

**HOME CARE NURSES' EXPERIENCES OF GRIEF  
AND LOSS WITH PALLIATIVE CLIENTS:  
A NARRATIVE INQUIRY**

by

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## Abstract

Home care nurses' experiences of loss and grief with palliative clients have not been well documented in the literature. Home-based palliative care nurses provide supportive care to dying clients at home that includes both pain and symptom management as well as psychological support. Psychological supportive care along the death trajectory has been identified as the most difficult aspect of home-based palliative care nursing. Home-based palliative care nurses require ongoing support for their personal experiences of grief and loss as they provide care to dying clients and their families.

In this qualitative study, narrative inquiry was chosen as the method to understand home care nurses' experiences with grief and loss. Ten participants volunteered for the study. They had more than two years experience in home-based palliative nursing care and were currently employed in home care nursing. Home care nurses' stories were analyzed from in-depth interviews for content, structure, and interpersonal factors. Findings of the study emerged from the narratives.

Three narratives were identified in this study: *balancing professional attachments*, *entering into suffering*, and *honoring the memories*. The findings of the research study have implications for education, administration, clinical practice, and further research. Home care nurses are currently practicing a variety of effective self-care strategies as they continue providing supportive care to dying clients and their families. The study findings suggest that the current organizational structure may be inadequate in providing home-based palliative care nurses with the ongoing support needed to provide supportive care to the dying within the context of a relationship.

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## Chapter I: Introduction

The hospice movement was developed in the 1960's in England by Dame Cicely Saunders who was educated as a nurse, social worker and physician (Saunders, 1996). Dame Saunders opened St. Christopher's Hospice in London in 1967 to provide care for the dying who often had poorly managed symptom control (Williams & Wheeler, 2001; Seymour, 1999). The hospice movement spread to the United States in the 1970's with a greater emphasis on the psychological preparation for death (Seymour). The client and family became a unit in need of care as they struggled to find meaning in their present experience. The definition suggested by the World Health Organization (WHO, 1990) reflects the philosophy of palliative care for clients and their families when cure of illness is no longer possible:

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. (p.11)

The hospice movement began in Canada in the 1970's centered mainly in hospitals (Williams & Wheeler, 2001). Dying continued to be an institutional experience although the occurrence was within a specialized environment (Stajduhar & Davies, 1998). Some clients and their families were unhappy with the care they received in hospitals that was based on the medical model (Seymour, 1999). The process of dying was extended as the western medical profession inadequately provided care for the terminally ill with aggressive and invasive treatments (Donaldson, 1998; Stajduhar & Davies). Physicians worked hard to save lives and felt like a failure when someone died;

death was something to be feared and conquered. With the palliative care movement emphasizing quality of life while dying, death became less feared and more accepted by some practitioners.

The terms palliative care, hospice care, and terminal care are used interchangeably throughout the literature when a cure for disease is no longer possible. Recently, the term supportive care has surfaced as an alternative to palliative care to describe the non curative treatments for the terminally ill (Payne, Sheldon, Jarrett, Large, Smith, Davis, Turner, & George, 2002). Palliative care nurses assist clients and their families to live to their full potential by addressing issues in the physical, spiritual, psychological, and social realms (Krisman-Scott & McCorkle, 2002). Palliative care nursing has a historical beginning based on the belief that care of the dying was of great importance.

### *Background to the Problem*

Home-based deaths has become a viable cost-effective option in an era of decreasing health care dollars (De Conno, Caraceni, Groff, Brunelli, Donati, Tamburini, & Ventafridda, 1996; Gomas, 1993). Hospital beds have become scarce as government cutbacks have affected hospital budgets. Palliative care can be delivered to clients in the home at a lower cost than a hospital admission (De Conno et al.). Dying in the hospital may soon no longer be an option as palliative care beds close. Palliative clients will either die at home or remain in hospital while on the waiting lists for scarce hospice beds. Dying clients are a vulnerable group in our society and care of the dying is an accurate measurement of our health care system (Donaldson, 1998). Adequately prepared home-based palliative care nurses will be critical to ensuring the health care system can

provide the support required for the dying at home.

Home-based palliative care can become a better alternative option to hospital based care (Jarrett, Payne, & Wiles, 1999) even though the majority of deaths presently occur in hospitals (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000). Care of the terminally ill involves supportive measures around comfort that can be provided in the home by a family caregiver who is available and willing. For some families, a dying loved one at home becomes a challenge and a burden (O'Neill & Rodway, 1998). Families become responsible for much of the physical care and may not have the opportunity to meet the emotional needs of themselves or their dying loved one. Exhaustion for the caregiver occurs when physical and emotional needs of the dying become prolonged and overwhelming. Home-based palliative care is successful only if there are adequate support services available in the community to support the family at home (Gomas, 1993).

The place of death is not a determinant of whether the death was a good or bad experience (McNeil, 1998). A good death is determined when a dying client is managed well symptomatically and is able to complete living and die without pain, peacefully and with dignity (McNamara, Waddell, & Colvin, 1995). Canadians cite five criteria associated with quality terminal care: maintaining adequate symptom control, avoiding prolongation of death, relieving caregiver burden, maintaining a sense of control, and achieving improved relationships with significant others (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000; Rittman, Paige, Rivera, Sutphin, & Godown, 1997). Other important aspects include the experience of dignity and respect and being at peace (Ruland & Moore, 1998). When a client has been adequately prepared for death, a good death can occur anywhere: home, hospice, or hospital.

As financial cutbacks to the health care system result in fewer number of hospital beds, the number of palliative clients in the community is increasing. Furthermore, as the acute palliative care beds are limited, there are increasingly more acutely ill clients remaining at home. Home care nurses often work independently throughout the day and do not have the support systems that oncology or hospice nurses have available at their worksites. Home care nurses often manage complex emotions alone that accompany the loss of a client as the available support systems are not easily accessible. Unresolved feelings of grief and loss can be stressful and without adequate education and support, emotional exhaustion and resulting burnout may occur.

Cancer deaths in the Vancouver/Richmond region are expected to increase 23% by 2010, from 1221 in 1998 to 1503 in 2010 (Vancouver/Richmond Health Board, 2000). The need for palliative care will be felt most acutely in home care nursing as the hospice and palliative beds are scarce. In the Vancouver area, there are two hospices, May's Place and St. James Cottage Hospice, that have a total of sixteen beds. Palliative care units currently exist at St. Paul's Hospital (12 beds), Burnaby General Hospital (11 beds), and Vancouver Hospital (14 beds). Although many clients have expressed wishes to remain at home during the final days of life, in reality, most die in the hospital. In 1998, only 20% of deaths were at home, while 65% were in acute care, palliative care units, or hospice beds (Vancouver/Richmond Health Board). Clients and families who have decided that a home death is not possible may have to wait for a palliative care or hospice bed to become available at the appropriate time. The only other choice is an admission to an acute care bed through the emergency department.

Palliative care nurses have been called midwives to the dying as nurses share a

client's dying experience (Boyle, 2000; Taylor & Amenta, 1994). Death is regarded as a normal process and life is affirmed, even when a client is dying (Williams & Wheeler, 2001; Payne, 2001; Vendlinski & Kolcaba, 1997). Many physicians believe the care of the dying is a nursing rather than medical responsibility as the physician's role diminishes when the client no longer requires therapeutic interventions with the aim of restoration to health (Goodman, Knight, Machen, & Hunt, 1998; Ruland & Moore, 1998; Davies & O'Berle, 1990). Palliative care consists of providing nursing interventions; thus, nurses are the most essential profession in the care of the dying (Wright, 2001). Many nurses find increased nursing expertise, job satisfaction, professional autonomy, and educational development as benefits to caring for dying clients (Goodman et al.). Sharing the experience of a client's dying process may result in an opportunity that is meaningful and privileged for nurses (Rittman, Paige, Rivera, Sutphin, & Godown, 1997). When a cure is no longer a possibility, nursing is able to provide the supportive care required which focuses on the relief of suffering (Krisman-Scott & McCorkle, 2002).

The work setting for home care nurses becomes the family home where the environment may not be controllable, predictable, or familiar (Coffman, 1997). As nurses are integrated into the family, professional boundaries may become blurred resulting in under involvement or over involvement (Taylor, 2002). Families may begin to view the home care nurse as a friend or guest and expect assistance with family conflicts (Durkin, 2000). Complex psychological issues often become the main focus of home care nurses as opposed to biomedical issues in the hospital setting (Wilkes, Beale, Hall, Rees, Watts, & Denne, 1998; Coffman). The therapeutic relationship may become intense as the home care nurse provides supportive care to the dying without the controlled environment of

the hospital or hospice. When the client dies, the nurse may have little or no occasion for expression of feelings around loss (Copp & Dunn, 1993). Home care nurses' experiences of providing supportive care differ from hospice and oncology nurses because their work environment becomes the client's home rather than an institution with safe boundaries (Wilkes et al.).

Home-based palliative care nurses' experiences of providing holistic supportive care differ from oncology or hospice nurses. Home care nurses, unlike hospice or oncology nurses, have not chosen to work exclusively with palliative clients. There is an expectation for home care nurses to provide palliative care to clients even though some may not have developed an interest in this field (D. Graham, personal communication, February 4, 2002). Many home care nurses visit palliative clients every day and are unable to limit the number of palliative clients on their caseload. Home care nurses have a generalist rather than a specialist approach to palliative clients and may lack the skills and resources needed to provide supportive care to the dying (Seymour, Clark, Hughes, Bath, Beech, Corner, Douglas, Halliday, Haviland, Marples, Normand, Skilbeck, & Webb, 2002). Home care nurses may function as case managers with the responsibility of delivering and coordinating patient care (Goodman, Knight, Machen, & Hunt, 1998). The research specifically on the roles and experiences of home care nurses working with palliative clients is scarce (Wilkinson, Salisbury, Bosanquet, Franks, Kite, Lorentzon, & Naysmith, 1999; Goodman et al.). Much of the work of a home care nurse remains hidden as the range and complexity of their role is not well understood.

Copp & Dunn (1993) identified problems that nurses experience when caring for the dying and their families. Their research sample included nurses from the acute

care setting, community, and hospice. Some areas of difficulty they identified were watching patients die, the intensity of the nurse-patient relationship, and fear of losing control. Copp & Dunn suggest reflective practice as a strategy to prepare nurses to raise their self-awareness and acknowledge their feelings when caring for the dying. Research aimed specifically at home care nurses working with the dying may increase our understanding of strategies that may be useful to overcome personal feelings when caring for dying clients at home.

### *Problem Statement*

The Regional Palliative Care Planning Project Report (Vancouver/Richmond Health Board, 2000) cites 30% as the palliative caseload for a home care nurse in Vancouver. In reality, an experienced home care nurse may have a much higher palliative caseload than the report estimates. The Home Hospice Program provides nursing support for palliative clients 24 hours a day, 7 days a week. After the death of a client, home care nurses admit new palliative clients to their caseloads and they may not have the time to grieve the loss. Continuing to provide care while grieving is difficult for home care nurses and may result in emotional stress. Unresolved grief may interfere with a nurse's ability to provide supportive care to other dying clients.

Although home care nurses are generalist nurses, many find themselves working primarily in the specialized area of palliative care nursing. The ability to support families with complex psychological needs is an advance practice role (Jones, 1999). Many nurses have not received the education in their basic nursing education to support dying clients and their families (Saunders & Valente, 1994). The Enhanced Generalist model was developed to provide palliative care in the community and attempts to amalgamate the generalist and specialist approaches to nursing care. (Vancouver/Richmond Health

Board, 2000). Palliative care education for home care nurses consists of a one day basic hospice orientation. After completion of the workshop, a nurse is expected to care for clients with minimal palliative care needs. The two advanced hospice courses, four hours in duration each, prepare the home care nurse to provide supportive care to complex palliative clients and their families. The advanced education courses focus mainly on symptom management and psychological care of the dying; education regarding self-care is lacking. Due to the lack of adequate preparation through education, many home care nurses may be poorly equipped to deal with their emotional reactions to the loss of their palliative clients. Burnout may be the end-result of ongoing unresolved losses for home care nurses.

#### *Purpose of the Study*

Home care nurses working with palliative clients may experience a sense of loss and need to process their grief when their clients die. The experience of loss may not be the same with every client. Nurses make choices about coping strategies when they experience loss after the death of a client that was meaningful for them. Some choices may be more effective than others to process feelings of grief.

The aim of the study is to investigate the experiences of home care nurses and how they cope with the loss of palliative clients.

#### *Research Question*

How do home care nurses describe coping with their experiences of loss and grief when caring for their palliative clients?

#### *Definition of Terms*

A. Home care nurses-Registered Nurses working in the community who care for



palliative clients in their homes as part of their nursing practice. Home care nurses are part of the Home Hospice Program that offers education and support to home care nurses working for the Vancouver Coastal Health. Their remaining caseload includes extensive wound care, elder care, medication management, and diabetic management.

- B. Home-based palliative care nursing- Home care nurses who provide supportive care to dying clients and their families in their homes.
- C. Oncology nurses- Registered Nurses working in the acute setting provide nursing care for clients diagnosed with cancer. The aim of treatment is usually prolongation of life through active treatment and interventions.
- D. Hospice nurses- Registered Nurses who provide nursing care for clients in the hospice setting. Clients in hospice receive care that promotes comfort before death. Dying clients in hospice are not able to be cared for by family members at home and no longer wish active treatment for cancer and other end stage illnesses.
- E. Palliative clients-Clients who have less than six months to live due to a variety of causes: HIV/AIDS, terminal cancer, or end stage disease processes such as cardiac or respiratory disease.

### *Significance of the Study*

The importance of the research is to identify coping strategies that will prevent emotional exhaustion and burnout for home care nurses working with palliative clients. Recruitment and retention of nurses in the community is essential for the Home Hospice program. Educational opportunities are important for novice nurses to be recruited into the palliative care area. Preceptoring novice nurses will assist them to develop strategies as they learn from expert nurses how to practice self-care and process their feelings

associated with loss of a client. Ongoing support for nurses who have experience working in palliative care in the community is important for the retention of experienced home care nurses. The retention and recruitment of nurses during the global nursing shortage is essential to provide the support to respect clients' wishes for a dignified death at home.

### *Organization of the Report*

Chapter I introduces the research project and offers background information to the problem. The purpose of the study, research question, assumptions, and definition of terms were described. The significance of the study and potential implications for practice were outlined.

Chapter II will contain a literature review that includes some historical research studies that have contributed to the current body of significant literature pertaining to the research question. Chapter III will include a description of the appropriate method for the research question. The research design, ethical considerations, data collection and analysis procedures will be identified. Chapter IV will include a description of the participants and outline the findings of the study. Chapter V will conclude the study with a discussion of the research findings and limitations to the study. Further, I will make suggestions regarding the relevance of the findings as they pertain to nursing practice, education, administration, and future research.

## Chapter II: Literature Review

The literature review in the following chapter will focus primarily on research-based reports that have been published within the last ten years. Databases accessed for the literature search included CINAHL, MEDLINE and PSYCHINFO. Search terms used for the literature review include the following: grief; bereavement, death & dying; attitude of health personnel; terminal care/psychology; nurses/psychology; terminal care; palliative care; end of life care; palliative care nursing; hospice nursing; burnout, professional/psychology; and burnout, professional/prevention & control.

The literature on professional loss will include definitions of the concepts related to loss. A historical review of the important theories of loss is discussed to verify the complexity of working with clients who are dying. How grief is experienced has changed since the concept was first identified and some of the conflicting research will be presented. How nurses experience grief in their professional relationships with dying clients will be expanded upon. Much of the literature uses hospice and oncology nurses as samples in research projects (Kulbe, 2001; Loes van Staa, Visser, & van der Zouwe, 2000; Hawkins, 1999; Froggatt, 1998; Mazhindu, 1998; Hutchings, 1997; Booth, 1995; Saunders & Valente, 1994). Both hospice and oncology nurses work at institutions where the support is on site. Home care nurses' work environment is the client's home where the isolation from colleagues and support staff throughout the day poses different problems. Applying the research findings that are based on hospice and oncology nurses directly to home care nurses may not be accurate.

There is a vast amount of literature during the 1970s on burnout when the concept was first identified. A brief historical overview will be presented. The literature on stress and burnout pertaining to nurses focuses mainly on oncology or hospice nurses working

in an institutionalized environment (Payne, 2001; Stordeur, D'hoore, & Vandenberghe, 2001; Kash, Holland, Brietbart, Berenson, Dougherty, Oulette-Kobasa, & Lesko, 2000; Taormina & Law, 2000; Murrant, Rykov, Amonite, & Loynd, 2000; Janssens, Zylicz, & Ten Have, 1999; Dean, 1998; Florio, Donnelly, & Zevon, 1998; Vachon, 1998; Costantini, Solano, Di Napoli, & Bosco, 1997; Vachon, 1997; Farrington, 1997; Duffy, 1996; Farrington, 1995; McNamara, Waddell, & Colvin, 1995; Bennett & Kelaher, 1994; Cohen, Haberman, Steever, & Deatrick, 1994; Hartrick & Hills, 1993). A gap in the literature exists pertaining to the experiences of home care nurses and how they cope with their feelings of loss when their client dies.

