sexual approaches from carers or clients were angered and repulsed. Three participants described this behaviour, which was extremely disturbing for them. All that the nurses were and all that they gave was misunderstood. The nurses were loyal to their clients and the approaches called into question the nurse's professionalism and ethical values. Sandra was distressed by an experience with a carer of a dying client.

> *I found it really repulsive because as I was sitting with her, as she was dying and there was a young son and gross husband. He was just gross and he was*

> *basically chatting me up and wanting me to go out like while she was dying, like she hadn't died and I found that really, really difficult.*

Sandra was concerned not just for her own feelings, but for the dying client and her son.

Martha reported a similar experience with a male carer the day after the death of his wife. The nurses often returned after the death to collect equipment and to assess the needs of the family for follow-up care. Martha's follow-up visit was not as she expected.

> *He came out to the car and he suggested that I should marry him and I nearly fell out of the car. I couldn't believe my ears. I thought, "What do you mean? How dare you! Your wife has just died you know. I'm a nurse. I'm not a lover; I'm not a prostitute, you know. Get lost you dirty old man." I didn't say any of that because I kept my professional cool.*

Martha was angry but nevertheless able to maintain her professionalism while burning with righteous anger underneath.

Inappropriate communication or behaviour from male clients was disturbing and insulting to the nurses. Tanya referred to a situation where a client was perceived as lecherous, and described the actions the nurses took to protect themselves against unwelcome sexual innuendo and advances.

> *He was lecherous, but also not very nice to the nurses, lots of sexual overtones and that sort of thing, and we were beginning to hone in on discussing this stuff and working out some of these things. We did two things. He was the first one where we made a contract amongst ourselves in the office, and I think it was in writing that we went in, did the foot dressing, and focused on the ulcer and got out, and did no other care because his behaviour was so difficult.*

When visiting clients' homes the nurses saw some of the wonderful aspects of family love and care but they also saw the hateful aspects of some family relationships. Tanya was distressed by the hostile relationship between an aged mother and her carer daughter. The client needed assistance with her hygiene and almost all activities of daily living. Her daughter not only neglected her mother's physical care, but also verbally abused her and seemed to have no insight into her disabilities.

> *The mum has had a stroke and really needs nursing home care, and to transfer her needs two people to lift her and stand her up and turn her around and all that, whereas the daughter wants her to rehabilitate and [says] she's like she is because she's lazy; she's a lazy bitch and she's a lazy cow and all that sort of stuff.*

Tanya was repulsed and angry at the hostile interactions between the client and her carer. It was difficult for the nurses to go to this home. They had sought guidance on how to manage the situation.

The clients might also reveal a past grief or painful experience to the nurse and some found peace or release after having done so. It was sometimes a discussion about the death of a child, or being abused themselves as a child or by their spouse, or abuse perpetrated on children. They may never have spoken of this to anyone before, especially people who lived in smaller communities. Whereas the nurses felt rewarded when the sharing of this trauma enabled a troubled client to find peace, they were also angered. Sandra reported the following experience:

> *It all blew up on the weekend where the son bashed her and they called me and I came down and it was good because she does know me slightly but she was able to pour out her life history. A violent husband, alcohol abuse, a son that was tragically killed when he was 18 years old, and now a son who's been bashing her up for the last 3 years, and as I said to her it is no wonder she's got breast cancer, you know, a mother's heartache. Goodness me!*

Deathbed confidences could reveal an ugly side of the client. The confidences have left nurses with harmful, unresolved feelings such as anger and disgust about past actions of the dying client. Sandra gave an example of community nurses needing debriefing after clients confessed to incest and sexual abuse of others in their past.

> *I had calls from nurses at X [another country town] where perpetrators [of incest and sexual abuse] were also disclosing, but they were literally dumping their acts onto the nurse before they died, which left the nurse carrying a whole lot of stuff, and we needed a lot of debriefing and stuff like that.*

Carers were also victims of violence at times, and this angered the nurses. Tanya recalled visiting an older couple. The couple appeared to be managing well. The carer was not the wife of the dying client but they had been together as partners for quite some time. After the client's death Tanya undertook a routine follow-up bereavement visit and discovered the carer in great distress. Her dead partner's grown children had attacked her on the night following his death.

> *She was wonderful to him. … I went out to do the bereavement visit at 11 o'clock the next morning and she was draped over the steering wheel in the car, in the stinking heat, and they'd been dragging her round the house and knocking her about. He had been in the black market for years and $20,000 were missing and they'd been virtually torturing her all night trying to find it, stole her handbag. We had to get the police in.*

This carer's reward, or rather wound, was to lose her home and be forced to flee interstate for her safety.

Summary of sustaining wounds

The reverse side of experiencing joy, learning and appreciation for the nurses was sadness for the client's sorrow, remembrance of their past sorrows and their vulnerability. The nurses saw much of what could be described as misguided, cruel or even evil in human relationships. They were angry or afraid about their treatment, but were often unable to express these feelings to the clients or their family. It was difficult to see how they could manage these feelings in the absence of debriefing or supervision. The anger for some could not even be acknowledged, as this emotion seemed incompatible with the image of a caring nurse.

8.4 Summary and conclusions from Chapter 8

This chapter explores the nurse's descriptions and experience of receiving something back when giving care to suffering people. Pleasurable and painful experiences were identified. Rewarding components of the experience included feelings of privilege, fulfilment and personal growth. These experiences were more intense than the usual enjoyments of work, and served to inspire the informants to continue in their caring role.

8.4.1 Ways of receiving

The first aspect of the theme describes the gifts given to the nurses. The nurses felt rewarded in many ways. There was joy, fulfilment, and a feeling of privilege in doing all that they could to relieve the suffering they saw and to bring about what they described as a good death. They appreciated the learning and wisdom acquired when giving care to people who suffered. The nurses were also heartened when seeing the carers move on with their lives following the clients' deaths. These nurses experienced the appreciation of the clients and carers as a gift and this was something in which they took pride.

Not all that the nurses experienced was joyful. The normally hidden, painful and ugly aspects of human experience and relationships were revealed. Informants saw suffering, cruelty, and were both witness to and subject to abuse, threats and misunderstandings. They were wearied, saddened and reminded of their own past traumas and their personal vulnerability. They experienced isolation, feelings of helplessness and seemed to take o the suffering of their clients.

Although the participants' descriptions focussed strongly on the unpleasant aspects of their role, they perceived the gifts received to amply compensate for the wounds. They sought ways to weather the stresses and strains of their role.

In receiving both gifts and wounds there was a sense that the participants learned something of the mysterious depths of human experience not revealed to many. This experience left them irrevocably changed.

8.4.2 Being enhanced

In being enhanced, the nurses became more than they had been. They experienced their care giving as fulfilling and rewarding imbuing them with a sense of privilege. The appreciation expressed by their clients and the carers was also enhancing since this built confidence in the nurses and they felt that all that they had given was useful, valued and acknowledged. These gifts were received with open joy.

The nurses recognised and valued the wisdom acquired through their care giving. They learned much from the clients, their carers and other health professionals. They learned about love from witnessing the love and care demonstrated by the clients, carers and families when the client was suffering and dying. This learning increased their faith in others and changed their views about what was important in life. They also learned about the greatness and courage of the human spirit and this was inspiring. They recognised their own vulnerability and saw the courage and faith those they cared for brought to situations of loss and grief.

The nurses, when caring for suffering people, experienced a range of emotions. The joyfulness was sometimes exchanged for feelings of vulnerability, sadness, anger, helplessness and fear. The informants faced and overcame these hurdles. They found ways to manage and learn from their emotional responses to the clients and carers. The nurses most often recognised the source of client or care's behaviour that hurt them and were forgiving and understanding. Even when angry the nurses endeavoured to behave professionally and to reserve their angry reaction to events for an appropriate setting for debriefing.

The nurses were also realistic in their appraisals of situations. They accepted there were things they could not change no matter how they might try. Tragedy was a part of living and was set in motion often by past events. The nurses could not change outcomes of unhappy situations generated in the past.

In being enhanced, the nurses gained from the joyful aspects of their role and gathered wisdom and strength in their ability to overcome the effects of the wounds they received.

Chapter 9 – Finding a Balance

So there was this balancing act all the time. — Martha

9.1 Introduction to finding a balance

The nurses loved their work and received the gifts that went with it. A sense of joy, privilege, and reward were just some of these gifts. There were also risks for them being employed in such an emotionally charged setting. The nurses identified the risks, their vulnerabilities and the strategies they employed to protect themselves. This task of finding a balance between high points of care giving and the low points of despair, failure and being overwhelmed by the suffering was ongoing. Their experiences provided an understanding of what it is to find a balance This enable them to survive the dangers in caring for people who are suffering.

The aspects of the theme *Finding a balance* were drawn from the nurses' messages in their description of their practice and how they cared for and protected themselves and their families from the effects of the suffering they saw. The three aspects of the theme *finding a balance* were:

- Knowing oneself.
- Helping oneself.
- Building boundaries.

These aspects of the theme are discussed, and following reflection on and interpretation of their experiences, the hermeneutic of finding a balance emerged as *Being mindful*. Being mindful is to be conscious and wary of something, and in the case of the participants in the study, they were mindful of the perils in caring for people who suffered.

9.2 Knowing oneself

It was essential that the nurses come to know and understand themselves as embodied beings. They needed to learn how and why they responded physically and emotionally to situations in which they found themselves as nurses.

9.2.1 Seeing the need for help

One of the problems for nurses was their expectations for themselves. Nurses have been socialised to believe they should be strong, competent and in charge of the situations they faced. Martha emphasised the importance of being able to ask for help, and recalled her past experiences as student nurse. Seeking help from others was difficult for her.

> *I have been most frightened at times when I didn't know what to do and I was expected to know what to do, and that was very hard, to actually ask someone for help.*

Martha considered that she and nurses in general were socialised to believe that asking for help was a sign of weakness. She recalled observing registered nurses at a social event when attending a conference. The behaviour that Martha described indicated a lack of confidence or ability to be assertive.

> *There were a couple of nurses in our group and several of them I noticed said sorry about things that you know, "Oh! I'm sorry, just getting up to go and get a drink." There was that sort of tentativeness that I know. I've been there; I know what that's like. I probably still do that occasionally, apologising for being alive, apologising for breathing.*

Martha believed that it was important to be able to ask for help rather than controlling emotions and pretending that all was well. Nurses should be assertive and ask for what they believed could help them at the time.

> *It's really important to be able to say what you need to say, ask for help, say when you're tired or really buggered, say when you feel like a good cry, say when you're feeling it's all too much.*

Lillian provided an example of a nurse taking charge and doing just that. She was one of the primary nurses who had taken stress leave in the past, and had recognised that there were limits to what she could endure.

> *One of the nurses has actually put a limit on the number of clients she'll see [in palliative care]…. It's not actually a number; it's more like in terms of degree of the time she has to spend with someone.*

As the end of their life drew nearer some clients needed longer and more frequent home visits, and this was factored into the work load of this nurse. Lillian thought it reasonable.

> *She's already had stress leave after a particularly difficult palliative care case, so you know she's quite adamant about what she will and won't do, and I think that is fine.*

Lillian did acknowledge, however, that a reduced load for one nurse meant others had to take more.

For Marie, asking for and receiving help was one means of enabling nurses to continue to practise as palliative care nurses. She had sought help for the nurses who had been unable to control the suffering of a young client. This situation was very disturbing for those involved in the client's care.

> *I think just to be very aware at all times and to recognise when we're feeling a bit drained and a bit down and to able to ask for help which I think I did earlier this year. I certainly did that time.*

The implication of Marie's statement was that she sought help that time, but there were other times when she did not seek help.

Martha found that she had to learn to accept help from others. She found that she was able to give, but to actually ask for and accept help from others was difficult and something she had to work to change.

> *From my own experience it would be that I have had to make a conscious effort to go and have therapy myself, like it's much easier to give than to take,*

The nurses learned over time how to protect themselves and to recognise when they needed help. Melissa spoke of having seen others need time out from providing palliative care because of not caring for themselves.

> *There's only so much you can do for other people. There's a time when you should put up your hand and say, "Hello, what about me?"*

Getting to know oneself could be a shock. Lillian was shaken when reading an article in a palliative care newsletter that proposed that some palliative care nurses were driven by their own need for intimacy rather than the desire to help the client.

> *It talks about intimacy, a need to be special. To experience and express emotion, to belong and be appreciated and needed, and I was reading it and thinking, "God, I fit into all of those categories," and I thought, "Well, hang on a minute."*

Lillian feared she fitted this description but on reflection believed it was a matter of finding a balance between that and her life at home. She considered she was able to find that balance, but saw that the need to be needed was a threat of which nurses must be aware. The need for intimacy was a problem requiring help for a nurse who recognised herself as giving care to fulfil her needs rather than helping the client.

Martha presented a similar analysis of nurses, but in a more general way. She believed nurses carried on their role in caring from their life before nursing.

> *Nurses tend to be caretakers. They've often come from a background which has built that into them, that they are the soothing ones in the family or the ones that rush in and help, or the first ones to volunteer for anything or the do-gooders, if you like.*

It seemed, according to Martha, that some nurses had accepted the role of the caretaker long before they became nurses. Martha distinguished between care taking and care giving. She believed that care taking was assuming responsibility for the other, and this was not healthy.

Some nurses found difficulty in asking for help, and had the expectation they should take care of others, they should be able to manage any situations and were responsible for everything that happened to their clients. The participants in the study learned to read the signs indicating they needed help.

9.2.2 Listening to their body

The nurses learned from experience about self care, and so did not pressure themselves, and they monitored their health. Some participants recounted their experiences of illness and what they had learned from these. Alison had experienced debilitating symptoms before her medical problem was diagnosed. She believed that her health problem resulted from forcing herself to meet impossible demands.

> *But that was actually terrible suffering when I think back to it but it left me sort of knowing a lot of things. Like one is if you push yourself too far you actually do go over the edge. My health gave out then and so I'm aware of that. I keep an eye on myself as far as all of that goes.*

Sandra recognised how the pressures of life and work could affect health. She recalled being sick the previous year, although her health was generally good. This participant saw illness as having a use in terms of forcing nurses to rest.

> *We do get sick when things [get too much], you know. Something has to stop us. I think that's very true, and fortunately I don't think I've quite been in that situation. Oh yes I have. I got pretty crook last year with a bad ear infection and what have you.*

Martha held the view that the body tells the nurse when she needs to rest. She experienced respiratory problems intermittently and realised that her propensity for respiratory problems revealed the most vulnerable part of her body.

> *My lungs have been my vulnerable point all my life long, so it's always an indicator of the body. The body is the wise one that tells us, you know when we need to take things easy or you know, "If you don't listen to me I'll have to make my message loud and clear for you next time."*

Fatigue was a problem for Melissa. She dealt with this by taking holidays as needed. Moreover, she guarded her health by consciously maintaining firm boundaries and not carrying painful thoughts of clients and their situations.

> *I think that makes me survive. I think I'd have a nervous breakdown if I didn't. I don't think I would be very healthy.*

Kirsten was ill when her final interview was scheduled. Sandra worked with Kirsten and believed the illness related to work load. One or other of the two nurses providing palliative care in this regional centre were on call in the evenings and at night, In the period leading up to Kirsten's illness Sandra was on holidays, so Kirsten carried the load alone.

> *That phone can go at any odd time, and I'm sure it's one reason why Kirsten is sick. She's been really, really busy.*

There were others signs indicating that the nurses were coming to a point of being vulnerable to illness. Robyn knew when her sleeping patterns changed that she needed some respite from her work.

> *I'll start waking up early in the morning. I think I probably verge into an anxiety state or something. I'm not sure. I mean this is all undiagnosed or anything but, I mean you just observe it in yourself.*

Lillian knew that, for her, forgetfulness indicated an unacceptable level of stress.

> *But for me when I'm stressed, if I forget something, that's the first sign that I'm stressed. So it's like, "Oh, damn I've forgotten something. Oh, gosh I'm stressed and now I've got to get through this man dying at home."*

The importance of paying attention to their health was something of which the nurses had to be aware, and those nurses who became ill or saw others with health problems learned from these experiences.

9.2.3 Recalling their own wounds

The nurses carried painful memories and sometimes they were revived. The nurses understood that these emotional responses related to past hurts or experiences rather than the present situation.

Melissa was interested in this experience and wondered about it.

> *What are the triggers that, you know, help? What are the triggers that crack us? What are things that help us? I mean, I know some of mine, obviously I don't know all of them.*

Beth's grief on loss of her child returned on the death of a child client when Beth witnessed the grief of the child's parents. Beth knew why she felt distressed but was still pained by the experience.

> *Having that mother's last words in my ears, "I'll feel sad for the rest of my life." You know, I just found that really distressing and, you know, I had to work the next day and I was totally wrung out.*

Beth was able to speak of her past experience that gave rise to sadness and distress.

Robyn found she was not managing emotionally and resigned from her positions as a CNC in palliative care nursing before completion of the study.

> *Over my career I've got close to lots of people, but perhaps too many dying people and too many personal losses and, yeah, perhaps you put it all together.*

The losses and the grief she had experienced multiplied, and her personal grief combined with the grief for clients was more than she could bear. Robyn left both palliative care and nursing.

Marie was another who was aware of past grief that could emerge suddenly for her. She believed that nurses needed to explore the reasons for the uncomfortable or painful feelings arising when nursing certain clients.

> *It's not that the pain would be any less. It's just that maybe you recognise it and deal with a bit more… in terms of your own grief for things that have happened to you in your own life and these continue on through your life. The pain doesn't get any less, but maybe you've worked out strategies and maybe you're recognising things more quickly because you've been there before.*

Tanya noted the importance of recognising when the past affected the present.

> *I think there's a very real issue that you will go into stress factors and burn out more easily even though you're gaining in experience from your work, if you haven't dealt with the past.*

Tanya was aware of her sensitivity to domestic violence because of her past experiences, and that other people had different sensitivities.

> *I will react to psychological, emotional violence in a home more easily than some members of staff because I've come from it, whereas others will react to something else.*

Taking on other people's emotional responses was a danger. Martha believed that nurses needed to explore what seemed to be inexplicable emotions they experienced.

> *It's like a situation where you have to judge, "Is this my stuff or is it someone else's stuff?" It's very easy to wear other people's anger or guilt or unexpressed emotion in a group, in a close-knit group especially.*

Martha learned to take responsibility for her own emotions. She described the dangers of making assumptions about the nature of others people's experience and emotions based on what she was feeling, since these assumptions may be incorrect. Martha believed advocates for euthanasia might reconsider the basis of their arguments if they were the individuals assumed to be suffering rather than observers of what they considered to be suffering.

> *You start to feel what you think is the other person's emotions.... We don't feel other people's feelings we actually feel our own feelings...the reality is you feel your own grief when you see somebody else sad.*

Recognising past traumas, and distinguishing their issues from those of their clients, enabled the participants to understand that the source of disturbing emotions was sometimes their own pain, and not from the suffering of the client.

Summary of knowing oneself

The nurses explored their reactions to what they faced in caring for people who suffered and the importance of recognising when they needed help. It was essential that they differentiate between their pain and that of the clients or carers. They were aware of the necessity of monitoring their physical and emotional reactions in order to remain healthy.

9.3 Helping oneself

The nurses were proactive in helping themselves and found strategies for respite from their sometimes painful and dangerous journey. These strategies included having time off when their levels of fatigue were becoming unmanageable. They also sought expert help when needed, and developed other helpful strategies.

9.3.1 Having time off

The nurses became very tired in their palliative care role and were aware that they needed a break from their care giving responsibilities The participants broke their annual leave into smaller components rather than taking the total leave available to them once a year. Melissa liked to ski, so a short break during the ski season was the only routine time for taking some of her leave.

> *Skiing has always been a holiday, and that hasn't changed, but that would be the only set holiday time that I'd take. The others are as they come or as needed or when something comes up. I don't have a set pattern outside of that time I work to.*

Melissa was aware of how refreshed she felt after taking a holiday, and of her increased energy and enthusiasm for her work.

> *I always get tired before I go, and now I'm back and rearing to go, which is nice. Really I have been back 6 weeks now, but I've had my batteries charged and had a nice break and I know I'm coming up for a busy time, but I feel I have lots of energy and things.*

Robyn was another who acknowledged the demands of her role and its effect on her. Taking leave was a strategy she employed to reduce the stress of her workload and the other pressures she experienced.

> *If there is a lot of work and a lot of pressures from work I need to head for a holiday. I need to get out, just have a break. I mean, I've never been off on stress leave but I'll say, "Right. I need a couple of weeks off. I'll have a couple of weeks annual leave."*

Tanya outlined her plan for her holiday. The weather was cool and Tanya was planning curling up in a warm place to catch up with her reading.

> *I can't wait for my holiday. I'm finding a little hole somewhere and I'm taking a box of books and my cigarettes and probably a box of beer and disappearing into some good continental quilt therapy and not surfacing for a while.*

Kirsten found a month's vacation each year was insufficient for someone working full time in palliative care and planned to seek additional time on leave. She was so tired and feared being burnt out.

> *I want three lots of 2weeks …I'll take that time without pay, you know because I have to. I don't want to finish work, and this is what happens when people do change jobs. They get burnt out.*

Taking leave as needed was an important strategy of nurses helping themselves. This rest was vital for the few participants in the study who could be called out in the evenings or during the night.

9.3.2 Seeking professional help

The nurses all acknowledged the need for debriefing and clinical supervision. There were some opportunities for debriefing opportunities but not always when needed. There were no formal avenues for clinical supervision.

Martha recalled when she initially began working in the community as a palliative care nurse. The staff had organised and paid for workshops intended to support them.

> *We actually paid for a psychologist to come and give us debriefing.... All the time it was this sort of growing in the dark thing and very painful too.*

Most participants acknowledged that palliative care nurses needed clinical supervision.

Kirsten believed clinical supervision was to be a strategy for improved practice and emotional care that many nurses had not embraced. The response of many nurses to emotional difficulties was to find a way to cope, which may not be helpful to the client or nurse in the long term, or to leave the practice setting. Kirsten could see that this situation was changing.

> *There are a few training courses and things around now that, you know, to get nurses established into using supervision 'cause it's something we've never done. We've always coped or changed jobs.*

The rejection by some nurses of opportunities for debriefing was believed by Tanya to reduce opportunities for debriefing by their peers who did seek this help. She considered the nurses who rejected debriefing or clinical supervision failed to see the importance of emotional welfare of nurses.

> *Then you've got people who don't want to look at their issues, and are absolutely dogmatic that they're okay.... It impacts on the opportunity to debrief because the message is, very, very clear [that] the people out there*

> *and this paperwork and this school and this child's card is more important than us.*

These nurses did not recognise emotional welfare as an occupational health issue.

Formal debriefing sessions were not often available when needed. Marie noted that nurses employed in a hospice or hospitals were never as alone as community nurses were.

> *You always have someone around you can debrief to and that's not always available to a community nurse.*

Marie also wondered how a community nurse's distress might affect their driving ability.

Robyn, although needing this, was unable to participate in activities aimed at helping her when she felt overwhelmed by her workload. Robyn had helped to organise regular meetings to assist the nurses with debriefing.

> *I'd go to those meetings but I would be totally distracted because I didn't have time to be there.*

Robyn's thoughts of clients needing her help made benefiting from the debriefing sessions impossible. She believed in retrospect that help had arrived too late for her.

The participants in the study had to find their own way through the trauma associated with their role. A number had sought formal counselling. Martha recalled becoming aware at a palliative care conference that she had not addressed some personal issues with grief. Subsequently she decided to seek help with these issues for fear that her buried grief may affect others.

> *I learned that I had not addressed my own grief issues, and I won't go into how that happened, but that was a deep touching of a deep core inside me. I realised then that I needed to go to a counsellor and work through some of that stuff, because otherwise it might be impinging on other people and I did not want to do that.*

Martha was aware of the emotional burdens that nurses carried. She had been involved in a workshop for nurses aimed at addressing some of these emotional issues. The stories told by some individuals evoked an emotional response in the listeners. Martha commented on the number of nurses who smoked cigarettes, despite their knowledge of the harm it could do, and what she had observed at the workshop.

> *Those people didn't shed tears. They just smoked harder, and it was a classic example of how nurses have to cope with having their own natural emotions absolutely stuffed and damped down to such a degree that they go into painful and sometimes addictive practices of potentially self [harm].*

Martha considered smoking an unhelpful coping mechanism. A number of nurses present at the workshop, who did not smoke cigarettes, could express their feelings by shedding tears.

Kirsten made her own arrangements for the clinical supervision she desperately needed. She had spoken of this need with the palliative care counsellor who suggested she approach the palliative care physicians at the hospice, and Kirsten was pleased with the result.

> *That was one of the best ideas I think that she [the counsellor] came up with. She said, "Why don't you try the doctors at the hospice 'cause I knew I had to have someone above me more experienced, I think.*

Tanya became aware of the effect of her work upon her emotionally. Realising that she needed supervision, she arranged and paid for this herself.

> *The thing that impacted on me was that my present work was having an impact, and that I needed to look at my own supervision around the areas of emotional, psychological impact, and so I've put that in place.*

Clinical supervision was not an issue for Sandra, as she had the CNC to talk with about her clients, and perhaps this was informal supervision. Sandra acknowledged that if she did not have the CNC she would have to consider organising supervision for herself.

> *I would have to [have supervision] like Kirsten goes for supervision and I would have to do something like that. I would actually have to build it in now as maybe the whole style of working.*

Not all participants sought group debriefing or supervision. Melissa preferred to talk with close friends or find her own means of dealing with her emotions.

> *I'm a one on one person and so my strategies are talking one on one to people and usually to [close friends]. I have a very close friend who I used to work with.*

The nurses, for the most part, believed in the value of debriefing and clinical supervision. Debriefing was not always available when required and clinical supervision was not organised in the work place. The participants in the study had to find ways of accessing help for themselves.

9.3.3 Looking after one self

The nurses were aware that they needed to look after themselves by employing protective strategies. One strategy was to find ways to distance themselves from suffering.

Kirsten did not dwell on the suffering she saw, and believed that she did not need to question why certain people suffered and died.

> *That's my protection, too, in that I don't, not that I skim across the surface, but I don't have the need to go deeper.*

Martha put lessons learnt when she attended Al Anon to use in helping herself in the workplace. Whilst she did become emotionally involved with the clients, a degree of detachment was necessary to enable her survival.