#### *Home-Based Palliative Care Nurses*

The most extensive literature researching home care nurses' experiences with dying clients comes from Great Britain where Macmillan Nurses deliver palliative care in hospitals, hospices and in the community (Wright, 2001; Skilbeck, Corner, Bath, Beech, Clark, Hughes, Douglas, Halliday, Haviland, Marples, Normand, Seymour, & Webb, 2002; Clark, Seymour, Douglas, Bath, Beech, Corner, Halliday, Hughes, Haviland, Normand, Marples, Skilbeck, & Webb, 2002; Seymour, Hughes, Bath, Beech, Corner, Douglas, Halliday, Haviland, Marples, Normand, Skilbeck, & Webb, 2002; Jones, 1999). Macmillan Nurses were first introduced into the health care system in the 1970's with the aim of improving care to terminally ill clients and their families (Skilbeck et al.). Initially these nurses had specialist responsibilities when caring for the dying. More recently, Macmillan Nurses have become clinical nurse specialists and their role includes clinical, consultative, education, research, and leadership (Seymour et al., Clark et al.). Currently, there are 1810 Macmillan Nurses employed, including 810 home care nurses and 445 hospital nurses (Clark et al.). Even though the role has evolved over many years, there is

still little understood regarding the work of a Macmillan Nurse due to the role ambiguity and the role conflict experienced (Skilbeck et al., Seymour et al.). Macmillan Nurses are specialist clinicians involved mainly as educators of nurses and as agents of change. Their practice encompasses transferring information, giving advice indirectly, and attempting to change their professional culture (Clark et al.).

Referrals to the Macmillan nurses come from all three areas: hospital, hospice, and community. The main reason for referrals from home care nurses is for pain control and emotional support; more referrals were received from community than acute care settings. Previous research supports a higher incidence of physical problems experienced by clients in the community (Copp & Dunn, 1993). Reasons given for the higher referral rate from community are that hospital nurses can monitor and plan interventions more effectively because of the ease of patient access to services (Skilbeck et al., 2002). Also, the doctors and nurses were more stressed in the community due to staff shortages. Furthermore, clients in the community may receive more telephone consultation rather than home visits in the community due to geographical difficulties. These factors resulted in less effective care for community clients.

Home care nurses were found to have more responsibility when caring for the dying in their homes. The lack of resources in the community was cited as the reason for minimal educational opportunities (Seymour et al., 2002). An evaluation study of Macmillan Nurses was done between 1998 and 2000 to discover more about their work, their role, and their influence on outcomes (Skilbeck et al., 2002). One recommendation from this study was that generalist nurses lacked the time, resources, and skills to effectively care for palliative clients and required more formal and informal educational opportunities (Seymour et al., Wright, 2002).

Jones (1999) conducted a retrospective data collection method using audio taped recordings of five Macmillan Nurses to research the impact of emotional issues on palliative home care nurses. Macmillan Nurses are expected to offer psychological and emotional care through communication and, thus, are practicing at an advanced level of nursing. These nurses attempt to alleviate suffering through listening. Tolerating a dying client's strong negative feelings allows trust and acceptance to develop. Listening to experiences of distress, anxiety, and suffering supports a dying client's ability to endure and find meaning in illness. Client's feelings of fear and concern are expressed openly rather than remaining hidden. By engaging in complex issues that surround illness and death with their clients, Macmillan Nurses are emotionally impacted by these same topics within themselves. Jones cites that consequences of listening extend to both the narrator and the listener.

Macmillan Nurses who offer emotional support to the dying require support to confront issues surrounding death (Jones, 1999). Difficulties arising from working with the dying as reported by the Macmillan Nurses include saturation with death and suffering; feelings of grief, guilt, and powerlessness; unrealistic demands; and communication gaps. Macmillan Nurses also report achievements such as helping the dying to find meaning in their experience, a deep sense of satisfaction from comradeship, and being part of a profound human service that offer supportive care to the dying. Jones recommends that Macmillan Nurses require a safe place to examine their practice. Time for personal contemplation is essential as there is invaluable experiential knowledge contained in nurses' feelings. Opportunities for reflection upon the thoughts, feelings, and impressions that arise when caring for the dying must be granted. Insights that are gained

by examining the professional practice of supportive care of the dying can be beneficial to all.

Research focused on the home care nurses' role in Canada highlights some unique aspects of providing nursing care in the home. Higuchi, Christensen, & Terpstra (2002) conducted a qualitative study to investigate clinical decision making of home care nurses. Establishing a relationship with the family is one of the highest priorities since the family will be responsible for providing much of the care that nurses provide in the hospitals. Family expectations and willingness to provide care may not accurately reflect the health care resources that are available for the client. Home care nurses must be able to work independently to ensure their clients receive adequate care within the home environment. Home care nurses report working in isolation and describe their role as a guest or a stranger. All of the nurses in this study lacked home care nursing as part of their basic nursing education. Furthermore, home care nurses develop a unique relationship with their dying clients and families; when a client dies, home care nurses may be greatly affected by the loss.

### *Supportive Care of the Dying*

Working with dying clients constantly exposes nurses to death and loss. Many nurses who choose this area of nursing do so because they are able to develop an intimate relationship with their clients, they have the opportunity to make a difference in their client's lives, and they are able to learn lessons from the clients they care for (Hutchings, 1997). The reciprocity of meaning gives a depth to the relationship between client and nurse that is often not found in other aspects of nursing (Rittman, Page, Rivera, Sutphin, & Godown, 1997; Raudonis, 1995). Rittman et al. did a phenomenological research study with oncology nurses to describe their experiences while caring for dying clients. Nurses

claimed to manage the emotional aspects of their practice through developing different levels of intensity in their relationships with their clients. Nurses and clients do not always develop a close emotional bond; some nurses describe making a conscious choice to invest emotionally on a deep level with clients.

Working with the dying can profoundly affect nurses by offering both challenges and rewards. Some nurses claim to enjoy the present moment and live more intensely (Cornette, 1997). Life becomes more uncertain for others and living authentically, not planning the future too far ahead, and not postponing important matters becomes important (Rasmussen, Sandman, & Norberg, 1997). Many nurses develop an attitude of courage and thoughtfulness towards life (Maeve, 1998). The lessons learned from professionally caring for the dying can be translated into one's personal life. Research on palliative care nurses has discovered the impossibility of separating the nurse as a professional from the nurse as a person (Rasmussen et al.; Davies & Oberle, 1990). Developing a relationship with the dying can, at times, be costly in terms of the emotional investment required.

Emotional labour requires one to give a part of self in the relationship and the cost to the nurse has been overlooked in the past (Phillips, 1996). A deep emotional involvement with a dying client requires nursing expertise to know how to manage personal emotions while providing emotional support to clients and their families (Rittman et al., 1997; Barthow, 1997). Barthow discusses nurses' need to find a balance between their emotions and cognition in order to be present and connected, yet separate. Nurses who maintain both involvement and separation with dying clients are not overwhelmed by the experience. The costs of caring for the dying in terms of emotional trauma may sometimes outweigh the benefits and satisfactions involved in palliative care



nursing (Maeve, 1998; Ellis, 1997). Raudonis (1993) stresses the importance of nurses' self-knowledge of the meaning of their relationships with the dying in order to continue to provide quality care. Staying present emotionally in the face of death requires the nurse to develop courage to reach out and meet fear (Zerwekh, 1995).

Nurses working with the dying witness great suffering and have the opportunity to assist clients to find a deeper meaning in their current circumstance and their uncertain future (Rittman et al., 1997; Swift, 1994; Davies & Oberle, 1990). While helping clients find their personal meaning, nurses are challenged to face the same issues within themselves (Saunders, 1996). Raudonis (1995) researched ten hospice clients and their nurses using the naturalistic inquiry method in an attempt to understand the relationship that exists. The importance of nurses' self-knowledge of the meaning of their relationships with the dying is important in order to continue to provide quality care. The relationship is reciprocal; both the client and the nurse benefit from sharing the experience of dying. Raudonis stresses the need for introspection and individual reflection for the nurse as a means to promote self-growth as an aspect of nursing practice.

Zerwekh (1995) interviewed 32 hospice nurses using narrative inquiry in order to understand the role of palliative care nurses. A focus group of 10 hospice nurses assisted in refining the findings of the study. Zerwekh noted that in order to sustain the ability to continue to care for the dying, nurses must maintain their own emotional health by learning how to grieve, letting go of personal agenda, establishing personal boundaries, and replenishing oneself through self-care. Developing self-awareness and a personal philosophy assists with self-care while working with the dying. Nurses in this study also stressed reciprocity in their relationships with dying clients; while giving supportive care,

the nurses received extraordinary personal growth. Nurses who develop an awareness how working with the dying affects them and develop personal coping strategies to maintain their own resources will have the ability to continue to offer nursing expertise to the dying (Rasmussen et al., 1997; Cohen, Haberman, Steever, & Deatrck, 1994).

### *Definitions of Loss*

In order to understand the experience of palliative care home care nurses, it is necessary to review what is known about the experience of loss, grief, and burnout. Loss is defined as no longer having something you once had (Andrus, 2001). Loss is a part of life that may or may not include the death of a loved one. Individuals experience loss in different, and yet similar ways. Loss is defined as a disadvantaged state. One is without something that one previously had; a separation or deprivation from an object, status, or relationship that was valued occurs (Humphrey & Zimpfer, 1996). Grief, mourning, and bereavement are concepts related to loss that are often used interchangeably when describing the reaction of an individual to loss.

Grief is described as the response to the loss of the object of value that can be either a person or a possession (Engel, 1961). Grief may also be seen as a process that prepares one to let go of something valued and become ready for what is to come (Rando, 1984). The behaviours associated with grief are wide range and may reflect individual differences. Grief may be an intense or mild experience occurring at the time of loss or at some future time. For some, grief is a short duration; for others, grief never ends (Worden, 1991). Grief is an expression of subjective feelings including sorrow, pain, distress, and sadness when one experiences loss (Miller & McGown, 1997). Guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief, and numbness may be exhibited (Worden). Grief is not limited to the emotions but

can include physical sensations, cognitions, behaviours, social difficulties, and spiritual searching (Corr, Nabe, & Corr, 1997).

Grief has been described as a process that involves psychological, social, and somatic responses to one's perception of a loss (Rando, 1984). Physical sensations include tightness in the chest and throat, sensitivity to noise, sense of depersonalization, dry mouth, lack of energy, weakness, shortness of breath, and hollowness in the stomach. Disbelief, confusion, preoccupation, a sense of presence of the deceased, and hallucinations are common cognitive reactions. Behavioural reactions are sleep disturbances, appetite disturbances, absent-minded behaviour, crying, dreaming of the deceased, avoiding or focusing on reminders of the deceased, and restlessness. Social withdrawal is normally short-lived and an individual may avoid taking an interest in the outside world at this time (Worden, 1991). Grief is similar but different than mourning.

Humphrey & Zimpfer (1996) describes mourning as the period of time after a loss when one expresses grief in the form of pain and suffering. Mourning can be viewed as the behavioural expression of grief and often has a sociocultural basis (Sprang & MacNeil, 1995). Mourning is a process that individuals experience as they attempt to incorporate learning to live with loss (Corr et al., 1997). Some describe mourning as phases one needs to go through. However, phases suggest passivity; there is nothing one can do. On the other hand, some describe tasks of mourning where one can be proactive and do something to facilitate the process (Worden, 1991).

Bereavement refers to a state of being when one has lost a close relationship to death (Corr et al., 1997). Bereavement includes grief, the response to loss, as one must experience the painful emotions in an attempt to heal emotionally for the resolution of the

loss. Some believe that complete resolution of the experience of loss through grieving is not possible (Marino, 1998).

### *Theories of Loss*

From a historical perspective, research on loss and bereavement emerged during the 1950's and 1960's with the death movement (Benoliel, 1997). With the rapid production of research on loss and death in numerous fields, many different viewpoints on the processes and outcomes of loss and grief emerged. There will be six major theorists included in this section: Freud, Lindemann, Kubler-Ross, Bowlby, Worden, and Rando.

Freud (1957) was the first theorist to develop a theory of loss and to describe grief as a normal emotion. Freud pioneered the research on loss and grief focusing on an individual's attachment to objects and persons that are rooted in childhood. Each person has multiple layers of loss to address. Mourning, according to Freud, was the reaction to the loss of an object or a loved one. When loss occurs, one must give up attachments and, therefore, a part of the self must also be given up. Freud differentiated between mourning and melancholia. The former was considered a healthy response associated with grief, and the latter, a state of illness. Freud was the first to acknowledge grief as a normal reaction to loss and mourning as a difficult process of addressing multiple layers of loss (Humphrey & Zimpfer, 1996).

Lindemann (1944) described five characteristics of grief that he, like Freud, believed to be a normal reaction to loss: somatic distress, preoccupation with thoughts or images of the deceased, guilt, hostility, and a loss of normal patterns of conduct. Lindemann added a sixth feature when he observed that some people take on traits of the deceased (Worden, 1991). Grief is psychological work and there are specific tasks to

accomplish such as undoing attachment to the deceased, accepting the pain associated with the bereavement, readjusting to a new environment, and building new relationships (Lindemann). According to Lindemann, one grieves not only for the person that is lost but the unfulfilled expectations associated with that person in terms of hopes, dreams, and fantasies (Rando, 1984). Psychiatric treatment, if necessary, could facilitate the work of grief by assisting with accomplishment of the tasks of grief. Without the necessary grief work after a loss, severe emotional or physical problems may be experienced at a later date.

Kubler-Ross' (1969) research on loss was based on coping mechanisms of individuals faced with a terminal illness. Individuals undergo a similar process to grieving loss and facing their own death (Humphrey & Zimpfer, 1996). Kubler-Ross developed five stages of grief similar to Lindemann's (1944) tasks: denial, anger, bargaining, depression, and acceptance. Kubler-Ross was criticized for attempting to interpret her client's emotions and behaviours and for identifying linear stages that were predictable (Humphrey & Zimpfer). Kubler-Ross attempted to organize a dying client's reactions into stages that were understandable and meaningful.

Bowlby (1980) relates the loss experience in relation to attachment and developed an attachment theory. Bowlby researched children who were separated from their mothers to develop his theory. Attachments are instinctive, are formed early in life, and are a basis for security and survival. The threat or experience of loss in a child provokes strong feelings of anxiety as safety and support are threatened. Attachment behaviors maintain affectional bonds that are considered normal behaviour in both children and adults (Worden, 1991). Unwanted separation from an object of attachment is the basis for a response to loss. An individual's response to loss as an adult is affected by childhood

experiences with loss (Bowlby). Mourning is the term Bowlby uses to describe the process one undergoes after a loss.

Bowlby (1980) cited four psychological phases of mourning: numbing, yearning and searching, disorganization and despair, and reorganization. Bowlby differentiated mourning from grieving. Grieving is the condition of an individual who is overtly expressing distress due to the experience of loss while mourning is the process one undergoes after a loss. Bowlby's attachment theory furthered the understanding of the emotional disturbances of individuals when attachments are broken through loss (Humphrey & Zimpfer, 1996). Bowlby believed that future losses are influenced by past experiences with loss. Life, although never the same after a loss, may become meaningful again.

Based on the work of Bowlby (1980) and Lindemann (1944), Worden (1991) identified four tasks specific to grief. Worden uses the term grief to describe an individual's personal experience of loss (Andrus, 2001). Working through the emotional pain experienced in grieving allows an individual to accept the reality of the loss. Mourning is the process of the adaptation to loss and involves an adjustment to a new environment without the lost loved one (Andrus). The process of reinvesting emotion in life involves letting go emotionally of the deceased. Worden's unique research is in the area of assessment and interventions for resolving loss.

Worden (1991) claims that an individual can actively participate in influencing the process of mourning rather than passively going through phases or stages. Individuals can complete the tasks by interventions and grief counseling. Worden's four tasks are as follows: to accept the reality of the loss, to work through to the pain of grief, to adjust to an environment in which the deceased is missing, and to emotionally relocate the

deceased and move on with life. When the tasks are accomplished, the process of mourning will end. However, there will never be a return to the pre-grief period. Worden's research offers the mourner a proactive way to manage grief but does not suggest a linear pattern to the accomplishment of the tasks.

Rando (1986) deviates from defining the experience of loss within categories and believes that mourning or grief work should be focused on the process and not the outcome. Rando uses the terms mourning and grief interchangeable and claims that mourning is an intrapsychic process, expressed in the psychological, social, or physiological domains. Although Rando agrees with Worden (1991) that mourning is a process, she believes that by focusing on tasks, stages or phases, one is focused on outcomes (Corr et al., 1997). Rando's Six "R" Processes of Mourning include recognizing the loss, reacting to the separation, recollecting and re-experiencing the relationship, relinquishing old attachments, readjusting and reinvesting in a new world (Corr et al.). Rando believes that these processes of mourning are nonlinear, interrelated, and may occur simultaneously. Processes of mourning are necessary to develop a life after the experience of loss.

Research on loss has changed from a focus on stages, phases, or tasks to a process of grieving that is dependent on the individual and their experiences with loss. Many factors influence an individual's process of grief such as the meaning of the loss, the characteristics of the mourner and the characteristics of the death, what else is happening in the mourner's life, and the previous experience of the mourner with death (Andrus, 2001). Working successfully through the process of grief to acknowledge the loss in one's present life is complex and requires much effort to complete. Nursing literature is rich in research for clinical interventions to assist families and loved ones with loss and

bereavement (Benoliel, 1997; Joffrion & Douglas, 1994). Somewhat lacking in nursing literature is research that includes interventions for nurses to overcome their own losses and grief processes when exposed to death in their professional lives (Loes van Staa et al., 2000; Mazhindu, 1998). Saunders & Valente's (1994) research with oncology and hospice nurses found that the nurses' experience of professional loss was a similar process as the experience of overcoming a personal loss.

### *Palliative Care Nurses and Loss*

Many nurses remain committed to working with the dying for years. Hardiness is a personality characteristic that may effectively buffer the negative effects of stress (Costantini, Solano, Di Napoli, & Bosco, 1997). Hutchings (1997) discusses the relationship between hardiness and hospice nurses in an attempt to understand what draws some nurses to work in an area with such rigorous demands. Hardiness, a characteristic that Hutchings claims has been determined to be a benefit to palliative care nurses, is composed of three aspects: control, challenge, and commitment. Nurses who demonstrate hardiness experience numerous challenges when caring for the dying but are committed to overcoming the obstacles by exerting personal control. They have a positive attitude regarding change, believe they can influence or modify outcomes, have a strong value regarding quality of life, and are highly motivated to serving others. When faced with challenges, hospice nurses increase their drive to serve others, stay committed, and attempt to exert control over the challenge. Palliative care nurses who demonstrate hardiness deliver compassionate care and critical competence. Hutchings suggests that hardiness is responsible for strengthening hospice nurses during difficult times and enables them to utilize committed energy. Kash, Holland, Breitbart, Berenson, Dougherty, Ouellette-Kobasa, & Lesko (2000) support Hutchings' conclusions and their



research with oncology nurses found that those with a hardy personality had less emotional exhaustion, fewer stress-related physical symptoms, and less demoralization. These nurses had an enhanced sense of personal accomplishment. The findings in both these studies, however, represent hospice and oncology nurses and applications to home care nurses may or may not be accurate.

Working with dying clients and their families, while rewarding at times, may become stressful and emotionally exhausting for nurses (Kash et al., 2000). Wilkes, Beale, Hall, Rees, Watts, & Denne (1998) researched 21 community nurses who cited the major source of stress was poor family relationships and the family's demand for friendship. Durkin's (2000) research supports there is a difference between home care and hospice nurses; home care nurses may be perceived as a friend because nursing care is provided in the home. Froggatt (1998) interviewed hospice nurses to explore the emotional work of nurses with families and how nurses understood the emotions and the consequences of working with dying clients. Nurses cite feeling a decrease in emotional energy as they listen to palliative clients and their families discuss grief. Nurses utilize practical strategies to manage the emotions that accompany working in hospice. Distancing, switching off, standing back, and hardening were concepts nurses describe to maintain the emotional resources needed to provide care effectively. Witnessing another's pain and suffering on an ongoing basis can be burdensome (Andrus, 2001).

Nurses experience loss when one of their clients die and if their own grief is unresolved, they may be unhelpful in assisting other clients to work through their pending losses (Andrus, 2001). Saunders & Valente (1994) held bereavement workshops and 300 oncology and hospice nurses were either interviewed or they filled out questionnaires. Few nurses identified models of bereavement as their knowledge base of the grief

process; most nurses derived their knowledge from personal experience. Saunders and Valente developed a model of bereavement that included four tasks: finding meaning, restoring and maintaining integrity, managing affect, and realigning relationships. The model of bereavement attempts to help nurses identify normal patterns of bereavement through the identification of phases, tasks and expected outcomes.

Nurses working with the dying cite experiencing difficulty providing nursing care while coping with their own grief reactions (Saunders & Valente, 1994). There may not be sufficient time for nurses to grieve a client's death before becoming involved with another dying client. Booth, Maguire, Butterworth, & Hillier (1996) interviewed 41 hospice nurses to determine the frequency of blocking patient disclosures. Some nurses tend to focus on managing physical symptoms and overtly avoiding emotional issues through distancing. Nurses who have not come to terms with their own mortality may feel anxious or uncomfortable discussing issues with dying clients and deliver ineffective care. McNamara, Waddell & Colvin's (1995) research with 22 hospice nurses confirmed that nurses working with the dying must evaluate their own personal response to death. Saunders and Valente encourage nurses to examine their responses to bereavement and to become aware of their own thoughts of mortality as a means of self-care.

Cumulative grief is bereavement overload that occurs with constant exposure to death and dying and a lack of opportunity to process the grief (Marino, 1998; Vachon, 1998). Ongoing stress and emotional exhaustion without a means for alleviation eventually accumulates with adverse results such as burnout. Redinbaugh, Schuerger, Erill, Brufsky, & Arnold's (2001) research on the grief experiences of health care professionals claim that although health care professionals are vulnerable to the grief reaction, little research has been done on the relationship between work-related grief,

stress and burnout. Supportive care for the dying in the home is on the increase. Home care nurses, the main providers of palliative care in the home, may become emotionally exhausted and deplete their resources for coping with sorrow and grief. Education that focuses on strategies to assist home care nurses to manage their emotions of grief will contribute to coping with the effects of burnout.

### *Burnout*

Human service professionals are particularly prone to burnout as they are humanitarians by nature (Pines, 1983); that is, they offer understanding, sympathy, and deep concern for those in need. Kash et al. (2000) found that nurses who worked with the dying showed a great degree of altruism and a responsibility to be committed even when there was a high personal cost. In their literature review on nursing burnout, Duquette, Kerouac, Sandhu, & Beaudet (1994) discuss the autonomy, endurance, and personal commitment that nurses show when caring for those that are in pain, agony, and death. The paradox is that often the most caring and compassionate nurses, those with the highest ideals, are the ones prone to burnout.

Freudenberger (1983) was the first to identify and coin the term burnout in the early 1970's. As a psychoanalyst, Freudenberger attempted to understand burnout within a psychosocial context rather than a medical framework that places emphasis on signs, symptoms, and disease. The interaction of personal and social variables will impact how an individual responds in a given situation. An understanding of an individual's psychology within the context of the society or environment assists in defining the process of burnout. Freudenberger believes the process of burnout is a signal to recognize stress and, consequently, monitor or alter personal and social systems that are

maladaptive. Burnout can be a beneficial experience when positive and health-promoting changes occur as a result.

Christina Maslach and Ayala Pines were social psychologists in the mid to late 1970's who built upon Freudenberger's work on burnout to further define the concept. They define burnout as the result of social interaction between a professional and client that becomes emotionally exhausting over time (Maslach, 1982). When emotional exhaustion occurs, one is not longer able to give to others. Burnout is defined as a process, phenomenon, or syndrome rather than an event and is characterized by emotional exhaustion, depersonalization, and lack of personal accomplishment (Maslach). The burnout syndrome is a response to chronic stress on a daily basis; one's ability to tolerate the stress gradually changes as one's resources are depleted.

Individuals that are emotionally exhausted feel overwhelmed by the emotional demands of others. As their emotional resources are depleted they are unable to give of themselves to others. Feelings that accompany the emotional fatigue are hopelessness, helplessness, and a negative self-concept. Feelings of guilt, failure, inadequacy, and incompetence are reflective of a negative self-concept. Emotional exhaustion has physical and mental repercussions (Pines, 1983). Physical symptoms include sleeplessness, poor appetite, nervousness, headaches, backaches, and stomachaches. Low self-esteem or feeling badly about oneself may result in poor job performance that reinforces one's lack of confidence and sense of failure (Duquette et al., 1994). Depression, a mood disorder that is a result of loss or failure, may occur (Maslach, 1982). Alcoholism, drug use, and suicidal ideation may be associated with depression (Vachon, 1998). Treatment may be necessary to restore psychological well being, depending on the severity of symptoms.

Individuals put emotional distance between themselves and those with emotional needs that may be perceived as overwhelming in order to detach psychologically.

Depersonalization is a detached and, sometimes, dehumanized response to those in need (Maslach, 1982). A negative attitude towards work manifests itself when individuals hate their work, resent their colleagues, and become detached from the clients they once cared for (Pines, 1983). Clients become objectified and labeled as a problem rather than treated as fellow human beings. Burned out professionals become insensitive to their client's feelings, avoid spending time with their clients, and withdraw psychologically from meaningful involvement with their clients (Maslach, 1982). As the professional protects oneself emotionally, the client receives care but not caring.

Professionals may withdraw physically from work due to a reduced sense of personal accomplishment resulting from emotional exhaustion and depersonalization (Maslach, 1982). Chronic lateness and increased sick time result in inadequate client care. Professionals may begin to feel guilty about the standard of care they have been providing and develop low self-esteem. Some professionals may choose to leave their present employment and find another position that is less emotionally demanding. The link between burnout and staff turnover is associated with professionals who leave their present employment rather than cutting themselves off from their emotions (Kash et al., 2000; Maslach, 1982). Burnout results in higher organizational costs for the delivery of health care.

Research supports that nurses caring for the dying experience stress that leads to burnout (Cohen, Haberman, Steeves, & Deatrck, 1994). Kash et al. (2000) conducted research on 261 physicians and nurses working in a cancer research hospital. Palliative care nurses, the largest professional group working closely with the dying, offer

emotional support, symptom management, and assistance with end of life decisions (Hardy, 1995). Oncology nurses who had daily contact with patients rated the highest levels of emotional exhaustion, psychological distress, and burnout. Nurses' sense of accomplishment was lower than physicians' due to a feeling of being overwhelmed by the vast number of patient care tasks and a feeling of lack of support. The researchers described a stressor labeled, negative work events, as contributing most to burnout. Negative work events have an ethical overtone, are confronted by nurses daily, and are extremely frustrating and emotional. Examples of a negative work event are a high number a patient deaths or assisting a client to sign a DNR. Nurses in this study describe more physical symptoms such as headaches, tiredness, and back pain than the physicians because they empathized more strongly with patients and did not distance emotionally. Working with the dying is inherently stressful as one is exposed daily to suffering, tragedy, and loss.

Nurses are particularly at high risk for burnout as providing nursing care requires one to give a great deal both emotionally and physically (Duquette et al., 1994). Nurses cite increased workload due to financial cutbacks to health care as a major stressor. Symptom management, communication difficulties due to poor family relationships, and assisting with end of life decision-making can cause increased stress for nurses (Dean, 1998; Wilkes et al., 1998). The complex physical and emotional needs of palliative clients may overwhelm nurses and cause feelings of inadequacy (Barbour, 1994; Power & Sharp, 1988). Nurses cite inadequate preparation for working with the dying; their feelings of anxiety, fear of death, and frustration may result in poor provision of palliative care services (Thulesius, Petersson, Petersson, & Hakansson, 2002).

Not all the research supports that nurses working with the dying are at a higher risk for burnout. Vachon (1998) researched health care professionals working with critically ill and dying clients and found that palliative care nurses may experience less stress than their counterparts in other nursing areas. The findings suggest that stress was usually due to environmental factors such as patients and families, occupational role, and work environment. When support mechanisms were built into the palliative care programs from the beginning due to the recognition that working with the dying was stressful, nurses described decreased stress from their work. Vachon's research was with oncology nurses and applying the findings to home care nurses working with the dying may not be accurate.

#### *Strategies to Prevent Burnout*

Nurses need to learn strategies for self-care to mitigate the effects of emotional exhaustion and burnout. Taormina & Law's (2000) research uses the three dimensions of burnout identified by Maslach (1982), emotional exhaustion, depersonalization, and decreased feelings of personal accomplishments, to identify stressors and strategies to prevent burnout in nurses. Their findings suggest factors that contribute to stress are both internal or controllable and external or uncontrollable. Vachon (1998) identified three main sources of stress for nurses working with the dying: patients and families, occupational role, and work environment. Vachon concluded that the personal involvement required to work with the dying took precedence over organizational stress factors for nurses. In the past, approaches to burnout prevention focused mainly on the internal factors that promoted management skills for nurses as the nursing profession considered stress a personal problem (Farrington, 1997). A more current and holistic approach to burnout includes strategies that address both internal and external factors

such as personal stress management and organizational support for nursing, respectively (Taormina & Law, 2000; Vachon).

### *Personal Coping Strategies*

Professionals have personal needs that must be addressed if they are to continue to work with the dying. Personal stress management addresses interpersonal skills, self-management skills, and psychological preparedness as well as time management and a healthy, balanced lifestyle. Scheduled time is required for rest, relaxation, and exercise. Outside activities and diversions, social interaction unrelated to one's job, and good nutrition promotes a healthy lifestyle. Adequate sleep, meditation, and techniques for relaxation are strategies that will assist nurses to continue in a demanding profession (Strickland, 1998; Vachon, 1997).

To maintain their integrity, nurses must participate in self-reflection (Copp & Dunn, 1993). Self-awareness is the first step towards self-care (Murrant, Rykov, Amonite, & Loynd, 2000). Looking inward, valuing self, and acknowledging one's own reaction help nurses to maintain satisfaction with work and prevent emotional exhaustion. Nurses support their clients as they experience loss but may neglect their own care which may, consequently, interfere with their ability to provide care to the dying (Murrant et al., Vachon, 1998). When nurses feel emotions associated with loss, learn strategies to help themselves heal, and adapt their loss into their life experience, they will reap the rewards of working with the terminally ill and prevent the occurrence of emotional burnout (Andrus, 2001).

Finding ways to care for oneself emotionally is a personal choice. Some nurses connect with family and friends to discuss work related issues while others may benefit from a professional support group. A spiritual connection or religious belief system



results in less emotional exhaustion as nurses view life and death differently from a spiritual perspective (Kash et al., 2000). A personal philosophy of illness and death may assist nurses to find meaning in their work (Vachon, 1998). Acknowledging the death of individual clients affirms the importance of the relationship for the nurse. Nurses need to care for themselves first in order to remain in a profession that involves service to others.

A personal philosophy of one's professional role may assist nurses to provide supportive care to the dying (Vachon, 1998). Setting limitations over one's practice and establishing boundaries help nurses to experience a sense of control over their work (Strickland, 1998). Nurses must realize there is only so much they can do. Association in a professional interest group that supports their work can be fulfilling. Developing a specialty focus within the context of palliative care contributes to a sense of competence. Control over one's practice and other internal factors will reduce stressors that lead to emotional exhaustion and burnout.

### *Environmental Coping Strategies*

Employers need to take an active role to develop strategies to address the external or uncontrollable factors that contribute to stress and burnout for nurses. Nurses who sense they have a lack of control over external factors experience higher degrees of burnout (Vachon, 1998). Ongoing collegial support creates a sense of community for palliative care nurses and provides an opportunity for sharing feelings (Toarmina & Law, 2000; Wilkes et al., 1998; Dean, 1998; Vachon, 1998). At times, these meetings can provide opportunities for review, evaluation, and education (Marino, 1998). Simply identifying stressors that result in emotional exhaustion and burnout can have a therapeutic effect (Dolan, 1987). Some nurses, however, cite a level of dishonesty or a conspiracy of silence around the expression of feelings after a client's death; nurses who

express their personal pain may be perceived as not coping professionally (McNamara, Waddell, & Colvin, 1995). Nurses who find a balance between the rewards and challenges of caring for dying clients are less likely to experience prolonged stress and develop burnout (Wilkes et al.).

Nurses need to receive adequate education for preparation to manage the stresses of working with the dying. Education regarding death and dying, feelings one may experience when working closely with the dying, and the theories and processes of grief will assist nurses to deal with feelings of loss in a healthy manner (Marino, 1998). Professional counseling may be required if nurses have difficulty with a particular death and begin to experience the effects of cumulative grief. Employers may need to provide nurses with opportunities during work hours for professional counseling and ensure time away from palliative clients after a stressful experience in order to recover.

The prevention of prolonged stress and burnout in palliative care nurses has far reaching benefits for nurses, clients, and the employer. Financial commitments from the organization for strategies to decrease stressors for nurses will prove cost effective by decreasing sick time and staff turnover. Nurses who experience a degree of control over their work environment report less emotional exhaustion, depersonalization, and lack of personal accomplishment (Vachon, 1998). More research is needed regarding the outcomes of burnout prevention programs focusing on education and staff development to verify their cost effectiveness. In the current era of a global nursing shortage, government and administration need to actively participate in strategies to guard against the loss of nurses due to burnout. The retention of expert palliative care nurses who have developed strategies in their life for self-care can be beneficial for the profession, the clients, and the health care budget.

### *Summary*

In summary, much of the research on professional loss and burnout has been done with oncology and hospice nurses. The research supports that the nurses working closely with the dying do experience emotional exhaustion from ongoing exposure to death and dying. The research from Britain regarding the Macmillan Nurses demonstrates some aspects of nursing that may be different for home care nurses than for oncology or hospice nurses. The concepts of grief, mourning, and bereavement were briefly defined. A historical overview of the literature on the theories of loss was included to provide an understanding of the emotional investment that occurs when a client dies. Grieving the loss of a client requires the ability to understand and to process the emotions. Burnout has been defined; interventions and strategies have been identified to prevent burnout caused by emotional exhaustion, depersonalization, and lack of accomplishment at work.

The gap in the literature exists for home care nurses to tell their stories about their experiences of loss with palliative clients. Providing supportive care to the dying in their homes as well as caring for other clients with various illnesses poses certain types of challenges for home care nurses that are specific to their work. The importance of the present study is to gain an understanding of home care nurse' experiences of loss when their clients die and to attempt to identify the strategies they have developed to practice self-care. Developing knowledge that is specific for home care nurses regarding interventions to prevention emotional exhaustion and burnout would be beneficial. As more clients are dying at home due to the lack of hospital beds, home care nurses need to be recognized as a valuable resource for health care.

### *Chapter III: Methodology*

As I have indicated in previous chapters, home care nurses working with palliative clients have different experiences in their role as palliative nurses than hospice or oncology nurses, due to the nature of their unique work environment, working with families in their homes. Home care nurses can become “part of the family” by virtue of the extended and intense relationship with the dying person and his/her family. Experiencing the loss of these clients may be emotionally traumatic to home care nurses who do not always have opportunities to share their experiences with peers due to the isolation in their work environment. A concern about client confidentiality constrains their ability to discuss their clients with family and friends. Sometimes discussions may take place informally with colleagues over coffee, lunch, or in the office hallways during the afternoon. Some home care nurses may seek out time with the educator or clinical nurse specialist on-site if problems arise. Rarely, home care nurses are asked to tell their stories about the personal impact of working with death and dying to an attentive listener.