> *I was trying very hard to keep a sort of detached level because I knew that I had learned the process of loving detachment earlier, and I knew that was going to be a means of keeping my sanity in the midst of it all.*

Melissa knew that she could not continue in her role if she did not care for herself. One way of nurses doing this was to let go of the client's family following the client's death. She gave as an example the follow-up visits to families after the death of the client. Whilst she encouraged these visits, she believed they should be time-limited.

> *I don't think it is healthy for them to be going ad infinitum. The family must network within themselves and the nurse must let go. I guess that's the term I'm looking for. Another cliché, one amongst all the cliques – Letting go. And if I did that I would burn out.*

Letting go was something Sandra had to learn. She recalled the time she first began providing palliative care and how she would feel responsible for the problems of her clients and carried their suffering with her.

> *I remember the days when I used to take all that [responsibility] on. I mean, it makes a huge difference, a huge difference if you are actually able to let go and not take all that on board and think that you have to be all things to all people. It's very freeing and much less stressful.*

Ellen recognised the importance of letting go of a family and the relationship she had formed with them after the death of the child. She was tempted to maintain contact with some families.

> *I guess there are some families that you think, "Oh, I'll really keep in touch with this family and I actually noticed that over the years that doesn't happen. It may happen initially, but that doesn't happen, and in some ways I think perhaps that's probably healthy.*

Alison found witnessing the suffering of others to be intolerable at times, but thought nurses became accustomed to this. She recognised that there were times that she could not change the situation for the client or carer and learned to accept this.

> *Maybe people could say that you become cold or something. It's not that you don't feel for them, and it's not even that you don't show it. I don't believe*

> *but you can accept it without feeling even that you can or have to do anything at that point because actually it is their problem in a sense.*

Martha spoke of the need of the nurse to let go, and the relationship of this to loving detachment. She described this in the following way.

> *It's learning not to be attached to the outcome because if you get attached to an outcome of something then it's your ego driving you.... It's like a point of sanity, too. I mean, the letting go is a very obvious thing with dying, because you literally lose the physical presence of a person. They're there one minute and then they're not.*

Alison learned that she was not responsible for everything that happened to the client, and did not have to take on the suffering of others. She acknowledged that there were times she was unable to be involved emotionally with the clients. Alison wondered if nurses ever should risk emotional involvement with suffering clients.

> *You don't have to feel if you can't, you know, on that particular day if you just can't enter into it with them. Maybe you never should really because it is probably too heavy for anybody but you can certainly be with them for it.*

Alison left palliative care nursing 6 months before the commencement of the study.

Lynette spoke of distancing herself emotionally from the clients after a complaint from a primary nurse about the way she functioned as a CNC. She found this very distressing.

> *I've operated differently and since then I've been totally emotionally cut off. I forget people's names as soon as I walk out the door. I used to do that out of sheer business. You couldn't remember people's names, but I felt guilty about it. Now I do it as a mechanism of, well, I just think it's saving myself.*

Complementary therapies were helpful for some nurses. Martha had tried a number of strategies for self care. One of these therapies was shiatsu, which she found helpful. Martha then learned how to practise this therapy with others.

> *I would have quite a number of strategies that I used to help myself in the process. That was where I learned shiatsu, actually. I learned to receive shiatsu and I found that was the best debriefing I could find. It was wonderful.*

There were other strategies such as meditation and attending various workshops. Beth had previously attended a 2-day intensive program in spiritual awareness offered by a palliative care physician. Refresher courses were held during the year in a peaceful bushland setting. Beth was able to attend the refresher course at a time when she really needed it.

> *Normally I'm rostered on, but I was rostered off. It was on enlightenment, and I thought I could do with just a tad of enlightenment at the moment, but I know that they're always soothing and calming, and I like meditating and I love nature and you always meet incredible people at these things.*

Although she felt tired she made the effort to attend, and found this workshop beneficial.

Five participants referred to holding Christian beliefs, and believed that these sustained them. They spoke of belief in an afterlife. Martha thought about the time when she would go to heaven.

> *I used to think it'll be real fun going to heaven 'cause I might see all these people again, you know, all those terrific people we were graced to meet, and be in their homes and some of them of course became very strong attachments.*

Kirsten expressed similar thought about what might happen following her death.

> *I still have this vision that when it is my turn to die, I that'll be there, you know. I'll head up there and the word'll go, Kirsten is on her way up, you know, and I'll see all these people. I reckon that'll be grand.*

The participants found various ways of helping themselves. The strategies varied according to the nurses' beliefs but it was clear that they had to find a balance between engagement with clients and distancing themselves.

9.3.4 Finding outlets

Another protective strategy identified by the participants in the study was that of finding outlets and ways to experience joy. Melissa really loved Christmas and participating in all the festivities around that time. She felt joyous anticipating the approaching Christmas.

> *Christmas is coming, and I love Christmas, and so I'm buoyant and full of the joys of spring, or Christmas or whatever. I love this time of the year and I love entertaining and making things. There's this big outlet outside of work.*

Socialising with friends was experienced as being helpful for some participants. Melissa enjoyed an active social life.

> *I'd always be out and doing, and [I] love to go to dinners and things and I think that's my method of releasing that tension. [It] is by being with friends, talking to one or two of them, or going out to dinners or just having a good social life.*

Melissa introduced playful social activities into her workplace to help with group cohesion and relaxation. She told of having cake making competitions when working in oncology before her appointment in the community. This took place one day a week, when medical rounds took place.

> *Someone would be selected to make a cake, and it was absolute trivia but it bound the group. The doctors, the nurses on the ward, the chemotherapy group and so we used to judge the cakes by taste like the Torville and Dean sort of scale.... And one out of six being for difficulty.*

The cake maker would invent fanciful tales of difficulty to entertain the judges of the cake. Melissa had introduced fun filled strategies to build the palliative care team of which she was now a part.

Beth called on friends when in need of comfort. She did not talk about work with these friends, but enjoyed the warmth and contact with people she liked.

> *I'll just, you know, contact a friend and say, "Are you interested in going down to get a video?" or just doing something so there's some contact and some warmth.*

Three nurses found release in writing. Martha, for example, wrote poetry to express her feelings and to bring a sense of closure.

> *Sometimes I would write those sorts of things actually literally in the car, you know, coming away from a place. It would just sort of bubble up like a well of words that had to be written down. So quite often I would get out my sense of completion through poetry.*

Release could come through shedding tears, this being what Robyn did. Shedding tears occurred in secret, but ultimately proved to be ineffective. Robyn left the setting of palliative care before the study was completed, as she wanted no more of suffering.

> *I think I cry and I think that's part of my healing, you know. I think that's what I do, cry; more weep, you know, probably more weep. Just the tears flow and that seems to release probably the endorphins. That sort of seems to heal it up pretty well.*

Laughter and humour were important to maintaining a balance and reducing stress for the nurses. Nurses have traditionally made a joke of those things they feared or caused them distress or sorrow. The participants in the study were no different.

Martha told of attending a conference for palliative care nurses. One of the social events was a dinner, and Martha had a wonderful evening. As one of the participants who had resigned from palliative care nursing before the commencement of the study, she was almost lured back to palliative care, as she enjoyed the camaraderie of her fellow nurses.

> *There's a wonderful rapport that happens between nurses when they get together and they talk about situations that they're all had in common, which*

> *they could never talk about in any other grouping because nobody else would understand or believe half the things that happen.*

This humour was not the kind that the nurses could share with others outside of nursing, and Alison noted that there was a need to mock death and what went with it.

> *You would have the most dreadful sick jokes as well as black jokes. We've had those in the community as well about death and you just have to step back and kind of make a mockery of it as well at times, because you do get the most terrible stories of some really incredible things that happen.*

Alison was not always comfortable about the laughter and jokes, and thought that in the usual social situations she might be judged as being unkind or unprofessional. However, it did serve as a release for staff.

> *It's almost hysterical, the laughter. And you sort of feel a bit bad about doing it in that if you were to go to a dinner party or something you wouldn't feel you could tell people 'cause they'd think, "Oh! This isn't very good," but staff actually do that a lot and it's quite okay.*

Kirsten could make a joke about trying situations. She told of a carer becoming angry when Kirsten had problems with the client and carer's antique four-poster bed when making the client's bed. When they next met the carer attempted to make up for her outburst by making Kirsten more comfortable on a hot day. Kirsten laughed as she told her story.

> *She's an old English registered nurse and very correct in how she does things; and she told me I was too hot and shiny and she had to get a bit of spirit for me this afternoon, and I'm allergic to perfumes and I had been sprayed with perfume…. Well I thought when she said I needed a touch of spirit; I thought she was going to get me a dab of whisky.*

Melissa used humour when giving care to one client. She was trying to discourage the client from becoming too dependent upon her. She laughingly recalled a shared joke with this client, who looked forward to her visits and would tell her he didn't know what he would do if she left. This man was Melissa's client for about 8 years until his death. Melissa turned his words aside in the following way.

> *I said, "Oh you're just so fickle," I said and, "One of these days I will probably leave and then the next one will come along and you'll think, "What was that last one's name?"*

Melissa was aware he said the same of each of his primary nurses when they left the service. Melissa discouraged his dependence but in a humorous way that brought laughter for both of them.

> *I quickly put a downer on that one... in a nice way that we can both enjoy the joke and he used to love it.*

Summary of helping themselves

The nurses sought outlets for the release of emotional tension. Socialising with others and writing were two means of release. Jokes and laughter with their peers and their clients served to reduce tension and fear. The humour shared between nurses could not be shared with those who had not experienced caring for people in the way the nurses had.

9.4 Marking boundaries

The nurses set boundaries to keep their world separate from the one they visited as nurses providing palliative care. They developed strategies to assist them in marking the transition point between their professional life and their personal and family life.

9.4.1 Using the border

The nurses began preparing for closing off the working world from their life outside. They used the journey home and prevented as far as possible any interaction relating to work once they left for the day. They also protected their families as much as possible from the taint of sorrow and suffering they saw each day.

Alison began the separation process before she left her workplace. This helped in not requiring her to think about her work until the next day.

> *I have always tried as I physically leave the place I work to sort of leave it behind me. I have also tried to, before I actually leave, have a few things in order so that there is nothing unresolved for the next day, if I can. That means that I can leave it behind, you know, that there's nothing I need to work on.*

For some it was once the journey to and from work started that they mark the border between home and work. Melissa found this transition time when she drove to and from work to be relaxing and providing an opportunity to unwind following her working day.

> *You know it's a time to unwind and just listen to the news and I don't mind driving at all. I could get into the car and drive. I find that relaxing.*

Melissa alternated the routes she would take to and from work depending on traffic problems. She enjoyed the drive, and alternating the routes made the journey more interesting.

Alison was another who used the time spent driving between work and home helpful in separating the two worlds.

> *I've got quite a long drive to work now and I find that's useful. Coming here I sort of brief myself. Going back I debrief myself. As I get further away I'm more into the other world. I try to forget what happened during the day and have a good 20 minute drive.*

Alison enhanced the benefit of the driving time by playing calming music as she drove, particularly when she felt distressed.

> *I have a tape in my car. It's by Rick Wakeman and it's called, Ooh! It's to do with nature. It's not nature sounds but it's beautiful piano music and it just works wonders for me.... I can sort of get very calm just listening to it, and if I am feeling agitated then I will actually put that on.*

The time driving home was a time for separation and distancing for Lillian.

Not all participants drove to work, but could still use the journey to separate their two worlds. Sandra lived in a small town and walked to and from her workplace each day. She used the time in between the world of home and the world of work in much the same way as those who drove.

> *I feel I can give all when I'm at work, but when I go home that's it. I walk to and from work so I start switching onto work as I'm walking to and I start switching off as I walk home, and that's the way I deal with it.*

The boundaries extended to not allowing any aspect of their work life into their private life. Melissa did not allow clients to contact her after hours.

> *I don't believe in giving my number out to patients after hours.*

Work was left behind each day when the nurses returned to their own world of family and friends. One way of doing this, described by Melissa, was to not think about the clients or the workplace once she left each day. This shutting off thoughts relating to clients was the only way Melissa could continue to care for suffering people.

> *Look when I've finished work, I've finished work. That's my way of staying in this job.*

Ellen found that her husband's response to her sadness helped keep the sadness of her work away from her home and family. Her husband did try to support her, but he did not dwell on this.

> *He moves on very quickly and so in some ways I think that's perhaps good. I don't come home and go over things. If I really needed to I would, and he would be there for me, and so perhaps that helps, that keeps it separate.*

Sandra recounted the various tragedies that befell people she cared for in the clinical setting and how she had to keep the sadness associated with these events where it belonged. Sandra had learned that she could not take this with her when each day ended if she wanted to practise effectively and look after herself.

> *Yes, it's all tragedy and I do think you have to put it where it belongs and I think a lot of nurses make that mistake. I know I used to years ago, take it all in and worry about it and now – a lot of people they could see me as extremely callous and noncaring because I don't take it all home and all that sort of thing.*

While the nurses tried to separate their two worlds this was not easy, and the sadness seeped into their personal life. Alison spoke of her struggle and of the indications that she was not succeeding. This nurse wanted to integrate her experiences as a nurse as part of her and be a whole being, but found this difficult. It seemed for Alison that she was closing off her nursing life from her other life.

> *I was thinking more about taking work home and I think that is a continual problem and a continuous struggle to actually have a separation.*

Lillian was another who tried to keep her professional life separate, but was not entirely successful.