Qualitative research uncovers the emic or insider’s view of a phenomenon that is particularly important when researching home care nurses’ experiences with the dying (Guba & Lincoln, 1994). Qualitative description is the retelling of informant’s stories by summarizing the data to describe a cohesive representation of the events or individuals (Sandelowski, 1998). Qualitative analysis organizes the data, by commonly used techniques, into forms that allow interpretation (Sandelowski, 1995). Often coding and categorizing during analysis helps the researcher to see the data in a new way. Qualitative interpretation creates something new from the analyzed data, yet remains loyal to the original data. By balancing the description, analysis, and interpretation of collected data,

the qualitative researcher finds emergent themes that would previously be hidden (Sandleowski).

Narrative inquiry, a form of qualitative research, is an appropriate method to explore home care nurses' experiences with dying clients. The purpose of narrative inquiry is to examine how participants make sense of certain events in their lives and how they impose order on their experiences (Mishler, 1995; Reissman, 1993). The aim of this study is to represent and understand a particular experience that is not easily understood. Not only is the understanding of the experience important, but the meaning that is ascribed to the experience is also important. By understanding the meaning of the experience, one is better able to understand the experience the participant describes. To give meaning to experience is to find not only the personal significance but the social significance of a phenomenon as well (Clandinin & Connelly, 2000). Narrative thinking and writing offers the best means of capturing the essence of the topic under investigation.

In the following chapter, I will outline the research design and explain the principles of narrative inquiry. The sample, selection procedure, and setting will be described. The procedure for approaching and informing participants will be explained. I will explore the ethical considerations and methodological rigor. Finally, data collection and data analysis procedures will be described.

### *Research Design*

People naturally tell stories about their lives and researchers use narrative inquiry to attempt to make sense or find meaning within such stories (Poirier & Ayres, 1997). Stories consist of actions and events that are transformed by narrative inquiry into meanings that have a common purpose- the outcomes or findings of the research

(Polkinghorne, 1997). Narrative inquiry differs from other forms of qualitative research in that the informants become narrators or social actors rather than only providers of data; interview data become stories or narratives rather than textual responses to an interviewer's questions (Coffey & Atkinson, 1996; Sandelowski, 1991). The stories, as data, are meant to increase our understanding of human experience, rather than to merely code or categorize information in an attempt to find emerging themes. Thus, the researcher retells the stories and, through analysis and interpretation, gives greater understanding to the human experience. People's lives are storied lives and the telling of these stories provides education value for the participant, the researcher, and the wider audience of readers (Clandinin & Connelly, 2000).

### *The Principles of Narrative Inquiry*

Stories need a listener and the telling of a story suggests a relationship (Frank, 1998). Storytelling becomes a shared experience as the researcher gives the gift of listening to a narrator who has an untold story. Stories have a dual nature. The narrator and audience have different viewpoints of the same story; the former is the creator while the latter listens with the intent of interpretation (Poirier & Ayres, 1997). Participants jointly construct their stories with the researcher whose skills may influence the narrative. The narrative that emerges is a result of spontaneous, mutual interplay of conversation between speaker and listener (Mathieson & Barrie, 1998; Mishler, 1995).

The researcher continually balances voice, audience, and signature in the research text due to the relationship that exists between researcher and participant (Clandinin & Connelly, 2000). The researcher attempts to accurately represent the participants' voices while balancing consideration of the audience's voice. The researcher's aim is ultimately for a study that is meaningful to an audience, such as readers who are interested in the

topic. Exercising good judgment is required to balance loyalty to the participant's voice, the relationship between participant and researcher, and the creation of scholarly research that will have meaning for a wider audience's voice. The question of signature raises ideas of identity rather than whether the researcher has captured the participants' narratives accurately. Although the researcher's signature is on the final text, the participants must be able to recognize themselves within the work and find their own signature on the research. Narrative inquiry requires a shared effort to create a research text that is both personal and meaningful to others.

Narratives and stories are terms used interchangeably. Structurally, stories have a beginning, middle, and end, (Mishler, 1995; Sandelowski, 1991) with a focus on setting and characters. Individuals reflect on their past experiences and create meaningful stories that are personal and temporal; the stories have a scene, main events with resolutions, and a central point (Bottorff, Johnson, Irwin, & Ratner, 2000). Narratives are stories that are constructed after reflecting upon an experience (Mathieson & Barrie, 1998). Narratives focus primarily on plot and how events unfold temporally (Polkinghorne, 1997; Poirier & Ayres, 1997; Sandelowski, 1991). Narratives can be a means with which people come to terms with sensitive or traumatic life events. Thus, in narrative inquiry the researcher pays particular attention to how and why the events in the story are remembered and retold (Coffey & Atkinson, 1996).

Narration reveals who the author is, not just what the author did (DeConcini, 1990). The function of telling life stories is to give a narrative identity to the teller. By the act of storytelling, lives can be revealed, understood, and, at times, transformed (Sandelowski, 1991). The aim of the current study was to gain an understanding of home care nurses' experiences when their clients die and how the loss impacted their lives

through analysis of their narratives about these events; narrative inquiry provides a means for the participants to tell their stories.

### *Sample*

Qualitative sampling usually involves purposeful sampling; that is, the researcher may chose the informants based on the information they are likely to provide on the topic under investigation (Sandelowski, 1995). Researchers attempt to ascertain 'good informants' before the interviews begin in order to select the most appropriate informants for the study. In this study, home care nurses were selected based on their knowledge of the topic, their ability to reflect and provide details of their experience, and their willingness to share the experience (Morse, 1991). The sample size was large enough to generate rich data but was limited as saturation is not the goal in qualitative research. Ten home care nurses formed the sample of this study.

### *Demographic Data*

Demographic data was collected after the consent was signed and before the audio recorded interview commenced. The 10 participants are listed below in alphabetical order according to their pseudonym. The demographic information is presented in Table 1.



Table 1.

*Demographic Characteristics of the Participants*

Name	Age	Years worked as an RN	Years worked in home care nursing	Full-time, Part-time, or casual	Male or Female	Number of children	Level of Education
Anna	30	5	3	FT	F	No	BSN
Holly	32	10	7	PT	F	Yes	BSN
Hope	47	25	22	FT	F	No	N. Diploma
Irene	48	27	8	Casual	F	No	BSN
Jane	53	30	20	FT	F	No	N. Diploma
Jess	51	25	15	FT	F	Yes	N. Diploma
Louise	57	34	17	FT	F	Yes	N. Diploma
Lynda	53	32	6	FT	F	Yes	BSN
Marsha	53	31	22	FT	F	Yes	N. Diploma
Mary	31	8	2 1/2	FT	F	No	BSN

*Selection Criteria*

Participants were recruited from the community health centers of Vancouver Coastal Health. The home care nurses in these centers worked in the Vancouver area. I limited my selection to Vancouver as I believed there would be enough volunteers for the study. The support services available to home care nurses in Richmond, North Shore, and Sunshine Coast of the health authority may be different than Vancouver. There are currently six community health centers in Vancouver and I have the Assignment Nurse position in one of the health centers. The topic of my study was of a sensitive nature and home care nurses who knew me personally may not have felt comfortable sharing intimate details. For this reason, I limited my selection to the five community centers where I did not have a work relationship with the home care nurses.

The sample for my project was home care nurses who have been working with palliative clients for more than two years. Nurses new to the community are involved in acquiring generalist skills and their experience with palliative clients is often limited during the first year. Home care nurses who have cared for palliative clients for more than two years had experienced the death of several or, perhaps, many clients. These nurses had the time to reflect on the experience and the impact of working with these clients. Exclusion criteria for the study were those who did not meet the inclusion criteria.

### *Recruitment*

I received approval from the University Behavioural Research Ethics Board and the Vancouver Coastal Health ethics committee. I began recruitment by placing a recruitment poster (see Appendix A) at the community health centres. The poster asked those who were interested to telephone me for a more detailed description of the study. I answered their questions about the research project upon receiving the calls. Participants were recruited from five of the six community health centers in Vancouver. One center was excluded because it was the interviewer's workplace. Five participants were from Three Bridges, three participants were from Pacific Spirit, one participant was from Raven Song, and one participant was from the North Health Unit; there were no volunteers from the South Health Unit.

### *Setting*

The setting for the interviews was based on the informant's preference. I offered to go to the informant's workplace, provided there was a quiet and private area available. The participants chose to be interviewed at their workplace. My primary concern for setting choice was the participant's comfort to facilitate the telling of their stories.

### *Ethical Considerations*

Informed consent was collected from each participant prior to the interview. Before the consent was signed, I explained the study and asked if the participant has any questions. Participants were encouraged to contact my thesis supervisor if there were any questions or concerns that I was unable to answer. Participants were reassured that their names would not be included in the interview transcripts, in the thesis, or any future publication of my findings. The tapes and interview transcriptions were identified by a coded number known only to myself. They are stored in a locked case; I have the only access. Once my thesis was completed, the tapes were erased. The interview transcripts are stored in a locked box and they will be shredded in seven years. I provided a written summary of my findings to all participants.

As a researcher, I have a responsibility to not cause harm to any participants (Clandinin & Connelly, 2000). There was concern that some participants may relive some of their experiences through their telling of the narratives. Since the topic of study was of an emotionally sensitive nature, precautions were taken to ensure clients were not harmed. Participants were aware of the resources available to home care nurses that could offer emotional support if required: the palliative care clinical nurse specialist, the palliative care team social worker, and the employees counseling services. I was not a skilled counselor although I could offer emotional support. Professional support for participants after their interviews was not necessary.

### *Data Collection*

The researcher's capability to obtain rich and appropriate data depends upon perseverance and sensitivity (Morse & Field, 1995). Interviewing was the prime data-collecting mode. The participants chose where the interviews took place and, together,

we agreed upon a time. A private environment without interruptions was a priority. Nine of the interviews were conducted at the participants' work site after work or during their dinner or lunch break. One interview was conducted at the interviewer's work site after work. All participants chose their preferred interview site to be the workplace. By conducting the interviews after work or on their break, participants could be interviewed on their working days. Confidentiality was restated and an informed consent (see Appendix B) was signed before the interview commenced. Demographic data (see Appendix C) was collected at this time and remained confidential. The interview time was 60 –90 minutes to allow enough time for the participants to feel they had shared their complete story.

Participants know the relevant issues about the topic better than the researcher (Morse & Field, 1995). Open-ended questions such as "Tell me about your experience when your client dies" helped participants to start their story. I prepared open-ended questions about the topic of inquiry (see Appendix D) to use when the participants seemed unsure of how to begin their story. Once the participant started telling her story, there were occasional interruptions by the researcher to clarify points and to request more detail. However, the participant needed to control the telling of the story in the event there were stressful incidents that the participant was not ready to talk about.

The role of the researcher in interviewing is a calm and thoughtful listener (Morse & Field, 1995). The researcher becomes passive, prompting participants only if needed. Silences are essential to give participants time to reflect during the interview. I resisted guiding the interview. Instead, I waited to see where the participant lead the conversation. During the interview I assessed the participant's level of comfort by observing eye

contact, facial expressions, and body postures. When I detected any discomfort, I asked the participant if she wished to continue the interview or would like a break.

To end the interview, a concluding question was asked such as "Is there anything else you would like me to know?" Answers to this question can be revealing and begin the real interview (Morse & Field, 1995). I was prepared to leave time at the end of the interview in case the participant revealed undisclosed data upon realization that the interview was about to end. At the end of the interview I explained that the interview would be transcribed for me to reflect upon. I asked permission to contact the participant by telephone if required for further explanations to something that was said. I reviewed the transcript of each interview before beginning the next interview to assess my skills as an interviewer and to learn what might need to be improved.

#### *Data Analysis Procedure*

The aim of the analysis is to locate the narratives within the interviews as opposed to viewing the whole interview as a narrative (Mathieson & Barrie, 1998). To define a narrative one must consider three conditions: temporality, causation, and human interest (Cortazzi, 1993). Narratives not only have a beginning, middle, and end but these events are linked by time. In the beginning, a character sets the stage for what is to happen next. Events begin to unfold during the middle of a narrative and the resolution or outcome signifies the end. Causation occurs between the middle and the end of the narrative; the middle event causing the final outcome. Reflecting upon the outcome of the narrative gives meaning to what led up to the outcome, that is, the beginning. The last defining condition of a narrative, human interest, is subjective. Not everyone will find interest in how the events, actions, and causes fit together in a particular story.

Interviews are a form of discourse, speech events that are jointly constructed by interviewers and subjects (Mishler, 1986). Interviewers, in fact, pry into secrets of participants and hear the intimate details of their stories and explanations that may have previously been untold. Researchers become overreaders as they make attempts to ascribe meaning to the stories' events through theoretical frameworks (Poirier & Ayres, 1997). Analysis and interpretation, based on a theory of discourse, are contextually grounded. Mishler's (1995) approach for narrative analysis, which will be used in this study, considers structure, interpersonal factors, and content.

In structural analysis, one notes how a story is interconnected based upon syntactic and semantic devices (Sandelowski, 1991). Narratives are a series of events that are temporally ordered (Mishler, 1995; Sandelowski). People's narratives describe events in their lives and choices that accompany those events with an open-ended quality that lends well to analysis and interpretation. The narrative structure, plot, is the way people discuss the relationship between events and choices in their lives (Mathieson & Barrie, 1998). Plot distinguishes the beginning and the end of the story; supports criteria for which events will be selected; orders events, temporally, that results in a conclusion; and explains meaning as applicable to the story as a whole (Polkinghorne, 1997). Furthermore, plot is a narrative of events with emphasis on time sequence and causality (Mathieson & Barrie, 1998; Poirier & Ayres, 1997; Cortazzi, 1993; De Concini, 1990).

Special attention needs to be directed to the narrative's endings, inconsistencies, repetitions, and silences as they emerge during discourse (Poirier & Ayres, 1997). Endings are important as an ending implies a meaningful future that is the vehicle for the story's end. Inconsistencies are a natural part of the human condition and will be present in narratives. Narrative inconsistencies cue the reader to feelings of confusion, conflicting

emotions, or uncertainty. Because narratives are constructed from personal events and feelings, contradictions indicate the participant's struggle to make sense out of the experience. Repetition requires attention as indicative of a participant's struggle and overcoming or enduring an event. Silences, including evasions and omissions, may signify painful memories or feelings associated with an event. Over reading the silences calls for a different analytic approach. By ascribing meaning to silences, researchers read into what is not there; that is, they attempt to read what is not said. Interviewers need to take special care when silences occur such as listening attentively to the silence, honoring the participant's unspoken words, and accounting for the silences, evasions, and omissions in the research text. Interpreting the silences may not be possible as silences often protect the teller from painful memories (Poirier & Ayres).

Interpersonal factors, the second element of Mischler's (1986) approach to narrative analysis speaks about the distinctive qualities of interviewing as a research method. Since both interviewer and participant create the narrative, there is a dual nature in the findings (Poirier & Ayres, 1997; Sandelowski, 1991). Reciprocity exists in the relationship that develops between the interviewer and the participant; the interviewer gives the gift of listening while the participant gives the gift of the story (Frank, 1998). The narrative represents the narrator's life at the moment when it is told; that is, by the act of telling a story a life can be transformed (Sandelowski, 1991). Thus, the narrative is not a representation of the narrator's life but only a representation of a particular moment in time. The reader and the teller of the story may not come to the same conclusion. A different interviewer may elicit a different story from the participant due to different questioning and different interviewing skills and style and, thus, arrive at a different interpretation; that is, certain questions may elicit stories that would otherwise not be

heard if those particular questions were not asked (Poirier & Ayres). The narratives and, ultimately, the findings are co-created by author and participant in narrative analysis.

Content analysis, Mishler's (1986) last element, involves the exploration of themes within narratives and their relationship to each other. Interviewing, a form of discourse between interviewer and participant, is an attempt to understand what participants say in response to questions. The interviewer ascribes meaning to the words through systematic analysis and theoretical interpretation (Mishler). Not all elements in a story are appropriate for analysis; excluded elements will be those that do not fit the plot and are not pertinent to the plot's development (Polkinghorne, 1997). Narrative configuration allows a higher level order be placed on everyday life experiences allowing a meaningfulness to emerge that was not originally present. The final report must fit or stay true to the original story; that is, the participant's voices need to be heard in the research findings. Thematic analysis allows cultural and personal identities to be applied to broader contexts.

Lieblich, Tuval-Mashiach, & Zilber (1998) consider the story as a whole and focus on content to identify the narratives within the stories. A content-oriented approach attempts to convey the implicit meaning of a story, the symbolism behind the images, and the characteristics of the narrator that are displayed. Lieblich et al. outline a five-step process that integrates a holistic-content perspective into the analysis of narratives. The list below was used in my content analysis of the narratives:

1. Reading the transcripts several times and listening to tapes assisted in recognizing emerging patterns in the form of foci. Maintaining an open mind while reading or listening and not forcing themes allowed the text to speak. Paying particular attention to certain aspects of the life helped to focus on the content of the text as a



whole. Attempts to identify the orientation, plot, evaluation, and resolution of each story as well as data that involved silences, repetitions, omissions, and inconsistencies was useful for later review.

2. Making notes of initial and overall impressions was helpful. Noting unusual or unfinished aspects of the story such as contradictions or confused directions were considered highly relevant. Any exceptions to the overall general impression of the story were noted. Disturbances in the stories that produced disharmony were also instructive.

3. Making a decision regarding the special focus of content or themes to be followed. Foci or themes were denoted by the time participants devoted to recurring ideas, by repetitions, and by the amount of detail provided. Either omissions or brief references to a subject were interpreted as having focal significance.