> *I try to keep it at work, you know. I try not to bring it home, having just said that I usually tell my kids if someone dies.... Basically, I come home and I try to forget what's happened during the day.*

Lillian also discouraged people from telephoning her at home when off duty and would only talk with them if no one else were available.

> *I'm fairly clear about people phoning me at home. If they phone me if there's no one else available, fine, I'll talk to them but if there is someone else they can talk to it's like, "No. This is my day off. I don't want to know about it."*

Kirsten recalled that when she first started providing palliative care she would follow up on some clients to see how they were faring, but now did not need to do that.

> *I don't look through the paper to see who's died or I don't ring if I'm off [duty]. I don't ring the hospital to see how somebody is if they've been admitted to hospital. I do my work.*

This separation of work from home was more difficult for Kirsten as she was often on call should a client need help during the night.

Beth lived in a regional centre and had done for some years, so she was known in the community. She could not easily separate her work from her personal life, because she saw the carers when carrying out her usual activities outside of her work role.

> *I'd just like to be able to completely separate work from home at times, but you know, I don't come away from the shopping centre sort of feeling drained but I just think it would be nice sometimes if I could have another face so I could just slip in and pick up a few things*

Alison tried a number of strategies to separate from her work world but they were sometimes unsuccessful. She was troubled by dreams.

> *I feel I'm not winning, you know, like these funny dreams that pop up and that kind of thing, and you just get, it's a thing of how do you integrate and make it all you.*

Tanya considered that personal boundaries became more restricted when the nurses felt less able to cope. For Tanya, the effectiveness of setting personal boundaries depended on the individual nurse having an understanding of their emotional state at the time.

> *What I can take on board and what I can't. I'm feeling really well, you can throw anything at me.... I'm rather fragile, they don't have to know why or why not, probably I know so I don't want to do this.*

The participants tried to separate themselves emotionally from the cares of the workplace and maintain that separation at home in addition to the geographic separation that occurred at the end of each day. This separation was not always possible and there were intrusions into their lives related to their caring role.

9.4.2 Washing it away

Some participants told of their need to remove the remnants of the world of suffering from their bodies on returning home. There were times when they needed to cleanse themselves of suffering and feelings of pollution from their work. They did this by changing their clothes and bathing on returning home.

Alison noted for her a need to change her clothes served as an indication she needed to put a greater distance between her and what had happened that day in her work.

> *Symbolically, I sometimes go and change when I get home as well, and it's an indication to me of a great need to distance myself from work.*

She was happy when she had no need for this ritual, because she worried about separating parts of her life, and consequently not being a whole person in any area of her two worlds.

> *I'm quite happy when I don't feel the need to do that because I also have this idea you need to be a whole person. And so you've got to be careful of not just being, having separate bits of you either. I would just like to be more or less complete, I suppose.*

Lillian was another who found the ritual of cleansing herself and changing her clothes to be a way of disengaging from the world of work and suffering.

> *I'll go and have a shower and get changed. I feel that that physical kind of cleansing and getting out of my work clothes is a really big detachment thing for me.*

Lillian recalled the suffering of a patient 20 years ago, when she first had this need to cleanse herself after leaving work.

> *I can remember I used to go home and have a shower, and that's when I first started feeling, the first time that I ever remember having a shower to wash away all that unpleasantness.*

Cleansing her body was also a strategy for Beth after harrowing times while working.

> *I often feel as though I just want to have a shower and throw everything in the washing machine because it hasn't always been very clean, neat, and tidy.*

Kirsten used water to cleanse and relax. For her taking spa baths was a means of self care. She observed that when she most needed this self care she was too tired to employ self care strategies.

> *I take care of myself but it's really strange. I did notice when I was really exhausted and I was stressed out of my brain, I didn't do my meditation, or have my spas. It was like I was even too tired to do things that make me feel better.*

The ritual of cleansing themselves and removing the garments worn at work helped the nurses distance themselves from the world of suffering.

9.4.3 Keeping the family out

Almost all of the participants avoided speaking of their work when at home in an attempt to keep the suffering at bay and protect their family. Melissa's statement demonstrated this resolve, common to most participants.

> *I never talk work at home only to my colleagues.*

Alison struggled with keeping her family separate from her work. She tried to protect them from the suffering she saw each day.

> *It's probably more to do with the suffering, more to do with letting them in on the suffering, and I don't want to do that with them.*

She believed that it was unprofessional to talk about her clients but it was also unfair to burden her family with painful and unpleasant aspects of life.

> *It's really hard not to give away too much that is actually personal to the people you are involved with, so in that way I think it's not professional but then I think the other side of it is [that] it's not fair, because the work I've done has been often quite hairy sort of work and why should my family be subjected to all this seedy side of life.*

Few participants shared their feelings with their husbands, but Martha was one who found her husband to be supportive and someone to whom she could turn in times of need.

> *He was a very good partner for me, not necessarily to bring all the troubles home to. There would be times when [I] would tell him what was going wrong and have a good cry or something, and get it off my chest but he was just a very good support in the background, because I knew he understood what I was on about and that he acknowledged me for who I was and that was always a comfort.*

Kirsten was another whose husband understood something of her role, as he also had a stressful occupation.

> *My husband, he's a welfare officer, so he really has a stressful job as well. We do support each other and, you know, sometimes we get home and say, "This is ridiculous, you know. We're getting older and we're working harder then we have ever done."*

Most participants determined not to talk about their work at home with the intention of protecting their families. They also helped themselves by keeping their home free from the suffering and pain they saw when working each day. This choice was also consistent with the professional standards in which they believed.

9.4.4 Moving on

The nurses separated the past from the present by trying not to consciously remember and think about clients who had died. They recognised that they could not carry the problems of the clients with them, and must move on with their lives after the death or discharge of their clients.

Melissa spoke of how she managed this aspect of her work and believed if she was unable to put the past behind that she could not continue to provide palliative care as a nurse.

> *I couldn't carry all that. I'd crumble. I mean, it's finished and I think that's how I deal with things in my life. It's finished and on to the next thing. I don't think I carry a lot of baggage and I think I am realistic in that sense.*

The passage of time and the busyness of the nurses' lives tended to blur the memories of the situations they encountered. Beth saw this as a blessing, believing she could not function if she carried vivid memories of some of her experiences in the world of suffering.

> *The situations start to blur, which I suppose is a blessing in a way, because if everything stayed vivid you wouldn't be able to go on with it and deal with the next lot that's coming up. But they remember you so vividly 'cause you were such an important person in their life, because you were there for them in such a critical situation.*

Beth could understand why the clients and their families were never able to forget her, as the death of a loved was a unique experience. This nurse lived in a regional community where she known. She would see family members of clients when going about her daily life outside of her work. This experience was not something to which the nurses who lived in the urban centre related.

Time put distance between Robyn and feelings of sadness following the suffering she knew her clients experienced when their cancer returned after a period of remission. She would be distressed for them upon hearing this news and losing their hope for recovery.

> *Sometimes it takes a few weeks to think, you know, that person will keep flooding back into your mind and just feeling sad for them. I guess the acuteness of when they first tell [you] sort of mellows as time goes on.*

The nurses consciously tried to leave the past behind and were successful most of the time. The passage of time helped.

Summary of marking the boundaries

They began to erect barriers between work and home as they travelled homewards. Once home, some nurses tried to wash the world of suffering away. The nurses generally kept all discussion of their workday world from their home and tried to move on and leave past suffering behind.

9.5 Summary and conclusion from Chapter 9

This chapter, entitled *finding a balance*, described the nurses' ways of protecting themselves, and described the meaning of this experience as *being mindful.*

9.5.1 Ways of finding a balance

The interpretation of nurses' descriptions of the aspect of theme, knowing oneself, indicated their need to recognise that they were feeling human beings who sometimes needed help from others. This need for help was to be expected rather than being viewed as a sign of weakness and failure. The nurses believed they had been socialised to have unrealistic expectations of themselves, in being able to distance themselves completely from clients and carers and control their emotions. The nurses described how they became aware of bodily and behavioural signs indicating they were in difficulty, and needed help and care. In order to protect themselves the nurses had to be aware of the past wounds they carried. The pain of old wounds was revived when something in the present reminded them of past grief and loss.

Helping oneself, an aspect of the theme, described the strategies used by the nurses when they experienced fatigue that became unrelenting. Sometimes the nurses sought help from others. Formal debriefing sessions organised by their employing organisations gave some assistance. Some nurses sought help independently of their employing agency for counselling or clinical supervision. Clinical supervision was not provided or encouraged in the workplace. The nurses found ways of caring for themselves and various outlets for their emotions.

The protective strategies developed to contain the suffering in the workday world were described in the aspect of the theme building boundaries. The nurses consciously endeavoured to protect their families and free themselves of the sadness of the world of suffering when they returned home at the end of the day. Finding a balance provided a full and accurate description of how the nurses maintained themselves in order to be able to continue to care for people who suffered.

9.5.2 Being mindful

In being mindful, the nurses were wary of threats to their health and wellbeing. To be mindful was also to be honest, for without honesty the nurses could not truly learn to know more of themselves. Self knowledge was essential to self understanding and being able to seek and accept help and counsel. Honesty was also essential for the nurses to recognise their motivations for their actions. The nurses needed to be able to face unpalatable truths. An example is the realisation that they may be meeting their own needs rather than those of the people for whom they cared.

The nurses can be seen as caring of themselves when being mindful. There was consciousness of their lived bodies' signals of distress, indicated by changes in function and a sense of their bodies being polluted in some way. They washed the pollution away. In being mindful, they reflected on the reasons for their discomfort or distress and most acted to address the issues. The nurses, when mindful, learned to love and care for themselves, rather than ignoring their own needs when caring for others.

Mindfulness required the participants to be thoughtful in reflecting upon the nature of their emotions and the source of these. They became more self aware. The nurses learned to distinguish between their pain and that of the client, or carer, so avoiding taking on another's suffering or projecting their suffering onto the client.

The nurse in being mindful was vigilant in terms of protecting themselves and their families from the suffering seen each day. The boundaries erected between their own world and the world of suffering had to be maintained and strengthened to prevent the suffering impinging on their lives and that of those they loved.

Chapter 10 – Being a Nurse Caring for Suffering People

> *I have a sense of sadness that this is finishing and I think the wisdom is all very well but you see, you've listened and it meant something to you.... I feel that unless it's appreciated by someone else it hasn't got the same value. —*
> *Alison*

10.1 Introduction

This chapter presents the findings of the study as the hermeneutic description of the experience of nurses caring for people who are suffering. The nurses' descriptions of what it was like for them to care for suffering people revealed the essences of the themes. I have also included some reflections on the experience of the interviews with the nurses.

The hermeneutic description of caring for people who suffer constitutes the major portion of this chapter. This description is structured according to the essences of the phenomenon as they revealed the meaning of the nurses being as a nurse caring for people who suffer.

10.1.1 Entering into the experience

As we first met the nurses were eager to share their experiences as palliative care nurses. I shared something of my nursing life and the clinical settings in which I had practiced. Palliative care was not a context with which I was familiar and the literature I had read related to suffering rather than any particular context of practice. I came to the interviews knowing little of palliative care. I have included some thoughts about the interviews as these illustrate something of the experience of these nurses that emerges in the description and findings of the study and of the interview process.

First Interview

We had spoken to each other on the telephone but this first interview was our first meeting face to face. The first interviews with all participants took a similar path. As in the beginning if any relationship we were h a little tentative but after the formalities of clarifying the purpose of my enquiry, the conditions and possible risks of their participation, and giving consent the conversations began. I assure them that I know little of their work and their stories will provide an understanding of what it is to care for suffering people. I emphasise that I will not have much to say as it is their stories that are important.

The interviews for each nurse begin by asking how they came to palliative care nursing given there would be much suffering in this context of care. They speak of what this experience is like for them as nurses. Each of the first interviews reveal what the nurses think led them to palliative care and their thoughts on suffering. They speak of how they believe they found their way to the setting and what this experience became for them. Those who left the journey also speak of how and why the sojourn changed for them. There was a beginning discussion on the nature of suffering, as they understand that to be.

As the interviews progress we come to know each other and the nurses are generous in sharing their knowledge and experience. We become comfortable with each other and share a little more of our lives in the social exchanges at the beginning and end of each interview. The nurses are open and honest in describing their experiences and how they feel about these. When speaking of their joy and satisfaction in being able to relieve suffering the nurses' facial expressions and tone of voice are consistent with their words. They smile remembering the times when they felt useful.

At times, they are fatigued or stressed by all they have yet to do and by the sadness and the feelings of helplessness they experience. The nurses sometimes yawn and their bodies droop in the chair as they speak of their fatigue and need for a vacation. Some participants seem to look forward to the interviews. Speaking of their work and their feelings is something they are not generally able to do.

There was sadness on completion of the final interview. We came to know each other and they share so much with me but now this is ending. Even if we meet again it will not be the same. During this time, the nurses spoke of their experiences and how these affect them. Hearing their own words describing what they learned and their joy and pain as palliative care nurses is a new experience for them. There was a sense that the nurses feel their work and knowledge is unknown to and unacknowledged by others and this somehow devalues all that they achieve. This is a secret world. They speak, I listen and each of us gives and receives.