4. Marking the identified themes with colored markers as they emerged. Reading each theme separately and repeatedly helped to focus on the main components of the story.

5. Following each theme throughout the story by paying particular attention to the conclusions and where each theme appeared for the first and last time. Transitions between themes, context for themes, and relative importance for themes were noted. Any contradictions to themes were noted.

Throughout this process, analysis occurred concurrently using Mishler's (1986) approach to data analysis focusing on structure, content, and interpersonal factors. The structural analysis focused how home care nurses constructed their stories. Repetition of words or phrases, verb tenses, the voice of the informant, and shifts from the main story line were considered significant. The content analysis focused on themes, meanings and identities related to how dying clients affect home care nurses. The analysis of

interpersonal factors considered how the participant, the investigator, or the setting influenced the data.

Ideas that were generated inductively from the data were reviewed with the author's supervisory committee members. Further reviewing of the tapes and transcripts yielded more ideas. Some stories required coding using several colours when two different narratives occurred together. Analysis of each interview was synthesized for the purpose of identifying a common story. Due to their length, the interview synopsis were mailed to each of the participants with a request to telephone the interviewer for validation of their story.

### *Methodological Rigor*

Criteria for judging qualitative research to test for rigor are truth value, applicability, consistency, and neutrality (Beck, 1998; Sandelowski, 1986; Guba & Lincoln, 1981). Truth value or credibility describes the accuracy of the phenomenon under investigation; that is, how true to reality are the descriptions of the informants. Informant and readers of the study who have had the experience should recognize the descriptions as their own (Beck, 1993). To test the credibility of the findings I checked my results with an experienced home care nurse who was not a part of the study. A study has truth value if what is under investigation is measured, similar phenomenon studied yield similar results, and the findings fit with theories relating to the topic under investigation (Sandelowski, 1986). Comparing the stories within the study was not helpful as each participant's experience was different and each participant focused on different aspects of their experience. "Going native" is a major threat to the truth value of qualitative research and occurs when the investigator becomes over involved with the participants and may have difficulty separating the participants' experience from her/his

own (Sandelowski). Due to the dual nature of storytelling in narrative inquiry (Poirier & Ayres, 1997) and the close relationship that develops between researcher and informant, making field notes of my reactions was important to depict any threats to truth value. My journal contained descriptions and interpretations of participants' behaviours and experiences as well as my reactions to the participants.

Applicability refers to how the findings compare with other members of the same group (Sandelowski, 1986). In qualitative research, the emphasis is on the study of natural phenomenon and, therefore, generalizations of the findings is not an issue. An investigator is attempting to establish typical or atypical experiences of subjects under investigation and representativeness does not refer to the subjects but to the data.

Fittingness is an appropriate term to evaluate the applicability of qualitative research (Guba & Lincoln, 1981). Fittingness measures how well the findings of the study can fit into a different context, group, or setting outside the study situation and whether the audience views the findings as meaningful and applicable (Sandelowski). In this study, the narratives represented the individual participants and no attempt was made to apply the findings to other settings. However, I mailed the interview synopsis to each of the participants for verification by a follow up telephone call to confirm that I captured what they meant to say. Elite bias occurs when the most articulate or high-status members of a group are chosen for participants (Sandelowski). I included all the participants' interviews to overcome this major threat to validity.

Consistency is present when the findings can be repeated by another investigator using the same procedure and supports the generalizability of the study (Sandelowski, 1986). In qualitative research, consistency of results is not possible since the uniqueness of human experience is emphasized. Replicability is not a criteria for evaluation in

narrative inquiry (Lieblich et al., 1998). Guba & Lincoln (1981) suggest that auditability refers to the ability of another investigator to follow the audit trail. Thus, given the researchers data, another investigator could come to similar or comparable conclusions (Sandelowski). Description, explanation, and justification of all phases of a quantitative study achieves auditability (Sandelowski). During my research, I kept a journal that contained field notes made after each interview as well as memos made during the listening of tapes and reading of transcripts. My decision-making was documented throughout the research text to avoid "holistic fallacy"; that is, the findings were inclusive of the data obtained and not presented as more congruent than they actually were (Sandelowski). Another researcher may not arrive at similar results due to the influence that the researcher has in a study that utilizes narrative inquiry as the methodology. Since narratives are created and interpreted by different individuals, the reader and the teller may not agree on the story's meaning (Poirier & Ayres, 1997). Another researcher may not come to the same conclusions but will be able to understand the logic of the decisions in my study.

Freedom from bias in the research data collection and findings refers to neutrality. Thus, objectivity fits the criteria for neutrality in quantitative research (Sandelowski, 1986). Qualitative researchers believe that only an illusion of objectivity can be obtained since objectivity is a socially constructed phenomenon. In qualitative research, subjectivity is valued and each study is a reflection of the investigator as well as the participants. Guba & Lincoln (1981) suggest confirmability as the criterion of neutrality rather than objectivity and occurs when auditability, truth value, and applicability have been established. Overcoming the three major threats to qualitative research, going native, the elite bias, and the holistic fallacy, ensures confirmability is established.

Strategies to obtain confirmability were identical in this study to the strategies for the other criteria for testing rigor.

### *Summary*

In Chapter III, the rationale for the choice of methodology was explained. The research design and principles of narrative inquiry have been described. The reasoning for purposeful sampling has been explained as well as the setting and criteria for sample selection. Data was obtained from semi-structured interviews with home care nurses who have been working with dying clients for more than two years. Ethical considerations in place to protect the identity of the participants were outlined. The data analysis procedure included Mishler's (1995) approach for narrative analysis. Lieblich et al.'s (1998) five-step process of data analysis that integrates a holistic-content process perspective was described. Methodological rigor was discussed as it relates to Guba & Lincoln's (1981) criteria: truth value, fittingness, audibility, and confirmability.

## Chapter IV: Analysis and Findings

### *Overview*

The purpose of this investigation was to explore home care nurses' experiences with loss and grief when providing care to palliative clients. In this chapter, I will identify the findings that evolved from the interviews pertaining to the stories of home care nurses' experiences with the dying. Three central narratives are identified from an analysis of the interviews. First, *balancing professional attachments*, describes the relationships that home care nurses develop with their clients and their families and the difficulty they experience maintaining professional boundaries in these relationships. Second, *entering into suffering*, depicts how home care nurses witness suffering and loss with their clients and how participants are personally affected by this experience. Third, *honoring the memories*, describes the response of home care nurses to others' suffering and how their lives are changed because of this experience.

Chapter IV begins with an overall impression of the general characteristics of the interviews that will focus on structure, content, and interpersonal factors using Michlers' (1986) framework. The participant's narratives are presented using Lieblich, Tuval-Mashiach, & Zilber's (1998) process of analysis for narrative inquiry. Voices of the storytellers will be present throughout the narratives. A synopsis of each interview is detailed in Appendix E.

### *Descriptions of the Participants*

All 10 participants were currently working in home care nursing in Vancouver. They provided supportive care to palliative clients but continued to see other clients in their practice; that is, they were not exclusively caring for palliative clients. All participants were female. No male participants volunteered for the study. Eight of the ten

participants worked full time, one worked part time, and one worked on a casual basis.

The age range of the participants was from 30 to 57 years. The mean age was 45 ½ years. Three nurses were in their 30's, two nurses were in their 40's, and five nurses were over 50 years old. Half the participants had children. Four of the participants that had children were over 50 years and the other participant was in her 30's.

The number of years working as a Registered Nurse among the participants ranged from 5 to 34 years. The mean years of experience as a Registered Nurse was 16 ½ years. The years working in home care nursing ranged from 2 ½ to 22 years with the mean years of experience in home care nursing at 12 years.

Regarding level of education, five participants in the study sample had Nursing Diplomas, while the other five participants had Bachelor of Science in Nursing degrees. The three participants in their 30's all had Bachelor of Science in Nursing degrees. Of the two participants in their 40's, one participant had a Bachelor of Science in Nursing degree and was enrolled in a Masters of Nursing program, while the other had a Nursing Diploma. Of the participants in their 50's, one participant had a Bachelor of Science in Nursing degree and the remaining four participants all had Nursing Diplomas.

Eight of the participants were born in Canada. One participant was born in Hong Kong and the other was born in Mexico.

#### *General Impressions of the Interviews*

Recruitment posters had been placed at five community health centers and, as directed by the poster, potential participants contacted me by telephone. Prior to the interview, I made contact with each participant to explain the study and to answer their questions about the research. All participants fit the criteria for inclusion in the study.

Immediately prior to the interview, I obtained the participant's signature on the informed consent and obtained the demographic data. All participants were able to tell stories about their experiences working with palliative clients but appeared to have some difficulty recounting how the experience affected them. When asked a direct question such as "Can you tell me how working with palliative clients has impacted you?", most participants described in detail the client, their family or social situation, and their medical diagnosis and history, but only discussed their personal response to the situation with prompting by myself as interviewer.

An interview guide (see Appendix D) was prepared before the interviews. All participants asked if I would be asking them questions. Although I had prepared questions, I told participants they would be used only when needed as prompts to discussion. Most participants stated they were more comfortable when asked direct questions than when they were required to be free-flowing in their speaking. One participant stated, "I honestly don't know the best way to answer you. I need a little structure." For some storytellers, there was very little participation by the interviewer as they recounted their stories. These storytellers required minimal feedback about their story and they were able to continue at length. For other storytellers, they required some direct questioning to help them focus their story and then they were able to begin. When unsure, these storytellers asked, "Anymore questions?" All participants were eventually able to articulately describe in great detail their clients, their experiences, and how these experiences have impacted them.

To conclude the interview, participants were asked if there was anything more that needed to be said regarding the topic under investigation. Most participants continued to talk and concluded the interview a short time later. When asked how they



felt about the experience of the interview, all participants stated they had a positive experience. Participants were asked if they would like to choose a pseudonym for their synopsis that would be included in the report and five participants chose a name, the other five asked the interviewer to choose a name for the synopsis. The interviews were analyzed for structure, content, and interpersonal factors (Mishler, 1986) and general inferences; these will be described in the following section of the chapter.

### *Analysis of the Interviews*

#### *Structure*

The narratives were easily located in the interviews but did not have a defining beginning, middle and end. Most narratives began with an introduction of the client and these introductions were, at times, lengthy and detailed. Narratives began with "So probably the most significant one for me personally", "One case I can think of in particular", "I remember this lady", and "There was a fellow." When asked about how working with palliative clients impacted them, participants recalled details of their clients' situations first. One participant began with wondering which of two possibilities would be better: to talk about her current work day and how each of her palliative clients was impacting her or to talk about her early days in palliative care nursing and the difference between how she was impacted in her early days and how she is currently impacted. When given the choice, the storyteller launched into an extensive account about a couple that she had visited earlier that day. This story wove itself throughout the entire interview and was contrasted with her earlier experiences with dying clients.

A historical perspective was often presented although that was not one of the guiding questions. Because seven of the participants were over 40 years old and were

experienced home care nurses, comparing their current experience with their past experiences provided a progressive insight into the changes that have taken place for them over time. One of the participants in her 30's began her interview with a brief historical account of her personal experience with the loss of her mother at an early age. "I think if you look at your own personal background when you look at how it impacts you, you can tell a lot about how a person will react to it." Two of the participants contrasted their experience during the AIDS epidemic in the early 1980's with their current experience working in the same area downtown. The progression from past to present was not linear but interwoven alternatively throughout the interviews.

Silences were often linkages between one narrative and another. Most storytellers appeared agitated and uncomfortable during silences. When a silence signified that the storyteller had finished the narrative but was not certain how to begin again, she often requested the interviewer to ask more questions to continue the discussion. During an interview, one storyteller became silent and her eyes watered. With minimal prompting from the interviewer, she was able to recount her vulnerable feelings that emerged as she discussed her work with the dying.

Storytellers recounted their experiences with palliative clients easily. Stories often began in the past tense, "And I remember a day", "But in those days", "And I remember it was Friday", "Once in a while", and "And I guess to reflect back a little bit." These narratives had a 'once upon a time' quality and facilitated engagement of the listener. Their stories were ordered temporally by phrases such as "And then one day", "By the time", and "At this time." Common words or phrases to link events throughout the narratives were "and", "but", "and yet", and "and so." "So," was often used throughout narratives to continue to the next event. Participants, at times, wanted to clarify a point by

using a phrase, “but sometimes” and “and certainly.” Some participants spoke in absolutes, such as “you always come” and “you’ll never see” to emphasize the significance of their narrative. Phrases to prompt the ending to narratives were “and finally” and “at the end.”

Repetitions were used throughout the narratives to emphasize a particular point, “So that felt really, really good”, “I had really, really close partnerships”, and “very direct and very realistic.” The adjective ‘huge’ was also used repeatedly for emphasis: “a really huge lesson”, “the hugest thing”, “makes a huge difference”, “a huge responsibility”, “a huge debriefing session”, “a huge adjustment”, and “that’s huge.” The ongoing use of the word, ‘huge’, suggests an enormous quality to the storyteller’s experience. Accordingly, the degree of impact was extensive.

Participants expressed their feelings about their palliative care experience throughout the narratives. Some participants used the personal pronoun, “I’m feeling tearful”, “I feel sad”, and “I was feeling helpless.” Other participants distanced themselves from their feelings by using the pronoun, ‘you’: “you are feeling frustrated”, “you want to feel really sad”, and “you feel yourself.” Occasionally, participants excluded pronouns altogether, “it’s very sad” and “that was a huge sadness for me.” Often, the pronouns ‘I’, ‘we’, and ‘you’ were used interchangeably throughout the narratives. Sometimes two different pronouns would be present in the same sentence: “And so you...personally I’ve learned”, “You get to know a person and I like to know a person”, and “you can’t ...we have these...I think.” Storytellers would begin generally and, upon reflection, personalize their thoughts and ideas.

The interview ended with the interviewer asking storytellers if there was anything

more that needed to be said. Often the salient points of a narrative would be repeated for clarification or emphasis. The narrative, at the end, was told in the present tense to describe the impact that dying clients had for them. One storyteller concluded the interview, stating it was six o'clock and someone was waiting to pick her up after work. However, she briefly continued the interview describing some of the difficulties for her of working everyday with dying.

### *Content*

Most participants seemed concerned that the interview captured what the interviewer was researching and they had made a meaningful contribution to the research. When concluding one interview, I asked the participant what the experience of the interview was like for her. She answered, "I guess I would have to say I wished that at first I had some structured questions so that I could think more clearly and not be so scattered...I hope I am not missing anything." Several participants had similar sentiments. Phrases that suggest uncertainty about the topic are "I'm not so sure", "I don't know if that's making any sense to you", "I guess I'm rambling a bit here", and "Don't know where I'm going with this." One participant clarified her point after saying "I'm saying this wrong." Participants, at times, made more than one attempt to express their ideas about their experiences.

At other times, some participants had difficulty expressing themselves, which suggested they might have been struggling with some thoughts and ideas. Examples of this phenomenon were "and certainly...I mean...I guess", "it's kind of...yeah, but it's sort of like", "you know...I don't know...there might be." Other participants were able to articulate their experiences well and with confidence. "It's just the way it needs to be and that's kind of the way it should be", "That's kind of been my guiding light", and "I've

just never forgotten.” These statements conveyed that the storytellers had reflected upon these ideas previously and had arrived at some understanding of their experience.

The three narratives were identified as *balancing professional attachments*, *entering into suffering*, and *honoring the memories*. All three narratives were woven throughout each interview in a non-linear fashion. Each interview contained all three narratives; however, the quantity of the content pertaining to each narrative differed. The narratives were interdependent; that is, all three narratives may have developed within one story or a storyteller might recount only one narrative per story. All storytellers used the past and present tense throughout the interviews and, often, would switch from one tense to the other within a narrative.

#### *Interpersonal Factors*

The presence of the interviewer can influence both the structure and content of the narrative interview. Although I had met only one participant prior to the interviews, all participants knew I worked in home care nursing with palliative clients, as well as Assignment Nurse at one of the community health centers. Because I was researching experiences that I shared with the participants in my work life, my nursing background may have influenced the interview process. Some participants may have hesitated to share openly with me. One participant expressed concern during the interview, “It’s confidential?...because I don’t want any trouble.” Other participants expressed open criticism of the organization and expressed concerns that they “wouldn’t want anything said to get back to their managers.” They were assured that the interview was completely confidential and names would not be used in the report. Alternately, some participants may have been more comfortable with me because we had similar work experiences and

would be more open to sharing their experiences without feeling a need to explain. In truth, I did understand the stories well and identified with some of them. I wrote in my journal after each interview and while listening to the tape recordings to document and analyze my responses to the interviews to be aware of my personal bias.

The participants chose the workplace as the setting for the interview. One participant came to my workplace on her way home from work. The environment was quiet and the interviews were undisturbed except once, a participant had to take a phone call from her cell phone during the interview. The interview resumed immediately afterwards. There were no other disturbances and all the interviews were completed in the 60 to 90 minutes that were allotted. All participants requested that the interviews take place either on their lunch or dinner break or after work, although the interviewer was available on weekends and evenings. Some participants expressed they were having trouble articulating their thoughts and suggested the reason was they were tired from work. I also had worked the day of the interviews and on one occasion, did two interviews in one day as requested by the participants. The data from the interviews may have been different if the interviews were done away from the workplace and on a day off when both interviewer and participant were more relaxed.

As I have previously stated, most participants were more comfortable when asked questions. Although I had prepared an interview guide, my aim was to have participants tell their story about their experiences using prepared questions as little as possible. Two of the participants discussed their experiences throughout the interview with little prompting or guiding. The data obtained from these two interviews was rich with uninterrupted stories of their personal experiences. I became more proficient as an interviewer throughout the interview process. Rather than rely on the interview guide, I

would pick up on something the participant had previously discussed and say, "Tell me about...." I became more comfortable with silences. I attempted not to direct the interview as much as possible. All participants discussed their experiences extensively, but some needed more guidance from me as an interviewer than others. At times, these stories were like intense dramas. I was engaged, listening attentively, wondering how the story would unfold and how it would end. I was honored to be the audience for these very intimate accounts of personal and professional encounters with the dying and the difficulty, at times, of separating the two.

### *The Narratives*

The narratives will be presented in the order that follows the participants' explanations of home care nurses' experiences with the dying: *balancing professional attachments*, *entering into suffering*, and *honoring the memories*.

#### *Balancing Professional Attachments*

In the narrative, *balancing professional attachments*, the participants described their relationships with palliative clients. The main story line is as follows: "I became very attached to my client. I got to know him really well. He became entrenched in my work life and I became entrenched in his life. I know I was not family. I know that I could not be his sister or his mother. When he died, I felt sad and missed him. I still think about him sometimes." An example of *balancing professional attachments* is found in Irene's story in Appendix E.

*Balancing professional attachments* is a narrative full of a wide range of possibilities. Making judgments and decisions about relationships with clients is personal. Each nurse comes to an understanding of how to be in the relationship. The narrative also

contains contradictions. Some participants struggled with their involvement with clients to try to maintain their equilibrium, while others had clear ideas of where the limits in their relationship should be established. Participants agreed that each relationship with a dying client is different and, therefore, the home care nurse's response is different.

Describing a client's condition was a means of introducing the participant's relationship with the client in *balancing professional attachments*. The narrative is full of detailed descriptions of clients and events surrounding their medical treatments. The descriptions were vivid and often intermingled with anecdotes that revealed an underlying compassion for the client and his or her family. Although the relationship was mutual between client and nurse, the participants recounted extensive details about their clients in the narrative.

I can think of one case of a client that I had that was extremely well educated, extremely bright, had no medical background per se but worked in the medical field, and was dying...had a particularly horrible situation where feces were coming out of his catheter.

...the head...she looks...her head is actually physically grotesque now, mainly, because of the Decadron, the chemo, and the radiation and she's very sweet.

She was going through advanced stages of COPD and we finally diagnosed her with a CAT scan. She had 10% of her lung functioning left and she just thinks she's got a chronic cold.

The introduction of their clients with extensive and descriptive details was an indirect means of explaining the participants' involvement in the relationship. Although some of these details happened years earlier, storytellers recounted the nuances as if they had occurred yesterday. Their ability to juxtapose events uncovered the personal within the



professional role.

Certain factors were identified that contributed to the formation of a particular connection between storyteller and client. Participants concurred that shared common interests or common backgrounds can deepen the involvement. At times, participants would discuss topics unrelated to their client's condition that contributed to relationship building. For example, clients may remind participants of someone else, "...this fellow was so sweet...he was like a Grandpa to me." Relationships became like friendships as the participant and client spent increasingly more time together and the nurse got to know her clients intimately, both emotionally and physically. One participant remembers, "We would have been great friends had it been, had we met in a different environment. We were great friends but everybody knew that it was short-lived because of what was happening."

Although the relationship may at times seem like a friendship, participants knew that it was not. One participant stated, "I think the difficulty is that you're in a relationship with people and you're preparing them for death and sometimes it's not an easy thing...." The relationship had an end in sight. At times, there was a sense of urgency; that is, there may not be enough time or there may be no time at all to develop a relationship with a dying client.

The things I find different with palliative cases is that there is a finite amount of time because somebody is eventually going to die and personally I take on a really different focus with palliatives because I think it's the one time in a person's life we should do it right.

Participants were acutely aware of the tenuous nature of their relationships and of their

purpose, the provision of palliative care.

The environment or setting of *balancing professional attachments* was the client's home. Relationships developed and became more intense as clients in their homes became real people. "When you're in the patients' homes...everything is real...you get a sense of them and you are into their lives." Participants' personal knowledge of their clients deepened within the context of the home setting, particularly as the physical deterioration of the client was contrasted with reminders of how he or she had once been. One participant reflected, "I see photographs of her beside the bed and then I look at her and there's very little resemblance between the two." Participants often compared working in the home with previous work they had done in an acute care setting.

...you're in people's homes and you're in their real lives because when they're in the hospital they are under our rules and the family dynamics are there but they're very controlled and that kind of thing, then I would be in their lives and in their world and lots of times it was a world that I didn't understand at all.

Within the context of the home, home care nurses have to learn about a client's life history and the family dynamics. Each family will function differently and will develop different styles of coping. Participants perceived that family dynamics do not play such an integral role in the acute care setting where control over the environment is within the domain of health care providers or institutions. In the home setting, nurses did not experience the controlled and safe environment of the hospital with enforceable rules and regulations. Thus, the participants viewed building relationships with clients and families as an essential part of palliative care nursing that could significantly influence the nursing care they provided.

...if you have a good relationship established there is a trust there, then you can

work through things together as well as if there's any bumps in the road, any problems that come up, then they're more likely to be able to bring them up and talk about them.

Visiting often in their homes and building relationships with clients and their families contributed to some participants feeling like "one of the family." Participants stated they had to remind themselves of their role in the home. "You always have to remember you're the professional, you're not a family member." Although participants acknowledged they were not family and did not want a personal attachment, a professional attachment developed with particular clients. In one story,

We performed a function down there but we weren't...we couldn't personally attach to these guys...we weren't family...we weren't replacements for other support systems in their lives...this was a woman who lasted 2 ½ years in this state; went through heaven and hell together and I did become extremely attached to her.

Some clients did not welcome the relationship with participants in *balancing professional attachments*. One participant believed she had been "given a mission" but clients were not always ready to hear what she had to offer. Participants indicated that for some clients, they were a reminder of an outcome, death, that was unwanted and, at times, feared. "I feel like I'm a vulture, circling...she keeps us at a distance because...we bring a preparation of death that she really doesn't want." One participant creatively addressed her client's hesitancy for a home care visit in the following way, "I could tell he still really didn't want me to come so I said, 'Okay, I'll bring lunch.' Well! I'm telling you...all of a sudden I was a great hit!" Another participant patiently awaited an

opportunity to start relationship building.

I am basically pretty bad news to her. I'm in her face...things are not going well and so...I almost half-sensed that she didn't want me there but she needed me... Since I helped her though that excruciating headache I think she can see that I can actually be helpful to her.

Participants concurred that family dynamics could be extremely difficult to deal with in building relationships with dying clients. "You've got four daughters who want her to go to the hospital and a brother who wants her to stay home." Spouses were not always supportive of one another. "She and her husband seemed to just hate each other...we couldn't even keep the husband in the room." One participant described a situation where she felt in conflict with the family. "You try to please the client but at the same time the family is against you." Complex family dynamics contributed to participants' difficulties building and maintaining meaningful relationships. Participants were committed to developing relationships with the dying and their families as a means to provide the needed supportive care. The relationship with clients and their families had a central focus for all participants in the narrative.

The issue of maintaining healthy boundaries with clients and their families was prevalent throughout the narrative, *balancing professional attachments*. Maintaining boundaries was participants' way of *balancing professional attachments* and lessons were learned through experience over time in caring for the dying but the lessons could not always be applied in each situation. Although most of the participants had received basic and/or continuing education related to boundary setting with their clients, many found maintaining boundaries with palliative clients difficult or even impossible. The theories they had learned were not always applicable in clinical practice. For one participant,

contact with clients was not always limited to hours of work. "That's when we got into that point of having very close contact and he'd call me on my days off." Another participant learned a lesson about boundary setting through experience. "I used to give my pager number to people...you get a phone call at 3:00 in the morning, saying, 'I'm in pain'...I don't do that anymore because I learned." All participants acknowledged the difficulty of forming attachments in a professional setting. Some had developed clear ideas for their relationships with dying clients. One participant clearly explained,

This is a professional relationship. I don't meet them for dinner or have drinks with them or...it would be easy to get into that and I think you have to be really careful about keeping those limits on what we do.

Another participant questioned, "Does one never allow a client to have access to them in their personal life? That would be a tenet that I would have sort of started with and I crossed that line." Some other participants indicated that they were vigilant about monitoring their practice in an attempt to keep boundaries healthy and professional. "You keep watching that you're not doing too much and overstepping the bounds but making sure that you are doing enough."

Although, at times, participants became "too close" to clients, at other times, they "distanced" themselves from the client. Some storytellers described not developing an attachment or connection with their clients. They indicated they do not always have the time to develop relationships if the death happens quickly. One participant was not attached to her client and suggested this might have occurred because of a personal coping style. "If I'm upset about something I joke about it, then I forget about it."

Participants explained that they monitored their relationships with clients while

providing supportive care. In one story,

I'm going to have to start paying attention to what impact this is having on me,  
where am I going to go with this when she starts to get closer to the end, what will  
I do when she dies?

Participants described various means of detaching in their relationship with clients to whom they believed they were "too close." Many believed the team approach to providing palliative care was beneficial in this regard; nurses were able to "keep yourself apart to a degree" because the responsibility for the care of the clients was shared with others. Having other home care nurses visit their clients and become involved in their care was a means of maintaining healthy boundaries when they sensed their relationship with a client was becoming "too close." "I knew I had to get other people involved because it was getting too personal...it was getting just a little too close for me and I didn't think that was healthy...for me."

Participants concurred that colleagues often supported their attempts to maintain healthy relationships with their clients. During conversations with team members, participants frequently found strategies to decrease their involvement with clients. "I talked it over with one of my colleagues and he and I both felt that that was the best way to do it. Just to slowly phase out...which was good." They reported colleagues as saying, "You're getting too involved; you're spending too much time, it's not realistic." Support from colleagues was present in each participant's narrative as the most beneficial strategy for maintaining healthy relationships with dying clients. "And I think really and truly the most effective thing that we did for each other and certainly that they did for me was to say '...throttle back. You need to pull off this, you need to back off.'" Team members would visit each other's clients and keep each other updated with the client's progress

and condition. Although home care nurses usually support sharing palliative client with their colleagues, this strategy was not always practiced and, thus, occurred as a contradiction in the narrative. For one participant, the team-centered approach was impossible because the client refused to see other nurses on the team. The participant stated that the client had said, "If you're not the nurse that I deal with then take me off the roster...I'm not interested in dealing with anybody else." Although some participants would provide the only supportive care to clients, most agreed that the team-centered approach offered the best outcome for *balancing professional attachment* with their clients.

When clients were admitted to hospital or hospice, participants were required to give up the responsibility for the client's care to other health care professionals that "loosened" their attachment to the client. "So reflecting on what was my professional responsibility here, what was my personal attachment and I think it almost helped when she went into Hospice because what I could really do then was relax a lot more." An admission to hospice or the palliative care unit did not always end the relationship. Many participants went to visit clients after admission to hospital or hospice. However, they were no longer their primary health care provider and their relationship with the client had changed. "But it was more of a friend to go up there...not as a nurse and that was healthy I thought because I could pick and choose and I didn't go weekly or anything like that, it was very distant."

The narrative, *balancing professional boundaries*, is about the relationship that develops between participant and client. Developing the relationship is a process that may be difficult at times to navigate. The boundaries are not always well defined. Each

participant defined the boundaries within which the relationship with the dying client would develop and these boundaries were fluid and changeable, depending on a number of factors, such as the involvement of others as caregivers. Having other health care professionals involved in their client's care kept the attachment between nurse and client healthy, enabling the nurse to provide the best care for the clients.

### *Entering Into Suffering*

In the narrative, *entering into suffering*, storytellers described their experiences of providing care for their dying clients. The main story line is as follows: "Although I did feel sad when my client died, I knew it was her time to go. I did everything for her that I could have done. I tried to make her as comfortable as possible so she would not suffer too much. I talked with my colleagues about her and they also went to visit her. I know I had to take care of myself during this time or I would not be able to give her the care she required." An example of this narrative is found in the story told by Louise, in Appendix E.

Storytellers described feeling sad when their clients died and the feelings were expressed through tears or verbal acknowledgement. One participant stated, "I remember that I cried...it was very sad for me." Their sadness may be felt for an extended period of time. Another participant claimed, "And I don't know how they are coping now but it was very sad for me. It has been over a year I would say." One participant described an incident in which she was unaware of her feelings until "we were talking about grief and loss at that particular lecture and I talked about her and I started crying." Participants agreed that each client's death was unique and they felt differently with different clients' deaths. "Sometimes they affect you more than others but still you feel sad, you feel loss." For one participant, it was the suffering of a family member and not the dying client that



impacted her the most. She recalled, "...the Mom has emotionally really, really touched me...when I look into her eyes and I just see the pain...I can acknowledge the pain and the suffering. I can't change it but I can acknowledge it." Storytellers did not always agree with showing their feelings to clients and their families. One participant described her thoughts regarding showing her feelings with clients.

I usually don't let my own feelings show when I'm with clients...I try not to. I feel that I'm there to support them and that's my role and so usually if I'm feeling particularly bad or upset, it's later that it comes out.

Alternately, another participant did not keep her feelings hidden. "The aunt called me yesterday and started crying. Of course I'm going to start crying with her." Throughout the narrative, storytellers described how working with the dying and their families impacted them emotionally. For one participant, there was an acceptance that death was an integral part of life. A client's death, although sad, was expected and accepted. "Actually, by the time they die, there's a sadness but it's been time for them to go and so it's not something that I can carry along with me." In another story, a participant experienced acceptance but not sadness. "I didn't feel it was necessarily sad that he had died because he was so unhappy. And we weren't able to met his needs."

Storytellers described feeling a sense of responsibility for their client's death experience in *entering into suffering*. A good death was perceived as one where the client did not suffer and the family was happy with the care provided. Participants stressed the importance of knowing that they had done a good job for the client and family; that is, they had provided the required supportive care. Several participants associated their feelings of sadness after a client's death with the quality of care that was provided. "I

don't have the sense of loss if I know that I've done the best I could for the client." If the care provided to a dying client was not perceived as adequate, one participant believed she would suffer afterwards. She stated, "If I don't do the best job that I can then all of the other things that I do are not going to help because I'm going to have a huge weight on my shoulders." For another participant, the feelings of sadness after a client's death were directly proportional to the degree of supportive care provided to the client.

...she still hasn't had a dose or morphine in her at all so we know that she died in pain. So when that happens I feel more responsible; I feel more...grief in a way...not for her passing but for the fact that I'm not giving her the comfort and relief that I'm suppose to be doing when I'm looking after her as a nurse.

There were times when storytellers were powerless to change the circumstances around a client's death experience. "Sometimes it was things that were beyond our control that would lead to sadness." One participant took responsibility for her client's suffering, "...because I didn't see it, I didn't have the experience, my client suffered because of this." In this narrative, it was apparent that when clients suffer, regardless of who is responsible, home care nurses are left with unresolved feelings. "There was just so much suffering that didn't have to be...some patient's deaths are a little harder to kind of work around it because of frustration and tension." Most participants agreed that "being in a situation where you feel powerless is horrible" and their stories validated that their experiences in this regard were traumatic.

Working with the dying may trigger prior personal experiences with death. One storyteller described how her past experience impacts the present.

...I lost my mother when I was very young so I dealt with death and dying and loss and I watched my Dad grieve and so I think I have a different idea than a lot

of people because I've dealt with loss myself...I think that every time someone that I get to know dies in home care, I think that that kind of takes me back to the loss of my Mom.

Participants concurred that previous personal experiences with death cannot be separated completely in home care nurses' experiences of caring for a dying client. One participant acknowledged the association of a particular client with her father's death. "My Dad died within 24 hours of becoming ill...so I see that in some ways I was able to do for M\_\_\_\_ what I wasn't able to do for my Dad." The personal and professional experiences of loss are intertwined, but one storyteller related how the experiences were different.

My attachment is very intense and/or very professional up until that point where they die...once they've died my job is done. And so a good 90% of what goes on for me is done at the time that they die. Whereas when I think about my father's death, 90% of what I had to do around him dying happened afterwards.

Storytellers described how prior personal losses influence their work with the dying. Some participants agreed that personal and professional losses could not be separated.

In the narrative, *entering into suffering*, storytellers could not always separate their personal life from their professional life. They described how, at times, personal issues affected their ability to provide palliative care. One participant described, "This job is overwhelming and if you have something overwhelming in your personal life, it's just too much." Occasionally, a home care nurse cannot continue to work with the dying. One participant remembers,

...my father died really suddenly...then the next year my husband had a heart attack...then the next year my sister had an aneurysm...I found it much more

difficult to cope than I had thought I would...if I feel I'm not able to cope with work for whatever reason then I will take time off...I'm not going to be able to concentrate and I'm not going to take the chance of making a mistake.

Storytellers agreed that they could not provide supportive care to clients if they did not take care of themselves and, therefore, they developed strategies for self-care.

Participants agreed that supportive care for the dying was emotionally strenuous work and they wove self-care strategies into their practice. One participant said, "I ended up going on vacation soon after she died which was good...it really did affect me in feeling upset." Time away from work was cited as beneficial for all participants. One participant recalled that she used her vacation time strategically. "I'm a senior nurse here so I have lots of vacation time...I try to take four vacations a year. Two weeks at a time." Another participant changed from working full time to part time for more balance in her life. Further, a participant explained that she took an extended leave from work and "took six months off and my husband and I cycled across Canada." Home care nurses may leave community work altogether when they can no longer work with the dying. One participant stated, "I'm now looking at another change in my career."