10.2 Being a sojourner

The nurses told of how they came to make the journey of caring for suffering people. These people were individuals who suffered when knowing that they, or someone they loved, would never recover from their illness and were in the process of dying. Following reflection on the nurses' experience chronicled in the theme, *Making the journey,* an essence of the phenomenon of caring for people who suffered was uncovered. The essence, *Being a sojourner,* provided an appreciation of what it is for nurses to commit themselves to caring for suffering people. A sojourn is a visit, a temporary stay in another place or country. The word suggests a special purpose for this stay. A sojourner may temporarily dwell in this other place as an exile, a learner, because of a particular interest or for a vacation. The nurses were visitors to, or sojourners in, the world of suffering because of an interest, a desire for knowledge and a special purpose.

Being a sojourner, describes the being of the nurses as they lived their stay in the world of suffering. The nurses provided a number of explanations for how they came to be there but it was clear that on arrival they recognised their affinity and fascination for this world. The journey brought them a temporary stay in a fascinating satisfying world where they learned about the intense and complex aspects of human relationships, life, death and suffering. Being a sojourner is a way of being conveyed by searching and finding, seeking redemption, taking and relinquishing responsibility and having courage.

10.2.1 Searching and finding

The way to this other world was sometimes a tortuous route. The nurses searched for something they eventually found after sometimes making wrong turnings. The nurses found themselves contemplating, or caring in, practice areas that proved unsatisfactory for one reason or another. The reasons initially given for their sojourn in the world of suffering revealed what had taken them there but not what held them. Chance, directives or seeking opportunities for promotion brought them there but they were motivated to stay by a stronger force. This journey became an immensely satisfying mission requiring heroic effort. Martha expressed something of that effort when speaking of her learning and experience at the beginning of her sojourn.

> *It was a big learning curve. A part of me would rejoice at it because I think there's a sort of hero part of me that really loves to go out there and do it.*

The nurses were satisfied when connecting emotionally with clients and their carers at a depth not experienced before and perhaps never would be again. Relationships previously developed with patients or clients paled in comparison to the level of emotional involvement they now experienced.

Once in the world of suffering the nurses discovered that the caring required was something they felt already able to carry out. They became aware of an inclination and talent for caring for people who suffered. The nurses were fascinated and stimulated by the requirements of the role and what it asked of them.

This attraction drew them back each day and remained for three of the four nurses who had left the setting before, or during the study. These nurses looked back with some regret. Martha experienced both regret and grief for a time.

The nurses witnessed and were part of one of life's most dramatic and emotional experiences. They saw suffering, grief, reconciliation of family members and lost opportunities for these. Caring for suffering and dying people had symmetry with midwifery. Both were processes of struggle, pain and mystery. Birth is most often a joyous and emotional occasion. Death is equally emotional but accompanied by sadness and grief. The nurses' mission now was to assist the client and carers to a peaceful and loving leave taking rather than witnessing a jubilant greeting to new life.

10.2.2 Seeking redemption

The past held memories for the nurses of seeing people suffer because of poor pain management, excessive treatment and the indifference of those who cared for them. In the past, the nurses had been distressed and angered by seeing unnecessary suffering and a disregard for the humanity of the dying. Some spoke of their failures in recognising or relieving suffering. Inexperience, lack of knowledge or powerlessness led to inability to act to change situations where they saw patients or peers suffering.

Suffering could result from poor symptom management, excessive and useless treatment for the disease or the giving of false hopes of cure. The desire to provide better care than that seen or given by the nurses in the past drew some nurses to palliative care nursing. The nurses in the study aimed to do better and make up for their previous inability to relieve suffering.

For some redemption was more personal. Alison, for example, cared for her dying mother at home. She knew little of palliative care at that time and had no support from health professionals, particularly her mother's GP. Alison found later in palliative care nursing she could help others and some how make up for what had happened with her mother.

> *I felt a lot of what happened to me [at the hospice] was healing of that because I saw there was a possibility to look after people better.*

Helping others somehow helped the nurses put right the wrongs of the past.

10.2.3 Taking on and relinquishing responsibility

The nurses in being sojourners both took and relinquished responsibility. They felt responsible for maintaining clients at home, relieving suffering and achieving a good death for the clients and their families. The nurses were responsible for developing and maintaining knowledge of the drugs, technology and interpersonal skills required for symptom relief. The CNCs felt responsible for the welfare of the primary nurses. They monitored the primary nurses' case loads and noted factors that might make them more vulnerable to burnout.

Almost all had families with the accompanying responsibilities; those who left palliative care became aware that being a sojourner drew them away from their responsibility to their own families. Where conflicting responsibilities arose meeting the needs of family members took precedence over the giving and receiving in their professional lives.

As the nurses' lives progressed, they took on new responsibilities for family members. They became parents or grandparents and family members experienced problems. The visits to the world of suffering were demanding emotionally and the nurses' emotional resources were limited. The birth of a new child, the illness of an aged parent or the needs of their adult children and other family members took precedence over caring for suffering clients.

To be a sojourner implies a journey to another place and all journeys eventually end. This journey did for four of the nurses. Leaving the journey brought a sense of relief at the lifting of the burden of responsibility. This burden had weighed heavily upon these nurses. They did not realise this until the burden lifted. They felt freed from the burdens of sadness, grief and the intensity of relationships formed with clients and their carers. They were free to take on other roles and interests.

Ellen, for example was relieved to be freed of the responsibility of constantly feeling concerned about her clients and of the intensity of her relationships.

> *It's good in some ways not to have those relationships, not to feel, I don't know, beholden to the job if you like.*

Relinquishing responsibility and the emotional intensity of the care setting was not without regret. The sense of relief at the lifting of the burden was accompanied by a sense of loss for three of the nurses who left the journey.

10.2.4 Having courage

Being a sojourner in the world of suffering was a dangerous undertaking so the nurses needed courage to face the new and sometimes painful experiences. For the nurses learning new things was exciting but also challenging. The nurses met new clients and faced many new experiences alone. In the community, there was no escape or help readily available. As community nurses, they ventured forth not knowing what they might face. Martha was one nurse who reflected on the potential for danger in the community nurses role.

> *I don't think I've ever felt really threatened by anyone in the sense of my life at risk but there was always that uncertainty about who we were dealing with*

Courage was required for the nurses to endure the unpleasant aspects of their role such as suffering, grief, anger and a range of other emotions. A few were eventually overwhelmed. Witnessing the suffering of clients and their carers became unbearable for three of the participants as their tolerance to suffering diminished. They could not continue their sojourn as the suffering and sadness began to permeate all aspects of their lives.

Being a sojourner, as essence, is a way of reaching out to those suffering in the community. The nurses lived as courageous, responsible people who sought to bring relief of pain and suffering.

10.3 Being initiated into the world of suffering

The nurses' new understandings of the nature, meaning and causes of suffering were described in the theme *Knowing suffering.* The essence of this theme was revealed as *B*eing *initiated* into the world of suffering. To be initiated is to be admitted into a society or instructed in a field of endeavour. The nurses were admitted into the world of the client and carers' suffering and instructed in the art and science of helping those who suffered.

This essence reveals the nurses' being as they told of how they came to understand and identify the suffering of clients and their carers. The nurses reflected on the meaning of the experience of suffering and how they would know suffering when this occurred. They reflected on the ways in which people suffered and what caused this suffering.

10.3.1 Finding meaning.

To be initiated into the world of suffering was to search for meaning and purpose in this suffering. The nurses needed to understand why seemingly senseless suffering was visited on people. It was even more difficult to understand the suffering of children and young adults who anticipated many more years of living. The nurses sought meaning for the suffering they saw and some were successful. Religious or spiritual beliefs were a source of understanding for some of the nurses. Others accepted suffering as being a part of the experience of living.

Finding meaning in suffering was essential to be able to help the suffering find their meaning. The clients sought an explanations for their suffering. Some believed it was retribution for past sins. This view was not held by the nurses. Perhaps such a punative perspective is incompatible with a caring philosophy. Two of the nurses could find no meaning in the suffering witnessed thus making them more vulnerable to suffering.

The nurses sought for something good to result from the suffering. They looked and waited for signs. They were pleased when the sufferer or the survivors discovered some meaning or goodness emerge from their trials.

Those nurses who believed there was some meaning or goodness that could come from this were better able to help their clients seek and find meaning.

10.3.2 Experiencing and managing emotions

The nurses experienced many emotions they could not express openly. They were saddened and distressed by witnessing suffering. They were horrified and repulsed by the visible destruction and decay of the clients' bodies.

These emotions had to be controlled and contained when giving care to the clients. The nurses were saddened by the suffering they saw but shed their tears in private. Feelings of revulsion at the sight and smell of damaged bodies were put aside to give care as lovingly as possible. The nurses looked past the horror to focus on the human being inside the damaged body. Dealing with the body was accepted as part of nursing's brief and they acted in ways to reduce the client's suffering.

The nurses were angered by situations and people they believed caused Anger was an emotion that had drawn the nurses to the care of those suffering and drove some away. A number of nurses chose palliative care after becoming angry and disappointed by the poor care they saw given to the dying. There was also anger expressed towards doctors perceived to have failed in relieving suffering. Alison, for example was angry with medical practitioners because the way her family doctor chose to approach the care of her dying mother. Her emotional response to poor care had to be tightly controlled.

> *I saw a lot of bad practice and I had to be very diplomatic about dealing with it when instinctually I really wanted to get very angry and personally abusive towards them.*

The nurses sometimes bore the brunt of client and carers' misdirected anger. They were hurt and distressed by this anger but again had to manage their emotions and respond in a helpful way to their clients.

The nurses were frustrated knowing they could reduce the pain and suffering but someone or something stood in their way. They were powerless and could only watch events unfold.

10.3.2 Observing with care

The nurses learned about suffering and people by careful observation. The nurses made judgments about the causes of the suffering they saw based on these observations. The situations in which the nurses found themselves were complex, particularly in the realm of human relationships. They nurses became aware of family conflict which were sometimes covert but often overt. They observed and identified indications of suffering. These indications included behaviours and bodily changes. The nurses also listened to glean cues from the clients' words about their feelings. The wounds and other physical signs of bodily decay were difficult for the nurses to see but they hid their feelings of revulsion.

The nurses saw anger sometimes directed at them but most often the carer was the target. Tanya was one who commented on what she had witnessed in one household. She saw both the anger and the effect this anger had on the client's carer.

> *What I as an onlooker to in this situation [saw] was that the client was stressed and therefore chronically angry.*

The nurses also observed the relationships of the client and their carer or family. Troubled relationships could lead to suffering for the client or their carer and prevent the client from achieving their wish to die at home. The careful observations made by the nurses showed causes of client suffering which gave direction for intervention after full assessment by the nurses. The nurses

10.3.3 Demonstrating sensitivity.

The nurses were sensitive in their approach to clients and carers showing tact and delicacy in their approach. They were aware that some individuals were unable to face their diagnosis of cancer and the prognosis they had received. They were empathic and understanding when clients could not accept their fate and rejected the nurses' help. The nurses endeavoured to establish a beginning relationship that would allow the client or carer to feel able to seek their help in the future. Trying to force a client to face their diagnosis was not helpful and prevented access to help in the future.

Marie told of a situation where a nurse had tried to make a client face the reality of her diagnosis and impending death. This was a lesson.

> *She [the nurse] got sent away very quickly because I guess she was just trying to get her [the client] to face whatever reality, the reality was her reality, what she made for herself. Okay it wasn't the ideal but that was how she was dealing with it.*

Lack of sensitivity deprived clients of future opportunities for care. The nurses were sensitive in their responses to the client's choices so long as these were not harmful to the nurses or client.

They were also sensitive in how they dealt with family conflict, troubled relationships and disagreement with treatment choices of the GPs.

Being initiated into the world of suffering is a way of the nurses' being students of this world. They tried to make sense and meaning of this world and to learn how to recognise suffering and its causes.

10.4 Being all that they could

An essence of the theme, *Giving nursing care*, was revealed as *Being all that they could*. This essence contributes to an understanding of what it is to be a nurse caring for people who suffer. Being all that they could describes the being of nurses challenged by providing the clients and their carers with all the care they could give during this time. They gave physical and emotional care and control to their clients and the carers. In being all that they could the nurses gave something of themselves.

Being all that they could required the nurses to use all their knowledge, skills and the technology available to the clients' care. These clients wished to die in a familiar place and with the people they loved – their home.

Being all that they could is an experience demonstrating clinical competence. The nurses learned all they could and honed their skills to provide the care needed. The care required more than the nurse could offer so seeking timely help from other professional was essential. Relationships with others and knowledge of what they had to offer was therefore part of this caring.

10.4.1 Demonstrating competence

Careful assessment was the first demonstration of nursing competence. The nurses sought to provide holistic care and the assessment reflected this. The carers were essential to enabling the client at home so there was an assessment of their willingness and ability to assume this role. The nurses assessed the physical, social and emotional environment of the client and carer.

Skills in developing rapport with the clients and carers quickly were required since referral sometimes came at the very end of life. Assessment was a constant process measuring the changes in the clients' and carers' circumstances and condition.

The nurses became adept at recognising indications of suffering and assessing the causes of this. They had leaned much from their observations when initiated into suffering. There were individual differences in how clients demonstrated their suffering. There were also differences in how open clients would be about their suffering. These individual differences recognised by the nurses were related to the client's gender, age, cultural background and personality.

The nurses were confident of their competence in easing some pain and suffering of their clients through the use of medications. This aspect of care required a collegial relationship with the clients' GPs since they had the legal responsibility for prescribing these drugs.