Participants concurred that a team-centered approach enabled them to continue to work while taking time away from palliative clients. Although allowing colleagues to visit their palliative clients was an effective break, participants described concern for their colleagues who were caring for their own palliative clients. The break from dying clients was temporary and often short-lived. One participant explained, "The only problem with taking time off is that you burden your colleagues...your team members, so you feel like you're punishing them carrying your patients, so you feel guilty about that." Participants identified support from colleagues as the most beneficial coping strategy

throughout the narrative. Sharing clients with colleagues and receiving support and feedback were particularly helpful. One participant stated, "We seem to have developed a way of allowing ourselves to express our feelings when these things are happening and to talk about them...whether it's with a little bit of black humour...and sometimes there's a tear or two involved." Another participant remembered, "the love and compassion I received from my co-workers as I went through that process." Although participants cited colleagues as the most important source of support at work, they learned personal coping strategies through their work with the dying that were also beneficial.

Participants recounted personal self-care strategies that they developed and practiced during their time at work. One participant took time to be quiet and pray between nursing visits. "Before I go in, sometimes in my car I take some time just to be quiet and take some deep breathes...and I pray...which I find really does make a difference." Another participant described walking between client visits helpful. "One of the things I do as much as possible is walk...you can do almost a semi-meditation thing." Another participant noted that mentoring new staff or working with student nurses kept her "fresh" by challenging her to review her practice. Participants agreed that "eating well", "getting enough sleep", and "exercising" was important to stay in good health. Other strategies after work hours were listed as "getting into a good book", "being with a friend", "going for a massage", "a husband who's tremendously supportive", or "going to bed soon after I get home from work." Some participants stated they went for counseling through the Employees Assistance Program when their life was particularly stressful and working with dying clients became difficult. Each home care nurse developed her own style of self-care that was essential for her coping with the losses surrounding dying

clients.

Throughout the narrative, organizational factors were recalled by participants that were supportive in their work with the dying. Participants noted that having more knowledge about how to access various health care services improved nursing practice. Most participants agreed that clinical support services were valuable in palliative care nursing. Many reported the support from the Hospice team such as the clinical nurse specialist, hospice physicians, and the hospice social worker improved client situations. In addition, they mentioned that formal educational workshops from the Hospice team on pain and symptom management and psychological care were beneficial. Although participants frequently described the importance of pain and symptom management to alleviate a client's physical suffering, alleviating psychological suffering was identified as the more difficult task. "It's not impossible but just to enter into their pain is hard...it's the work of dying that's the hard part." Management was deemed essential to ensure a good working environment with "enough staff so workloads are manageable." Storytellers acknowledged that although organizational supports were available, home care nurses were expected to know what the supports were and to ask for them when needed. For example, "debriefing" was cited as a support service that was once automatically available after a difficult or traumatic incident. Currently, debriefing sessions are available only upon request by home care nurses if required.

Participants reported that at times the organization was a source of stress in their work with the dying. Some participants claimed they did not have "the tools" to provide adequate palliative care in the community. "The system is maddening, we're limited to 4 hours/day of home support as well as the fact that sometimes shift care nurses aren't always available." Another participant added, "They've taken away the Respite Program

at X Hospital.” Participants expressed concern that decreased health care services for palliative clients in both community and acute care settings impacted upon their ability to provide care to the dying. In addition, participants claimed that increased workload and staffing problems interfered with their ability to access organizational supports such as the monthly Hospice case reviews. One participant illustrated her experience,

I know that the monthly Hospice rounds are supposed to be a time for staff support but in reality that’s once a month. We’re not always working those days and sometimes the timing isn’t as well utilized as it may be...an hour isn’t very much time.

For one participant, the lack of organizational support was felt deeply. Her story illustrated the emotional impact of her work with the dying that, she believed, was not acknowledged in the organization. She explains,

...we are human beings and some people think that because we are dealing with those cases everyday we don’t have feelings. We have feelings! ...it’s not that we are getting hard...nurses seeing that someone dies everyday and you are used to that. No. Every death is different. Everybody is different.

Throughout the narrative, storytellers agreed that working with the dying was difficult for them emotionally. At the same time, they expressed a deep and heartfelt satisfaction inherent in palliative care nursing in the community. One participant indicated that working with the dying helped “people to cope with it.” Another participant recalled that helping clients buffered the sadness of the situation for her. “That’s been very satisfying too because people again will just reinforce how much I

helped...it makes up for the sadness and tragedy.” In reflecting upon the rewards of working with the dying, participants emphasized that their ability to make a difference in their client’s lives was gratifying. “It’s because I know I can make a difference for them and for their families and that’s really...that’s really energizing in itself.” In addition, another participant reaffirmed that the rewards of providing care to the whole family compensated for the sadness.

For me personally it helps deal with the tragedies and the losses of others that you get so much feedback...you really get to follow through...you usually still follow up with the family...we really do get to follow it right through all the way.

Another participant claimed that acknowledging a client’s death and supporting the family afterwards was viewed as a way of saying ‘good-bye’ and ending the relationship with a client and family. “Sometimes I do go to a funeral, maybe because the family asked me, sometimes there’s a little bit of closure.” Although participants’ work with the dying involved many sorrowful encounters, they repeatedly stated that the rewards of their work outweighed their experiences of sadness.

The ongoing ability to acknowledge another’s suffering is described in the narrative, *entering into suffering*. For participants, suffering includes both the physical and psychological issues of a dying client. Participants maintained that addressing the physical symptoms of dying clients with comfort measures and medication is an important aspect of palliative nursing care. Unequivocally, participants reported that providing psychological care to a dying client and family was the paramount undertaking; that is, one becomes personally affected by suffering. Their stories remind the listener that home care nurses are emotionally vulnerable and exposed when witnessing their client’s psychological suffering. Throughout the narrative, participants clarified personal



coping strategies that have proven beneficial in their work with the dying. However, there are mixed reports about effective coping strategies within the organization. The experience of working with the dying was personally rewarding for participants and compensated for their feelings of sadness when their client died.

### *Honoring the Memories*

In the narrative, *honoring the memories*, storytellers described how the dying affected them personally and how their lives were changed because of their experience of working with the dying. The main storyline is as follows: "Working with palliative clients has helped me grow as a person. I have tried to find answers to questions that I would not have asked if I had not been involved with dying clients. I believe it is a privilege to provide palliative care to clients in their homes. I have received more than I have given." An example of the narrative, *honoring the memories*, can be found in the story told by Lynda in Appendix E.

Throughout this narrative, participants acknowledged many lessons that they had learned about people through providing care to dying clients. In reflecting upon their experience, participants recalled clients in various situations in their disease process, in their family situation, and in their home environment that taught them lessons. "So she was a really huge lesson for me in just how disadvantaged some people are in life and just had a huge impact on me." One participant shared a story about how she witnessed clients coping in adverse situations and how this impacted her.

It's not even things you can describe, it's just their fighting spirit, that feistiness, their ability to just cope with whatever that's thrown their way...I often wonder to myself how I would cope if it was me going through this and I really don't know

so I really can't imagine.

In reflecting upon their experiences with the dying, participants attempted to make sense of their experience by asking questions about their client's responses. For example, one participant questioned why clients responded so differently when faced with death. "And I find I'm constantly learning about how people cope and wondering why some people cope so well and other people have such a hard time and why some people fight so hard and other people don't." Participants' questions added complexity to the narrative even though they were not always able to provide the answers.

Participants described new challenges in home-based palliative care as they applied previous learning into a new context. Prior to working in community nursing, participants conveyed that they had previous experience working in an acute care setting. Some participants recalled personal conflict as they expanded their professional nursing practice into the community. One participant described this conflict.

It was an interesting time for me to enter home care because I got disrupted in a bunch of stuff...a lot of that stuff got kicked up for me again and I felt very awash, very at sea and so part of what I had to deal with sometimes was feeling very much like a novice in an arena I previously felt very much like an expert, but it was in a different context...the people I came in contact with and cared for allowed me my personal growth at the same time.

Caring for the dying in the community was a different experience for participants whose prior nursing background was in a hospital. Participants attempted to make sense of the personal impact of working with dying clients in community. Some participants suggested their experience was a "process". One remembered, "how intense that whole process was for me as I went through it." Participants reported that they experienced a

personal learning process in their work with the dying. One participant observed, "You just have to live through it and learn through it. You have to go through it but you have to surface." Participants clearly expressed gratitude toward their clients for the personal lessons they had learned from them throughout the narrative. One participant summed it up well, "Through the generosity of other people who've shared with me...I have learned so much more and received so much more than I've actually given." Accordingly, participants affirmed that they have grown personally through their work with the dying.

Participants noted that they began to search spiritually as they worked with the dying. As clients talked about their death process, participants reflected upon their own questions about spirituality. Storytellers searched for answers to questions about the meaning of life and death.

You get to really start to explore for yourself where you're coming from around death and dying and what you believe is going to happen and in listening to people, when you're talking to them, a lot of them get into those things of what they think is going to happen after they die...I haven't quite figured out what happens after you die yet. And that's my big question.

Participants acknowledged that their questions about life and death were not always answered. "But it does also force you to deal with life and death...and what I think about life after death...I'm still not really too sure about that." One participant developed her ideas about death through conversations with her colleagues. She recalled,

I think people really choose when they're going to die and I've talked with a lot of the colleagues that have worked here for a long time and they talk about that too...about how they believe that people choose their time.

Another participant started questioning her faith that she previously had rejected. "So it brought up spiritual things for me that I looked at again after having personally rejected the Christian faith many, many years before." Narrators claimed that because of their work with the dying, they began spiritually searching for answers.

Participants reported questioning themselves about suffering in the narrative. "How could there be all this suffering? I just tried to make sense of it." In one story, a participant attempted to find meaning in the suffering for herself. "Because you see a lot of suffering and dying, you get stronger and you can learn from it." In another story, a participant described her thoughts as she learned how to respond to suffering.

I can't absorb other people's sufferings... 'You want to be a channel, not a vessel'. I learned that a long time ago. You have to let it flow through you. All the suffering to let it flow through you and not become a vessel and keep it inside you.

Throughout the narrative, participants expressed a desire to respond to suffering and yet to shield themselves without becoming "hardened." They reported an ability to "protect themselves", "not take the suffering home at night", and "to let it go." By questioning their client's suffering, participants learned strategies to support their client's suffering without being overwhelmed.

Participants explained they have developed personal convictions from witnessing their suffering that enhanced their nursing practice with palliative clients.

...one of the things that I have learned over that past three years working in home care is I don't take things personally anymore. It doesn't have to be the way that I wanted it...everybody is different...if the client or family feels that is the best for them, then that will be the best for them.

A participant who was experienced in home care nursing stated, “kindness was probably the best, the most therapeutic thing that I ever really did.” She identified kindness as the action that was an appropriate response to the suffering of the dying. She continued that kindness was what families remembered and was what would make a difference to the dying.

Participants agreed that palliative care nursing is not a “fine art.” However, they suggested that supportive care to the dying is “more an art than a science as the borders are not always clearly defined.” “I don’t think it’s always as black and white as that. The areas become smudged.” Within this undefined context, participants reported they practiced and refined their art of palliative care nursing. “It’s not a cut and dry fine art...this nursing of palliative people. Things don’t always go smoothly...you don’t really know...you can’t always predict and can’t always get the things that you want to be there immediately.”

In the narrative, storytellers described how the lessons they learned had influenced their nursing practice. Accordingly, participants developed more realistic expectations and realized there was a limit to what they could do.

I think maybe it’s that ability to not think that I know it all, to be willing to sort of say to people, ‘I have this set of knowledge and skills but you’re the one who really is in charge here and tell me what you think might help.’ I think that’s a better approach.

Furthermore, participants indicated that they became more realistic in responding to expectations from their clients and families. “I’m there to support them in the physical but I don’t think it’s possible to prepare yourself or other people for the loss of a loved

one.” Expectations became more realistic based upon what they were able to provide, as opposed to what they thought they should provide.

Participants further clarified that some lessons were applied to their personal life. For example, one participant conveyed a deeper understanding and acceptance of herself as a result of witnessing clients’ suffering. “I guess it’s about knowing who you are...and acting on it.” Other participants described learning to appreciate life and to not take things for granted. “It sort of helps you find a little bit more meaning around your life and what life means to you as a person.” Participants claimed that working with the dying contributed to experiencing more gratitude in their lives. For example, one participant reported feeling more thankful for her health. Another participant maintained that she “doesn’t put things off anymore.” “Don’t put it off because it might not happen.” She continued, “We’re a little bit self-indulgent in how we treat ourselves.”

In this narrative, some participants expressed they had developed an acceptance of death. They stated that, at times, death was welcomed when life lost all meaning. One participant said, “It was just time for them to die and it was better than struggling and going through whatever...their body was giving up on them so it was...seemed time for them to go.” A continuous theme throughout this narrative was that when clients died, it was their “time to go.” Participants confirmed that they had to reach the realization of the timeliness of death on their own. One participant described her searching through reading, “He wrote *The Tibetan Book of Living and Dying*...there’s a chapter called Impermanence...he said that death is what gives life meaning...I had to discover for myself. Nobody could tell me.” Another participant described her thoughts about her participation in her client’s death process. “This is the reality of people’s lives and you know it’s traveling with them...not for them. You can’t do it for anybody else. But you

can travel with them and try to make it as comfortable as possible.” Yet another participant summed up her experience of providing care to the dying as, “We all learn and if we learn from those situations, then we are honoring that person.” Home care nurses learn numerous lessons from their dying clients that they, in turn, apply in their nursing practice with other clients and in their personal life.

### *Summary*

In Chapter IV, I described the narratives contained within the participants’ stories. All 10 participants shared each of the three narratives in their interviews; some focused more on one narrative than on others. Given that the participants’ experience with palliative home care nursing was varied, the commonality of shared experience is significant. The stories that participants chose to share shape our understanding of what is important when providing care to the dying.

By sharing their stories about palliative home care nursing, storytellers offered insights into the complex nature of their work. Often the supportive care to the dying centers around symptom management while the difficult work of preparing for death occurs simultaneously. Addressing the psychological issues of the dying is often work that is unseen, not measurable. The narratives contain the invisible work of supportive care for the dying. By telling their stories and describing their experiences with clients, storytellers offered an explanation of the impact the work had on their lives. Within each narrative exists a deeper understanding of the work of palliative home care nursing. By recounting their narratives, participants make the invisible, visible.

## Chapter V: Discussion and Implications

Chapter V begins with a summary of the research process and findings.

I will discuss the limitations of the study and the research findings, including the meaning of relationships and professional grieving for home care nurses working with palliative clients. Further, I will discuss the importance of self-care for home-based palliative nurses, including both personal and organizational strategies. Finally, implications for nursing practice, administration, education, and further research will be identified.

### *Summary of the Research*

The purpose of this investigation was to understand home care nurses' experiences of coping with loss and grief while providing care to palliative clients. Participants told stories about how their experiences with dying clients impacted them. Three narratives evolved from interviews with ten participants. The first narrative, *balancing professional attachments*, described the relationship participants developed with the client and, often, the client's family. Relationships with clients and families were viewed as central for the provision of supportive care to the dying in the home. Participants indicated they often struggled within these relationships to provide adequate care; that is, their aim was to provide not too much or too little supportive care. Many participants formed an attachment to clients who were dying and attempted to develop professional boundaries to protect themselves and to maintain a therapeutic relationship.

The second narrative, *entering into suffering*, described the participants' personal experience with loss and grief when providing care to the dying. Participants described feelings of sadness surrounding the loss of their client. If the supportive care provided was not perceived as adequate, whatever the reason, participants



described feeling guilty which contributed to their sadness. Alternately, a lack of sadness surrounding the death of a client was due to the acceptance that it was the client's time to die, according to participants. Personal and some organizational coping strategies were identified as a means of self-care for participants to continue in home-based palliative care.

The last narrative, *honoring the memories*, depicted the responses of participants to their dying clients. Participants experienced personal growth that influenced both their practice and their private life. Spiritual questions regarding the meaning of life, death, and suffering caused many participants to reflect and search for answers to these difficult questions. More questions were asked than answers found. Participants reported they learned lessons through providing supportive care to the dying that they were able to apply to both their nursing practice and personal life. Inadvertently, their clients were instrumental in their personal growth process and many participants believed they received more from their clients than they gave.

### *Discussion of the Research Findings*

The aim of the study was to describe home-based palliative care nurses' experiences of coping with grief and loss. Home care nurses had an opportunity to tell stories about their experiences working with the dying. The findings of the study suggest the highest priority for home care nurses is the establishment of a relationship with the client and their family. Maintaining professional boundaries was a continual challenge in order to provide optimal palliative care in the home. Complex family dynamics contributed to difficulties in maintaining boundaries. Both personal and professional factors influenced the relationship for home care nurses suggesting the impossibility of

separating the nurse as a professional from the nurse as a person. The relationship, however difficult, could provide the home care nurse with unique lessons that could be applied both personally and professionally. Supporting clients and their families along the death trajectory may result in a personal growth experience for some home care nurses. Sustaining a relationship with the dying may, at times, provide a mutually beneficial experience for both home care nurses and clients. The findings of this study have significant implications for home care nurses who provide support to the dying within the context of relationship.

Unequivocally, the client's best possible outcome is the aim of supportive nursing care to the dying; such care takes place within the context of the relationship between the home care nurse and the dying client and family. The findings of this project reveal some of the challenges and benefits of this type of relationship for home care nurses. The most significant implication is that home care nurses require ongoing support in order to sustain their relationships with the dying. I will offer suggestions for education, administration, and clinical practice to ensure a supportive environment for home care nurses to practice palliative nursing care. Recommendations for further research will be identified.