Kirsten was confident of her skills.

> *I know that I've got the knowledge to alleviate a lot of the physical symptoms.*

The nurses therefore needed competence in building and maintaining relationships with other professionals involved in the provision of client care. This was not always easy but some of the nurses were better able to put aside past grievances to foster these relationships for the sake of client care.

Most participants were CNCs so they advised the primary nurses who actually gave the care. Implementation of their suggestions was dependent on the receptiveness of the primary nurse to these suggestions. The CNCs were aware that they needed to develop a trusting relationship with the primary nurses to ensure that the client received the care suggested and that they received feedback on the effectiveness of these interventions. Melissa was one who acknowledged the importance of this relationship and showed how she worked at building rapport with the primary nurses.

> *It takes time to build that [rapport] up and it takes trust on their part and my part and they have to know who I am and where I am coming from and the way I work as well as [that] I have to educate them and find out who they are and how they work.*

Carers and clients had control of the administration of the pain medication so their choices in administering the medications affected the efficacy of the drugs. Again the nurses' competence and the appropriate medication did not ensure relief for the client. Clients had fears related to the use of analgesics and their carers were not likely to cause dissention over a refusal to take these medications. The nurses' interpersonal skills in developing trust and allaying the client's fears were put into play for clients to put aside their fears and accept the offerings intended to relieve their pain and discomfort.

10.4.2 Countering helplessness

In being all that they could, the nurses recognised the client and carer's feelings of helplessness as they realised that their future, as they had envisioned it, was gone. There was nothing they could do, no treatment they could seek, and no one to save them. The nurses, in being all that they could, strove to counter feelings of helplessness and despair when giving over power and control o clients and carers in as many ways as possible.

The clients' choices were accepted and supported where this did not compromise the safety of all concerned. The nurses never presumed a familiarity when entering clients' homes but always acted as a guest in the home.

Giving information and teaching the clients and carers skills gave both clients and carer control. Giving information on alternative strategies or choices enabled the clients to make decisions more confidently. The nurses discussed the possible changes or complications of the disease, the effects of medications, or any other issues thus preparing the clients and their carers for avoiding problems and knowing when to seek assistance.

All of these things were especially pertinent to the parents of children who were dying. Knowing what to do, what to expect and when unexpected problems were arising allowed them to continue in their parenting role. This allowed parents to be confident and comfortable in nurturing and caring for their child in a way they knew was right for them.

The nurses learned not to encourage dependence and helplessness. After giving the client and their carer the information necessary for decision making, they encouraged clients to initiate action themselves so demonstrating a commitment to the course of action. Lillian spoke of learning her pursuit of an action did not mean client commitment. In the past, she had tended to manage everything for the clients but they did not always follow the course of action through to its conclusion. She realised she could not control everything.

> *You learn what works and that basically you can't fix everything and that these people, if they are going to be committed to going to see a social worker their very first step is making the appointment themselves.*

Being all that they could was conveyed in the support the nurses provided, particularly to the carers. The dearest wish of their clients was to die at home in familiar surroundings. Supporting the client and carer in achieving this goal was also the nurses' goal. They understood the desire to stay at home. This desire to be at home linked with the clients' need for control. A terminal illness was something they could not control but in remaining at home, they could retain control over the small every day decisions. They could eat when and what they liked. They could rest when they liked without the noise and routine of a hospital setting.

In considering the client, the nurses had also to consider the potential carer's ability and strength in taking on the carer role. The nurses supported the choices of individuals who were potential carers and bolstered their confidence.

10.4.3 Being perceptive

The nurses in being perceptive were intuitive and insightful. They were aware of the clients' and carers' feelings and were able to provide opportunities for them to speak of these. There was sometimes conflict between the client and their carer and the nurses recognised when both needed to vent their feelings separately with out feeling judged. They provided opportunities for client and carers to have their full attention and speak freely. Tension was reduced in a way that did not escalate the conflict.

The nurses also listened to feelings of grief, loss and sadness. They were unafraid of facing the suffering of others and provided openings indicating they were willing to hear all the client or carer needed to say.

The nurses were intuitive in being able sense the client was ready to discuss their dying and to accept help.

> *You can just be there and give them the opportunity to talk about it [suffering] and I think he got a few surprises when at times I was able to acknowledge where he was coming from.*

Sandra commented on the surprise of one her clients at the accuracy of her perception of his experience of his illness.

When being perceptive the nurses demonstrated empathy, compassion and an understanding of the human condition.

10.4.3 Taking risks

In being all that they could the nurses were in danger of being over involved with their clients and carers. The nurses became emotionally involved with their clients despite having been taught this was unprofessional. They could not provide the desired quality of care without some emotional investment. This involvement opened them to the possibility of experiencing grief and sorrow.

As one of few regular visitors to the home, the nurses sometimes were drawn into a relationship closely resembling that of a friend or family member. Whilst this was comforting to clients, it was a temporary state. The relationship ended when the client died. Caution was required with bereavement visits following the death of the clients so that these visits served their purpose of helping with the family grieving process rather than the needs of the nurse.

Dangerous practices for the nurses included giving some clients their home telephone numbers when there were after hours' services available. This practice could suggest a lack of trust in their peers or a need of the nurse to be special in some way. Most nurses in the study rejected this practice as being unfair to other clients and unsustainable for the nurse. Failure to refer clients to the primary nurses, with out good reason, could also indicate a problem in relationships with primary nurses or letting go.

The nurses took risks with their hearts when giving care. They could not distance themselves from the clients and some emotional involvement was necessary to care in the way thought most helpful. The nurses gave something of themselves to relationships with many clients. They listened to the clients' and carers' grief and sorrow and sometimes shared their tears. The attachments that formed between the nurse and the clients and carers led to feelings of anxiety and helplessness if they could not alleviate or reduce the client's suffering. The nurses experienced grief and sometimes wept with the family when the client's death was imminent. Kirsten's experience when a client was close to death demonstrates this.

> *We had a big cry with her mother outside. You know her mother was crying and things like that.*

Over time, the grief accumulated if the nurses could not find means of closure.

Being all that they could was emotionally demanding but satisfying. In addition to requiring technical skills, the nurses were perceptive and compassionate. They became emotionally involved thus exposing themselves to suffering grief and loss.

10.5 Being enhanced

The nurses described how they received something back from the clients to whom they gave nursing care. The essence of the theme, *Receiving something back* was experienced as *Being enhanced.* Being enhanced was to be enriched, elevated and strengthened. The nurses became more than they had been when receiving something in return for what they gave. The experience of receiving was not always positive but overcoming their negative emotions was strengthening. They became more resilient and wiser.

10.5.1 Receiving acknowledgement

The nurses were enhanced when clients and carers acknowledged their contribution. Being acknowledged was the recognition that they had made a difference to the clients' lives in reducing their suffering by their actions or their presence. They also made the dying and death more bearable for the carer and family. The nurses had received verbal and written acknowledgement of their contribution. The welcome of the nurses into the clients' home was also an acknowledgement of the trust the family had in the nurses' care and professionalism. This acknowledgement enhanced the nurses' belief in their competence as nurses and humanity as people. The wounding aspects of their role were rendered less painful and their efforts and struggle became worthwhile.

Acknowledgement by their clients was especially important as the nurses received little praise from the nursing administration and this hurt them at times. The pleasure they took in being acknowledged was obvious as they told of this. The hurt at the failure of the nursing management to acknowledge their care of, and concern for, the clients was also obvious. Not all that they had invested in their role was valued and sometimes they felt misjudged. Beth, for example, commented on her hurt when reprimanded. She believed she had handled a difficult situation well to the benefit of her clients.

> *You've got to be open to criticism in work but you've got to get a bit of positive reinforcement. That is all we're looking for, not praise just acknowledgement you know.*

There seemed to be little understanding or awareness of the nurses' role and their commitment to this. Recognition was given to the doing aspects of care but little to their spending time being with, and listening to their client and carers. These were important to relieving suffering. As community nurses their work was hidden from the gaze of others. It was the clients and their families who knew what this labour entailed and how much of themselves the nurses gave to client care. Their emotional work was not recognised.

10.5.2 Gaining wisdom

To become wise required the nurses to reflect on their own life experiences and to be present and listen to the client and carer's stories. The nurses gained wisdom from watching and listening to nurses and other allied health professionals who demonstrated a caring, sensitive approach to the clients. The nurses who were able to be present and open to the clients' suffering learn from this experience. The wise nurse provided openings for the clients and carers to speak of their grief and suffering. They knew when the client or carer needed time to speak of feelings they could not share with each other. The nurses in the study expressed this as giving permission for the clients to express their emotions and to shed their tears. They made a space in time and place for the client or carer to express their feelings. To be wise was to be unafraid of the emotions of others and to be able to contain these. Wisdom was knowing when and what they might foster the clients' hope in place of despair. Wisdom was knowing when to speak and when to remain silent. The wise nurse knew her own weaknesses and flaws and was honest about these and developed strategies for self protection.

10.5.3 Learning about love

The nurses were enhanced when seeing the love that was demonstrated by carers and clients. It was a privilege and inspirational to witness the great love shown by people soon to be separated by death. Many family members made sacrifices to be a carer and gave this care with love and tenderness. Those who chose to care for a dying partner, or family member, were able to survive the difficult times when pain and suffering were too much for the client to accept and bear with equanimity.

The love the nurses saw was one of the gifts they received. Beth, for example, commented of the love that she had seen demonstrated by the husband of a young woman who was dying.

> *There was the most loving, attentive husband. They both said they that they'd had a wonderful marriage and you didn't need them to tell you, you could just feel it.*

It seemed that for most carers making the commitment to care was born of great love. Dying clients sometimes showed their love for their family with their last words and actions. Whilst not all families were loving and kind and taking on the caring role was a great strain the nurses witnessed much love. They found working with a loving carer or family to be inspirational and rewarding.

Witnessing of love was emotionally moving and showed the nurses what love could be. Love was the glue that held everything together at this painful difficult time and being in the presence of this love was uplifting

10.5.4 Overcoming adversity

The nurses' ability to continue to care for the suffering in spite of the wounding and distress they felt at times showed endurance. The nurses were enhanced when finding ways to overcome adversity. There were a number of adverse experiences and the nurses persisted in finding strategies enabling them to continue to find joy and fulfilment in their caring role.

Isolation was an experience that caused them to be lonely and distressed. Most nurses did not share their angst over the suffering they saw; particularly unrelieved suffering. They kept their grief and suffering to themselves for a number of reasons. Firstly, it would be unprofessional to discuss clients and they feared that they might inadvertently reveal something about their client when speaking of their distress.

Keeping silent at home meant keeping the suffering at bay and protecting their family from knowing about the suffering. This could be a lonely experience

The nurses became tired. Other adverse experiences were feelings of failure and sadness when unable to relieve the clients' suffering

The nurses found ways to deal with hurts, grief and frustration they could not generally share with family or friends. Most sought counselling, debriefing and clinical supervision.

Others attended workshops to learn to deal with their emotions and those of others. Some participants identified writing poetry and keeping journals as useful strategies.

10.5.5 Facing mortality

The constant confrontation with their vulnerability and mortality was difficult. Suffering and death came to people like them, or those they loved, so there was no armour against disease, suffering and death. No one, despite their knowledge or care, was immune to suffering. This was something the nurses learned and came to accept. They were aware that sometimes their distress about a client or situation was related to the similarity to them or their situation.

Alison was aware of the arbitrary nature of the onslaught of disease and suffering. She had seen her mother die a painful death.

> *It just affects you somewhere. You just think it could be you.*

In being enhanced the nurses became more than they had been. They were stronger, wiser and clients validated their practice. Whilst they were wounded by experiences such grief, sadness and loneliness they learned the importance and value of love and care and were inspired by people they had met.

10.6 Being mindful

To be mindful is to be careful and aware of dangers faced on this journey. The dangers could be those from within themselves or external. Nurses who lacked self knowledge and insight were most at risk. Safety lay in knowing when to seek help and accepting that help.

10.6.1 Being Honest

In order to maintain their emotional stability the nurses had to be honest with themselves and others about how they were coping with the suffering they witnessed. Most had identified that they had been socialised to believe that a good nurse should remain calm and in control no matter what circumstances arose. Inability to cope was a weakness frowned upon by their peers. It was therefore difficult to admit that they needed help. Four of the participants stated they had sought counselling independently of their employing organisation for assistance.

Honesty was a first step in the development of self knowledge. The nurses reflected on their responses to clients and carers and thought of what these responses revealed about them. The nurses needed to discover their own limits and act before these were exceeded.

The nurses reflected on their reactions and responses to particular situations or clients. They spoke of realising when these responses or feelings related more to meeting their own needs for control, intimacy or the need to be special.

Past sorrows or painful experiences could be the reason for feelings of sadness or anger. Reflection and conscious awareness of the impact of the past enabled the nurses to own their own feelings of grief and sadness rather than attributing these to the clients or carers.

The nurses were honest about their behaviours when interacting with family members. Lillian had realised her children sometimes bore the brunt of her distress or frustration and the need to control expression of these in the work place.

> *You know you have to sort of do your very best to be nice and then you go home and it's like you don't have to be nice to your kids and I think I'm beginning to see they get the raw end of the deal.*

They employed a number of strategies to protect their families and to prevent the suffering from entering their family life. One way in which suffering could enter family life was through family interactions when the nurses were tired, distressed and perhaps irritable. Most nurses hid their feelings of sadness from their family sharing nothing of these.

10.6.2 Knowing oneself

Awareness of bodily responses revealed to the nurses when they were tired. This was a time when they were at risk and unable to continue being emotionally present for their clients. Fatigue affected their ability to listen effectively to the client so hearing their expression of suffering.

They were in danger of experiencing health problems both physical and emotional. Sleeplessness, illness, irritability were indications of excessive fatigue. Failure to recognise the physical and emotional burden carried was a danger in that the nurses could be unable to continue in the caring role and of suffering themselves.

> *I get emotionally tired. I get tired and I think I've learned to recognise that.* – Melissa

In knowing themselves the nurses needed to be able to seek and accept help when they became aware that they were experiencing difficulties and this was difficult for the some of the nurses. They were the helpers, the strong ones, and the givers. It was more difficult for the nurses who were CNCs. The CNCs felt a responsibility for the primary nurses and they were aware of factors that might make the primary nurses more vulnerable to being overtaken by the suffering. These factors might have included heavy workloads of palliative care clients or some personal losses they experienced.

They supported and advised the primary nurses as part of their role but who could they turn to when in need. For some help was too late. It was almost as if they could not see the danger they were facing.

10.6.3 Protecting self and family

The nurses in being mindful took steps to protect both themselves and their families. They created ways to build boundaries between the world of suffering and the world they returned home to each day. Mentally they distanced themselves from work as they returned home each day and prepared them for the transition from home to work in the morning.

Most of these nurses had provided palliative care for many years and over time had learned to achieve a balance between being overly involved and distancing themselves from their clients. Sandra, for example, believed she had achieved that balance.

> *I believe I do a better job because I am involved as opposed to be stand offish or what ever but I also am very careful. I have strong boundaries.*

In protecting themselves and their families the nurses maintained a silence about their work world and endeavoured to prevent contact regarding work when off duty.

They spoke of sometimes feeling a need to cleanse themselves on returning home. The suffering they witnessed seem to have polluted their bodies and clothing so had to be removed to keep it from their home. The nurses endeavoured not to think about the suffering or speak of it when with their families or friends.

10.6.4 Practising thoughtfulness

To be thoughtful indicated giving serious consideration to issues and to meditate on these. When practising thoughtfulness the nurses considered and reflected on their responses to the suffering they saw and what these responses meant. They reflected on their feelings and actions and questioned these at times. Reading, journaling and observing others assisted with this. Their reflections increased self awareness and the search for ways to help themselves. The nurses, as individuals, chose ways of self help that suited them. A number of the nurses sought clinical supervision as an aid to this process. Debriefing also enabled the nurses to tell of their concerns and worries. They then heard their own stories.

10.7 Summary and conclusion

This chapter provides an explanation of the meaning in the nurses' experience in being a nurse caring for the suffering. Adding to the first layer of meaning obtained from the description of the nurses' conscious experience of caring for suffering people. A second layer of meaning uncovered the experience as being a nurse caring for the suffering. Five essences of the phenomenon were uncovered and gave this further layer of meaning. These essences, as laid out in the chapter, reveal what it is to be a nurse caring for the suffering.

Chapter 11 – Conclusion and Discussion

11.1 Introduction

The investigation of the experience of palliative community nurses caring for people who suffered employed research methodology and methods underpinned by the philosophical traditions of the streams of phenomenological thought. The aim, when undertaking a phenomenological study, is to describe a particular phenomenon in human experience so illuminating the essential nature of the experience. This illumination allows it to be recognised, understood and the results of the research to be trustworthy in informing the field of endeavour being investigated.

The nature of the phenomenon of caring for people who suffer is presented as a phenomenological description of the experience of nurses providing palliative care. The phenomenon of community palliative nurses caring for people who suffer is described as one in which the nurses are on *a mission of privilege and peril*. This description is the final stage of this phenomenological study and encapsulates the core of the experience in a single phrase.

11. 2 Analysis and meaning

The analysis of the data firstly described the conscious experiences of the nurses participating in the study. A further analysis searched for an understanding of the being of the nurses when caring for people who suffered. Two layers of meaning were revealed through the process of analysis. The layers of meaning uncovered provide the full phenomenological description of the experience of the nurses and the method of analysis determines the meaning revealed. Each layer revealed a deep description of the phenomenon but when both layers of meaning were considered fully a complete and cogent description is provided.

11.2.1 The description of the phenomenon through consciousness

The first layer of meaning was uncovered through thematic analysis. In search of understanding of the phenomenon of caring for the suffering, the nurses' transcribed accounts were scrutinized for the messages contained within them. Five themes were developed from the messages and these provided a description of the phenomenon. This description was obtained from accounts of the nurses' conscious experiences. The term, *aspect was* used for the clusters of meaning held within each theme. These aspects formed the structure of the written description of the themes.

Five themes were necessary to the description of the phenomenon. These were present in the experience of each nurse participating in the study. Therefore, these themes are essential elements in the experience of these nurses caring for suffering people

The first theme, M*aking the journey*, surfaced in the nurses' accounts of how they came to be nursing where there was much suffering. In making the journey, the nurses identified a number of pathways apparently leading them to palliative care nursing. Once they began the journey, they found they had both an attraction and talent for this field of nursing. The experience of those nurses who left the journey and the events that led to them leaving were described as part of the journey. In *Knowing suffering* the nurses shared their thoughts on the nature, meaning and purpose of suffering and identified how they recognised suffering and factors they believed caused suffering. The theme, *Giving nursing care,* described the requirements for nursing care of suffering clients. This care giving incorporated the nurses' giving emotionally as well as giving clients physical care, support and control. The nurses received something in return. In *Receiving in return,* the nurses described both the rewarding and painful results of their care giving. The rewards received outweighed the painful and distressing results of giving care. The rewards held the nurses to this practice. Caring for people who suffered exacted a high toll on nurses and in *Finding a balance* the nurses revealed the measures taken for self protection.

Following a process of interpretation of the nurses' accounts these five essential themes provide a full description of the phenomenon of caring for people who suffer and provide the first layer of meaning. They are drawn from analysis of the conscious experience of the nurses discovered through questioning the data from the nurses' accounts to determine the meaning of these experiences.

11.2.2 The description of the phenomenon through interpretation

Following the establishment of the first layer of meaning from the nurses' descriptions of caring for suffering people, further reflection revealed another layer of meaning. The questioning this time sought to discover what it is to be having that particular experience rather than determining what the nurses were sharing about the experience. For example, in the case of the final theme *Finding a balance* the question asked of the nurses' accounts was what it was to be a nurse finding a balance? The answer for this theme was *Being mindful*. Each theme was questioned in this way. In this way the total experience of the nurses' experience of caring for people who suffer was sought.

The phenomenological approach chosen for the study required a hermeneutic interpretation of the nurses' experience. A further interpretive analysis undertaken of the findings of the thematic analysis revealed five ways of being. These are the essences of the phenomenon and provide a second layer of meaning.

The nurses chose a care setting directed towards caring for suffering people had their being in *Being a sojourner*. These nurses took a journey into a world of suffering they found after some searching and which was satisfying to them as nurses. Being a sojourner meant being responsible for others, being redeemed, and being exposed to sadness and other emotions. The sojourner was also courageous. In *Being initiated,* the nurses sought meaning in the suffering they saw when confronted by seeming senseless suffering. They experienced many emotions and learned to manage these. When being initiated the nurses learned to observe and to be sensitive. An essence, *Being all they could*, described the nurses being for their clients and the carers. They were competent in providing nursing care and aimed to reduce the helplessness felt by their clients. To be all that they could was to take risks. *Being enhanced* shows the being of the nurses in the joy and satisfaction they experienced in their role. They were enhanced by the wisdom and knowledge acquired and by their ability to overcome the effects of the sadness and other wounding experiences. In *Being mindful,* the nurses sought to protect themselves and their families from the suffering. To be mindful was to be honest, self aware and perceptive. Being mindful was an essential part of being in order to survive.

11.2.3 The phenomenon as a mission of privilege and peril

Two layers of meaning were revealed when investigating the phenomenon of nurses caring for suffering people. The first used the nurses' conscious experience. The second layer focused on interpreted meaning of being. While each layer alone may have been ample for the purpose of the investigation, the uncovering and use of two layers gives a creative and more complete description. Lastly reflection on the findings of the two layers of meaning of the experience of nurses caring for suffering people was understood as *A mission of privilege and peril* for these nurses.

In describing the nurses' experience as being a mission of privilege and peril, the researcher's choice of the word mission reveals something of the experience. To be on a mission is to be on a journey to fulfil a goal. A mission requires dedication and connotes a vocation or calling for the individual on the mission. Whether the mission aims to do good for society depends on the nature of the mission's goal. The word mission is one used by the military, for example, when individuals place themselves in danger to achieve a goal for their society but may cause harm to others. In the context of this study, the goal is the care of suffering people. Those on this mission are committed to caring for their clients and bringing relief from suffering. This mission could be dangerous but also bring honour.

The nurses, as sojourners in the world of suffering, feel privileged when finding a care setting that allows them to practice in a way that was satisfying to them. They also took pleasure in giving what they believed to be effective and empathic care. There is a cost associated with giving palliative care. For some participants in the study the burden of the suffering and the responsibility for their clients weighed heavily on them. When undertaking a sojourn in the world of suffering the nurses are in danger of being overwhelmed by the suffering they see and by the sense of failure when unable to relieve client suffering. Whilst feeling rewarded by giving effective care and the appreciation of their clients the nurses also need to feel appreciated and cared for by their employing organisation.

Giving effective care requires nurses to give more than physical care. They cannot prevent some level of emotional involvement with the clients and their carers and the nurses considered some level of involvement to be beneficial to those for whom they care. The nurses, therefore, took risks emotionally when forming attachments to clients and families. These emotional attachments exposed them to grief and sadness. For some nurses the level of emotion generated during the dying and death of a client was overwhelming but fascinating. This heightened emotional climate was something that the nurses found satisfying and most who left the care setting missed this aspect of care giving.

The nurses needed to reflect on their own feelings and actions to determine if the needs met are their own or those of their clients. Nurses must set boundaries between their personal and professional lives to safeguard their emotional safety and ensure effective client care. Reluctance to involve other team members, or refer clients to others, and the need to control all client decisions are issues of concern for all professional groups involved in providing community palliative care. These behaviours are indicators for caregivers of possibly meeting their own needs rather than those of the client which adversely affecting client care. Distancing themselves emotionally from clients is equally as hazardous to both nurses and the client care. Wanting to be all that they could for clients was an added pressure for the nurses and those nurses leaving community palliative care experience a sense of relief at no longer having that responsibility.

The nurses felt honoured and privileged when admitted into the lives of their clients at what can be a sacred and inspiring time for the client and their family. This is an intense and emotional experience. The nurses believe the experience of giving care and being all that they could was enhancing. They could learn about life, gain wisdom and be shaped by this profound experience. There were painful aspects of the caregiver role but these also contributed to the enhancing aspect of the experience. Pain, hurt and grief provide opportunities to learn and grow.

Being mindful of the dangers to themselves required the nurses to be thoughtful, reflective and honest. Inability to seek and accept help when needed could place the nurses in peril. The ability to devise strategies for self-protection and self-care is vital for self-preservation.

The short phrase, a mission of privilege of peril, provides the final description of the phenomenon of nurses caring for suffering people and the meaning is consistent with the study's findings and these nurses are totally committed to their mission.

11.3 Discussion

This section provides a brief overview of the findings and a fuller discussion of a number of a number of issues raised by the nurses. In research informed by phenomenology, some argue that conducting any literature review before collection and analysis of data will influence the researcher's mindset and contaminate the process of reduction required for pure description. (Streubert Speziali & Carpenter, 2003). If taking that perspective the literature should occur after completion of interviews and data analysis (Burns & Grove, 1997). In this study, the literature was reviewed before data collection and analysis to substantiate the need for the investigation. The initial literature review focused more generally on suffering. A further review of the literature was conducted following data analysis, to situate the findings in the context of what has already been discovered particularly in relation to palliative care in the community. The findings of the second literature review are included in the following discussion of the implications for nursing practice, education and administration arising from the study.

The study's main finding is that the nurses' experience of caring for suffering people in palliative care is one which gives great satisfaction and brings them an intense emotional engagement with their clients. Though rewarding, this experience places the nurses at risk. In caring for people who suffer, the nurses become as if on *A mission of privilege and peril.*

11.3.1 Issues for nursing practice

There were a number of issues raised for nursing practice in the nurses' accounts of their experience when caring for suffering people. The nurses' experiences, described in Chapter 5, as making the journey indicate that these nurses believed they possessed the personal qualities required for caring for suffering people in palliative care and they recognised this once they began practice in this context. Little is known about the course of nurses' lives that draws them to palliative care. Gaydos (2004) studied the life journeys of 5 hospice nurses and found that nurses' past life experiences were an important element in their choice of practice and the way in which they practiced. These nurses had all experienced loss and grief before becoming palliative care nurses. In Webster & Kristjanson's (2002) study of long term palliative care workers, the workers found an initial connection with palliative care that first drew them then held in this area. Both studies had few participants but suggest a particular dedication to palliative care exists for these individuals. The primary nurses who have a variety of functions of which palliative care is one provide palliative care. The CNCs support and educate the primary nurses. These primary nurses have not chosen palliative care specifically so their commitment to these clients may differ from that of a specialist palliative care nurse.

In Chapters 6 and 7 the nurses discussed the causes of suffering and giving nursing care. There are numerous causes of suffering but many, such as grief and loss and long standing family problems, are not easily addressed. Grief is a normal response to loss. All participants referred to their relationships with GPs and emphasised the importance of the GPs to the relief of suffering. They believed effective care required a collaborative relationship with the clients' GPs. This could be changed. Some nurses told stories of excellent collaboration in the real sense of the word but these stories were outnumbered by less positive ones. Roberts (1990) referred to the importance of nurse and doctor collaboration for effective client care and noted the lack of a common understanding of this concept. What nurses viewed as collaboration doctors saw as supervision. Bailey, Jones & Way's (2006) findings were similar in a study of nurse practitioners and family physicians in Canada. The physicians did not understand the nurses' role and valued a more traditional doctor nurse relationship. Larsen (1999) found conflict between physicians and nurses led to neglect of patients needs. Larson noted that nurses were the most concerned about the need for improved relationships. All nurses in this study were concerned about their relationships with some GPs and believed poor relationships increased suffering for the clients.

The nurses believed inadequate pain control and delay or failure by some GPs to refer clients to palliative care services caused unnecessary suffering for their clients. Similar difficulties with GPs are reported in other studies of community nurses providing palliative care. (Austin, Luker, Caress & Hallett, 2000; Dunne, Sullivan & Kernohan, 2005; Seale, 1992). The nurses considered early referral assisted in establishing a trusting relationship with the client and carer thus avoiding meeting the client for the first time when they were in crisis.

The nurses believed a GPs' lack of knowledge of medications for symptom control increased client suffering. Buchan & Tolle (1995) stated the major barriers to physicians prescribing adequate pain medication were physicians' moral objection to prescribing drugs that would also hasten death. They also feared litigation or sanctions by professional boards. Finally, they failed to give some control to the patient and other members of the health care team.

Wicks (1998) studied the relationship between doctors and nurses. She found there was potential for palliative care patients treated in general hospitals to be subjected to numerous unnecessary tests when what they needed was symptom control. These tests may function to inform medicine rather than help the patient. The treatment of dying patients by doctors was an area of conflict for hospital based nurses and doctors. The CNCs in this study identified a preference for their clients to be admitted to a hospice or palliative care unit should they need symptom control. There were stories of the CNC intervening to insure client were admitted to the palliative care unit instead of the oncology unit.

In chapter 7 the nurses' spoke of what they gave in their nursing care. Whilst technical expertise was important the nurses focused on the importance of fostering independence and supporting the client and their care. They believed they did all that they could to give control to the client and acknowledged that the relationships between the client and the carer in community setting differ to those in a hospital. Clients would do as they wished in their home. The nurses understood loss of independence held a different meaning in palliative care. This was an indication that death was moving closer and fearful clients fought to retain control.

Another important aspect of their care giving was listening to clients. Nurses rarely have time to listen but this is an important means of relieving suffering. Frank (1995) spoke of the power of narrative in making sense of suffering. More recently, Kuhl (2005) a palliative care physician, found that dying people longed to be listened to and be known through their stories before they die.

The nurses' told of the emotional involvement and relationships formed with many of their clients. The nurses had been taught that being professional required maintaining an emotional distance. They were unable to do this. The nurses believed in giving something of themselves and engaging emotionally with their clients as they were able to care more effectively. There have been similar reports of nurses' beliefs that emotional engagement or at least a balance between engagement and distancing in settings is essential where the aim is the relief of suffering. (Carmack, 1997; Henderson, 2001).

The participants in this study found great satisfaction in caring for their suffering clients. They felt rewarded, joyful and experienced a sense of awe and privilege when allowed into the lives of their clients at this time. This is consistent with the findings of Sherwood (1991) and the findings of later studies of palliative care nurses (McNamara, 1999; Rasmussen, Sandman, & Norberg, 1997, Webster & Kristjanson, 2002).

In Chapter 8 the nurses identified a number of troubling aspects of their role. These included feelings of isolation, sadness, fatigue and helplessness. Three of the participants had sought counselling in the past and a number believed they would be helped if clinical supervision was available to them. Jones (2003) suggested that clinical supervision could be helpful to palliative care nurses in a number of ways. The nurses may be assisted in recognising some aspect of the work organisation that needs changing, managing relationship with others both inside and outside work, searching for meaning in their work and dealing with the strong feelings aroused by their work. Access to debriefing was not always available when needed and this was frustrating for the nurses. Debriefing was not something one could schedule in advance. Community nurses are isolated in a way not experienced by nurses employed in an institutional setting so access to another for the sharing of their feelings was not always possible.

The nurses believed that most patients' painful and unpleasant symptoms were controlled by various analgesics and other medications. Uncontrolled pain and client suffering was distressing for all those involved in the care giving. The nurses felt distress, helplessness and failure when this occurred which confirmed findings in the literature (Bennett, 1993; Davitz & Davitz , 1981; Steeves & Kahn, 1994). They believed that this suffering required careful assessment since it was most probably related to a social, or spiritual or existential concern. A recent study of palliative care nurses by White, Cooper, Wilkes & Barbato, (2004) found similar responses to unrelieved suffering in their informants.

The informants in regional settings were disturbed by reports of family conflict and domestic abuse. The female carers most often reported abuse by the client in the past.. Family conflict and troubled relationships were considered a source of suffering for both clients and their family. The impending death of the client made the conflict more intense at times. Fisher (2003) wrote of the lack of discussion and research on abuse in families receiving palliative care and how nurses coped with this.

In Chapter 9 the nurses spoke of how they protected themselves and their families. The nurses were aware of the difficulties of managing their emotions and those of the clients. Whilst they felt emotions such anger, grief and revulsion, these emotions were controlled to maintain the emotional safety of their clients and provide comfort rather than the nurses being seen to need this. The nurses reflected on the underlying cause of these emotions and endeavoured to be self aware. They were also aware of the difficulty of this emotional work. The nurses did not use the term emotional labour but there is increasing discourse on this concept relevant to nursing suffering people. In order to protect themselves from over-involvement the nurses developed strategies that over time helped them find a balance between distancing and over involvement through what they described as creating boundaries.

11.3.2 Issues for management

The nurses in the study all spoke of their fatigue and how they managed this. They took leave throughout the year as dictated by their fatigue levels. Ekstedt & Fagerberg's (2005) phenomenological study investigated eight people diagnosed with unspecified maladjustment disorder that met the criteria for high burnout scores and had taken sick leave of three months or more from their employment. The participants were not nurses but the symptoms they identified before burnout echoed some of those identified by the participants in this study.

Flexibility is required in approving leave and time in lieu of additional hours worked. Replacement of staff on leave is essential for maintaining the nurses' health and wellbeing and retaining them in the workplace.

The emotional contribution that nurses give to their practice needs recognition. The nurses in this study sought strategies to assist in managing their emotions and to provide time for work of caring. The physical, or doing aspects of nursing, can be measured in terms of time but the emotion work is ignored. Whilst debriefing is offered to the nurses it is not readily available to community nurses when they need this. Opportunities for clinical supervision by individuals trained for this purpose is essential. From the nurses stories they sought assistance independently of their employing organization or sought help from the palliative care social workers where they could. Often organizations outsource staff counselling services. Some nurses refused referral to these services. If supervision processes are introduced to the workplace, it is essential that those supervising must be adequately prepared for this role.

11.2.3 Issues for nursing education

It is clear that all nurses will care for someone who suffers during their career. It is argued that student nurses require preparation for caring for the suffering. The nurses in the study found their ways of caring for people who suffered and coping with the aftermath of this. They were aware of the importance of self knowledge and the importance of seeking and accepting help when needed. Student nurses require education about self care and strategies for this. They are familiar with the concept of debriefing but the concept of clinical supervision is unfamiliar to many nurses and often ejected because of misunderstandings of its nature and value. Educational programs for both nurses, doctors and the interdisciplinary team members encouraging effective communication, cooperation and collegiality would be helpful for future team building and patient care. (Street & Blackford, 2001, Mulder (2000) a palliative care physician, noted she had not been prepared to be a team player and so was less able to offer support to others and able to allow them to support her. Sharing some unit of study may aid in developing a more collegial relationship between nurses and doctors.

11.4 Conclusion

The aim of this study was to investigate what it is like to be a nurse caring for suffering patients. I had experienced this previously only consider that in most settings, suffering does not loom as large as in palliative care. Listening to these nurses, reading their words, then reporting on the progress to fellow students filled me with pride. These wise, intelligent, generous women were nurses. Their wisdom, insight and humour amazed me.

When beginning this project I had not realised the enormity of the task ahead of me. I had chosen phenomenology as the research method. According to van Manen (1997), this required me to turn to the *lifeworld* and conscious experience of those who could tell me of the experience of interest. In seeking to understand the experience of the participants when caring for people who suffered, I read and reread their accounts of their experience searching for the messages in these accounts. This was the first stage of the analysis. The numbers of messages and wondering how to capture their meaning overwhelmed me. When rewriting the messages I asked myself what the nurse was telling me about this experience seeking a way that my insight could be transformed into a meaningful thematic statement.

This was not easy but Van Manen (1997) described the relationship of theme to the notion being studied. Understanding the purpose of the themes provided me with a tool for getting to the meaning of the experience, describing the content of the experience and giving it structure.

I had no expectation of what the nurses would tell me as I had no experience of, or preconceived ideas about this practice area. I came as a stranger to the setting. I followed the messages where they took me and searched for the words of the participants that best captured the overall meaning of each theme.

Phenomenology is indeed an exercise of writing and rewriting. It was through writing and rewriting that I was able to develop the themes from the interpretation of the nurses' conscious descriptions of their experience. This provided a description of the experience of caring for suffering people so enabling me to contribute to the foundational knowledge base of palliative care.

An answer to the ontological question of what it is to be a nurse caring for people who suffer was then sought. Using the themes I uncovered an interpretation of the experience from the nurses' conscious description and the second layer of meaning was developed. This layer provided an answer to the question of what it is to be a nurse caring for people who suffer.

While the result of the first analysis revealed a description of the experience of caring for people who suffer it was the uncovering of a second layer which provided a deeper understanding of what it is to be a nurse caring for people who suffer.

The object of phenomenological research is not to explain or predict but rather to describe and understand a human experience. To do this requires seeing anew which demanded a profound commitment on my part to seek the truths of these nurses' practice.

The project also surfaced questions for further study and indicated possibilities for change. The nurses' experiences in this study were captured at a certain point in time. The structures of the health care system change, there are demographic changes and the goals of the health care system alter. There are beginning calls for palliative care services to be available for people with serious chronic illness and the aged. This would indicate a greater need for nurses skilled in caring for suffering people.

Caring for people who suffer is a complex, emotional and universal task of nurses. The nurses in the study found the experience fascinating and it left them with a sense of joy and fulfilment. There were also dangers for the nurses and dark times. Overall, the rewards for the nurses exceeded the pain of their wounds. The nurses gained from this experience of being nurses on a mission of privilege and peril.

Appendix – Consent Form

I ....agree to participate in the research project “The Lived Experience of Nurses Caring for Patients Who Are Suffering “ being conducted by

Beverley Pegg
Faculty of Nursing
University of Technology, Sydney.
PO Box 123
Broadway NSW 2007 Ph. No. [redacted]

I understand the purpose of the study is to explore what the experience of caring for people who are suffering is like for nurses.

I understand that my participation in the research will involve participating in four audio taped interviews that will last about one hour and providing information about my experience of nursing people who are suffering in written form or on tape at times between interviews. My personal reflection on this raises the risk of possible emotional distress. I understand that the interviews will be terminated on request, time will be allowed for debriefing and follow up will be provided if required.

I am aware that I am free to contact Beverley Pegg or her supervisor, Dr. Michael Walsh should I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish and without giving a reason.

I agree that Beverley Pegg has answered all my questions fully and clearly.

I understand that my confidentiality will be maintained and agree that research data from this study may be published in a form that does not identify me in any way.

Signed by
Witnessed by

INFORMATION FOR PARTICIPANTS

Dear Colleague

I am enrolled in the Master of Nursing course at the University of Technology, Sydney and am undertaking a research project aiming to discover what it is like for nurses caring for someone who they believe is suffering. Nurses, and other health care providers, are exposed to much suffering in their daily working lives but little is known about what this experience means for the nurse. The context for the study will be the provision of palliative care.

The research is based on a series of four interviews with registered nurses who have worked in the palliative care context for at lease one year. These interviews will take place over a time span of 6-8 months beginning in April, 1996. Participants will be invited to provide additional relevant material on cassette tapes or in written form between interviews. Interviews will last about one hour although it may be longer or shorter depending on how much you feel like talking. The interviews will be recorded so they can be analysed and will be conducted at a time and place convenient for the participants. Tapes and a cassette recorder will be provided for those participants who wish to tape additional material between interviews.

The study is confidential. A copy of the signed consent form to participate will be retained by the researcher for ethical reasons but these will be kept in a separate place to the interview data. A code name will be given to each participant and any identifying features will be changed on the interview transcript so participants cannot be identified.

Participants have the right to withdraw from the study or stop the interview at any time.

If you have any questions or require further information please feel free to discuss this with me. I can be contacted on ([redacted] .

Beverley Pegg.

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