### *Limitations of the Study*

There are a few limitations of the current study that must be acknowledged in any discussion of the research findings. Home care nurses' experiences of loss and grief with the dying have not been well understood in the literature; consequently, narrative inquiry was selected as the most appropriate method to ascribe meaning to these experiences. The personal significance of home care nurses' experiences is better understood when meaning is attributed to the experiences. Although narrative inquiry

captured many of the participants' experiences through their stories, there were limitations with the research design.

Due to the nature of the sample selection, there were inherent limitations to the study. The study sample was limited to home care nurses who have a story to tell; that is, they have more than two years of experience with dying clients. A natural sampling bias was created that excluded home care nurses who may have provided valuable insights into the topic. Home care nurses new to the field or newly graduated nurses were excluded from the study as they had limited experience with dying clients. Further, the experiences of home care nurses who have left community nursing are missing in the study. In addition, there was a gender bias in the study sample. No male participants volunteered for the project even though there are a significant number of male home care nurses. Participants that included male home care nurses may have generated different narratives that would be useful. The lack of a male voice throughout the narratives may limit the study's findings. The sample of the study cannot be assumed to represent narratives about all home care nurses' experiences with loss and grief. Many of the participants who volunteered to be interviewed were experienced home care nurses who articulated their thoughts and feelings well. The findings of the study represent a small sample of home care nurses and an "elite bias" may be unavoidable.

Another limiting factor of the research is that I, the interviewer, was a novice. As the interviews commenced, more time was required to obtain data from the interviews. In time, I developed interview skills that produce deeper and richer data as the interview process progressed. For example, I learned to respect the silences; that is, I did not ask questions during a period of silence so the participant would have time to reflect. An interviewer with more experience would not need to learn interviewing skills during the

study and may solicit different data resulting in different findings.

A further limiting factor is that I have worked previously as a home care nurse and have had personal experience with dying clients that may have contributed to my personal bias. Many participants identified that they struggled with boundary setting with dying clients in their homes. While listening to participants, I had to acknowledge my bias around setting professional boundaries. The stories were to reflect the participants' experiences and my questioning or feedback could unfairly influence the narratives; that is, participants may hesitate to honestly tell their stories if they fear they will be judged. Whether some participants chose not to tell their stories about struggling with boundary setting with dying clients for this reason remains unclear. I wrote in my journal after interviews and while listening to audiotapes in order to be more cognizant of my personal biases. An interviewer without this previous experience of home care nursing may produce a different study altogether. Thus, narrative inquiry may not have completely captured the essence of these narratives due to my personal biases.

Narrative inquiry as a method was absolutely limited to the stories of the ten participants; that is, there were limits to the study's findings due to the personal perspective of the participant's stories. These stories, however, were rich with personal and professional details about participant's accounts of how working with dying clients impacted them. These nurses were remarkable in their self-care coping strategies, and really did seem to have a wide and creative range of ways of dealing with what seemed to be immense emotional, practical, professional, and psychological challenges. The findings relative to their coping strategies suggest that solutions to the challenges they face may not reside totally within the scope of their self-care behaviours.

### *The Meaning of Relationships*

As previously stated, a central feature of home-based palliative care nursing identified in this project is the relationships that developed between home care nurses and their dying clients and families. The relationship develops due to the home care nurses' competent clinical responses based upon intimate knowledge of their clients. Home care nurses often provide physically intimate care to their dying clients that may result in an opportunity to develop trust and emotional intimacy. Reciprocal sharing deepens the relationship and may provide the home care nurse with opportunities to provide supportive psychological care. Coffman's (1997) research with home care nurses confirmed that psychological issues predominated nursing care, whereas biomedical issues were the focus for hospital-based nurses. Previous research with hospice nurses also stressed the importance of initiating, building, and sustaining relationships with clients (Raudonis, 1995). The findings of this study support both Coffman's & Raudonis' research findings.

Participants in this study described forming "an attachment" with their clients that was not found in the literature. The attachment developed over time as the participants gained both physical and emotional knowledge of their clients. Attachment means "a state of being personally attached" and "affectionate regard" (Merriam-Webster's Collegiate Dictionary, 1993). A synonym for attachment is fidelity, meaning "strict and continuing faithfulness to an obligation, trust, or duty" (Merriam-Webster's Collegiate Dictionary). Home-based palliative care nurses in this study described how the attachments with particular clients evolved; a common background or shared interest may strengthen the relationship. Clients may remind the home care nurses of someone they

had previously been close to, such as a family member. Participants described their relationship as, at times, "like a friendship." However, it was unlike other friendships. Home care nurses described feeling "like family" with some clients who were dying alone without involved family members. Home care nurses who develop attachments with their dying clients place a special value on the relationship, although not all the relationships resulted in an attachment.

Coffman's (1997) research of home care nurses revealed that nurses felt like a part of the family, but still a stranger. Other home care nurses described their professional role in the home as a "guest." The home care nurses who participated in Coffman's study reported feeling close to their clients and families but needing to maintain some distance in the relationship. Durkin (2000) identified that clients and families facing the dying process in their homes may intensify the relationship with the home care nurse. According to Coffman's research, unclear boundaries could lead to over involvement or inappropriate actions by the home care nurse. Paradoxically, in the current study, successful relationships in the home depended upon the home care nurse blending with the family but this resulted in blurred boundaries; that is, in order for them to develop a therapeutic relationship with a dying client and his or her family, boundaries easily became blurred. The findings of this study support Coffman's & Durkin's findings and suggest that the attachment that develops within the relationship between home care nurses and their dying clients is both beneficial and problematic.

Participants in this study indicated that the attachment with their dying clients contributed to their difficulties maintaining professional boundaries within the relationship. Boundaries were not static; they changed over time and with different circumstances; what might seem appropriate as a boundary at one juncture may be

regarded as inappropriate at another. Within this ever-changing dynamic relationship, the home care nurse attempts to reach an equilibrium. An uneven distribution of either attachment or boundaries in the therapeutic relationship interferes with the home care nurse's ability to provide supportive care to the dying. Durkin (2000) suggests home care nurses require constant vigilance to understand both personal and professional boundaries with clients and their families. Many participants in this study cited that developing professional boundaries with dying clients was a problematic issue requiring constant attention. The findings of this study suggest that the current education regarding therapeutic boundaries may not be adequate for the complex relationships with dying clients that home care nurses describe as "attachments." Home care nurses may require guidance regarding the specific challenges that arise when caring for dying clients within the intimate home setting.

Participants identified complex family dynamics as another hazard to the relationship between home care nurses and clients. Durkin's (2000) research reveals that the clients and families may involve home care nurses in conflicts between family members. Coffman (1997) identified family conflicts as the most difficult aspect of boundary setting in the home. Coffman discussed the ethical implications regarding boundary setting within family conflicts. However, the research sample did not focus on home care nurses working with the dying. Participants in this study described the arduous task of making attempts to please everyone in the midst of conflicting family relationships. Although the home care nurse's primary role is in the provision of supportive care to the client, a holistic approach includes provision of support to all members of the client's family. Conflicts within family relationships can interfere with

the home care nurse's ability to provide supportive care to the client and the client may suffer needlessly. In home-based palliative nursing care, the family provides a measure of physical care to the client and the home care nurse is responsible for the teaching and monitoring of this care. In this study, participants described some painful experiences regarding conflicts between family members; they reported their clients suffered because of inadequate care. These traumatic experiences contributed to the home care nurses suffering, a finding that was not presented in Coffman or Durkin's research findings.

Finally, participants in this study indicated that they were, at times, required to attempt a relationship with a client who did not desire such a relationship. When clients are admitted to hospital, the general assumption is that they will receive nursing care and that care is provided within the context of a nurse-client relationship; that is, hospital nurses providing physical care to clients are in a position to develop a rapport with clients that may lead to a relationship. Within the home setting, clients may not always be open to home care nursing visits; some clients refuse visits in their homes altogether. Although home care nurses do provide symptom management, supportive care often emphasizes psychological support along the death trajectory. Participants report that they, at times, creatively ease their way into a client's life and home when they know they are not wanted. Participants in this study described the psychological management of clients as the most difficult aspect of home-based palliative nursing care, especially when clients were not ready to face death. They stressed their relationship with dying clients was a means to provide the supportive psychological and emotional care required during the death process.



### *The Meaning of Professional Grieving*

Jones (1999) explored and described palliative care nurses' feelings as they struggled to make sense of their experiences and help others find meaning in suffering. Jones suggests palliative care nurses confront issues surrounding death with support in order to prevent personal fears and emotional exhaustion. Participants in Jones' study cited difficulties in relation to caring for dying clients were associated with feelings of grief, disgust, saturation with death and suffering, powerlessness, resentment, and problems with communication. Alternately, their sense of achievements produced feelings of altruism, fellowship, and a deep satisfaction with their work with the dying.

Participants in this study described similar feelings identified by home care nurses in Jones' (1999) research. Although a feeling of sadness was often cited in palliative care nursing, participants claimed that each death is experienced differently. When participants in this study perceived their clients received adequate supportive care, their feelings of loss and sadness were lessened. At these times, participants accepted death as a natural part of life. Some participants reported that death could be a welcomed solution in difficult circumstances. The perceived quality of supportive care was, at times, linked with the participants' feelings of sadness; that is, when participants perceived the supportive care was less than adequate, feelings of sadness, guilt, and loss occurred. Participants reported that these feelings could continue for some time. Clearly, home-based palliative care nurses may assume a deep sense of responsibility for a client's death experience and the outcome of the death may impact upon their feelings.

The pioneering work of Bowlby (summarized in Chapter II), in which loss is understood in the context of the attachment theory, and it is recognized that future losses

are influenced by past experiences with loss, helps us understand how feelings of sadness and loss after a client's death may be influenced by previous personal losses of loved ones. In the current research, participants reported that attachments may be formed with dying clients when they are reminded of a previous personal loss. In addition, home-based palliative care nursing may not be an appropriate field of nursing for nurses who have had a recent personal loss. These nurses may be unable to provide supportive care to the dying while experiencing their own personal grief process. Counseling through the Employees Assistance Program may offer home care nurses support during the grieving process, as some participants described.

Froggatt (1998) discusses the high amount of emotional labour involved in nursing and the practical strategies of hospice nurses to manage the emotional aspects of their work. Nurses in Froggatt's study attempted to contain strong emotions using distancing strategies such as switching on and off, hardening, and standing back. Participants in this study support Froggatt's research in that much of the supportive care for the dying consists of emotional or psychological support. However, they stated they did not want to become "hardened", contrary to Froggatt's research findings. Home care nurses must be emotionally present to give emotional support to the dying. Emotional distancing will interfere with caring for the dying since the home care nurse will not be present to the suffering of the client. A metaphor evolved from this study that portrayed home care nurses who experience or witness painful emotions; that is, home care nurses need to become channels and let the suffering flow through them, rather than vessels that keep the suffering contained. Letting go of the suffering implies that home care nurses need to process their feelings of grief and accept death as a natural process in life.

From the perspective of the participants, grieving the loss of their clients was

important. To ignore grief by avoiding and denying the loss supports a culture of wounded healers (Boyle, 2000). Home-based palliative care nurses will not be able to help others with their emotional pain when they are unable to resolve their own.

Acknowledging and working through the loss after the death of a client allows closure of the relationship for home care nurses. Participants identified attendance at funerals as beneficial, a social acknowledgement of grief and sadness. Funerals provided a public venue for a private good-bye and afforded the home care nurse closure to the relationship. Participants indicated that searching for meaning about life, death, and suffering assisted them to grow personally, professionally, and spiritually as they cared for the dying. Boyle describes self-reflection and acceptance of sadness as a means of creating a culture of compassion. Similarly, participants in this study identified kindness as a means of treating the suffering of the dying.

In this study, participants described their experience of processing their loss and grief similar to the process of mourning described by Worden (1991). Many described accepting the death, experiencing feelings of sadness, adjusting to a new environment, and moving on with their life, tasks identified by Worden. In addition, participants described valuable personal and professional lessons they learned about humanity through accompanying their clients on their journey towards death. Moving on with their life often meant a richer, more appreciative life for participants because of their experiences of loss. Personally, life was cherished because of the experiential knowledge of suffering and loss through death. Professionally, the experienced gained could be beneficial to other dying clients as home care nurses gained expertise in providing supportive care.

Participants in the current study reported that they received support from colleagues, the Hospice team, friends, and family. They identified coworkers as their main source of emotional support. They stated that their team members supported one another throughout the day and, at times, after work hours. Currently, designated support staff for emotional support for home-based palliative care nurses at Vancouver Coastal Health are a social worker and a palliative care nurse clinician. They are both available for support at the Hospice case reviews that occur one hour each month. Home care nurses are not always able to attend Hospice case reviews due to heavy workload or time off and, thus, may be deprived of the needed support. In addition, the palliative care nurse clinician is available on site one hour every two weeks. At other times, both the social worker and palliative care nurse clinician are available for support by pager or appointment only. On site, a manager, clinical nurse specialist, and educator could be available for support but they have numerous other responsibilities within the organization. Thus, participants turn towards their colleagues for the daily ongoing support necessary to provide supportive care to the dying within the context of a relationship. The findings of this study suggest that collegial time is an essential aspect of delivering palliative care for home care nurses. Organizational recognition of nurses' ongoing need for personal support acknowledges the inherent difficulty in the provision of supportive care to the dying.

Home-based palliative care nurses require ongoing emotional and clinical support for the delivery of supportive care to the dying. Regular meetings are an integral part of delivering palliative nursing services for Macmillan Nurses in Great Britain (Clark et al., 2002). Each week the team meets to discuss clinical and educational strategies. The weekly meetings center around two objectives: the best outcomes of care for the client

and the maintenance of nursing standards. Loes van Staa et al. (2000) reports research findings that suggest ongoing weekly support meetings are needed for palliative care nurses that are accompanied by adequate resources, a supportive management, an extensive educational program, and attention to individual needs with the group. At Vancouver Coastal Health, the current organizational structure may be inadequate to meet the ongoing needs of home care nurses who are providing supportive care to the dying. Weekly ongoing meetings for home care nurses to offer collegial support are not presently in place in the current organizational structure. Home care nurses in this study reported time spent with their colleagues was their most effective coping strategy when caring for dying clients.

### *The Meaning of Self-Care*

Participants in this study identified self-care as the means for home-based palliative care nurses to continue to work with the dying. Previous literature supports that palliative care is emotionally stressful work and identified stressors in this project were similar to past research: paperwork, heavy workload, too many palliative clients, physicians, poor communication between staff, lack of organizational support, resource limitations, and difficult work environment (Kulbe, 2001; Loes van Staa et al., 2000). Previous financial constraints have impacted upon nursing practice and the client's health care needs. Participants in this study describe a working environment full of uncertainty, anxiety, and frustration that adds to the stress of home-based palliative care nurses. Kulbe (2001) listed coping measures in previous research findings as talking with colleagues, exercise, working part time, time away from work, humour, talking with friends and family, medication, and spiritual practices. Participants in this study listed similar

personal coping strategies that have been identified in previous research findings.

Davies & Oberle (1990) developed a model of the supportive role in palliative care nursing. One key concept relating to self-care in this model, “preserving own integrity”, relates to the idea that the nurse as a person cannot be separated from the nurse as a professional. Participants in their study described various means to assist in “preserving own integrity”: maintaining their self-esteem; looking inward; valuing their personal worth; and acknowledging and questioning their personal behaviours, reactions, and needs (Davies & Oberle). Many of the participants in this current study described similar self-care strategies to Davies & Oberle’s findings. Participants’ self-reflective practices confirmed that they were struggling to find meaning in their experiences with dying clients. Participants were challenged both personally and professionally; that is, their professional experiences were impacting upon them personally.

Murrant, Rykov, Amonite, & Loynd (2000) suggest a holistic approach to self-care that integrates the body, emotions, mind, and spirit. Their findings indicate that the arts provide a means for creative play and expression to increase nurses’ awareness of nurturing themselves; journal writing, art therapy, and music therapy were listed as self-care strategies. Participants in the current study indicated similar self-care strategies. They described a holistic approach for self-care strategies including journal writing, talking to others, listening to music, massage, walking in nature, and praying. In addition, some participants identified an area in their workplace that represented a memorial for deceased clients. This place of remembering may be a book including the name of the deceased and, also, the names of the health care providers involved in the client’s care. In this way, home care nurses honoured their client’s journey towards death.

In previous literature, problems with teamwork have been identified; lack of

direction and unclear structures of teams, inadequacy of organizational support, a lack of staff training in and orientation to teamwork, poor levels of trust, complicated power relations, tensions between professionals, and decreased continuity of membership can result in poor relationships amongst team members (Clark et al., 2002). Participants in this study did not report any of the negative aspects of teamwork previously cited in the literature; they reported primarily the benefits of working with a team in home-based palliative care nursing. Unequivocally, they identified team support as the most beneficial strategy for self-care in palliative care nursing. Many participants in the study indicated that team support was valuable as their colleagues offered emotional support during times of sadness. In addition, team members offered constructive suggestions for supportive care to dying clients. Through a team-centered approach, participants stated that they were able to maintain healthy boundaries with dying clients. Their colleagues would visit their clients enabling them to have a break from palliative care nursing when needed. In addition, colleagues would offer constructive suggestions to assist in maintaining healthy professional boundaries with dying clients. Further, colleagues would listen to each other as they told their stories about their dying clients and families. Clearly, collegial support promoted a shared approach that validated and supported each other's nursing practice..

Although measuring burnout in home-based palliative care was beyond the scope of this research project, the dimensions of burnout were evident in some of the participants' accounts. The Maslach Burnout Inventory reveals three dimensions of burnout: emotional exhaustion, depersonalization, and decreased feeling of personal accomplishment (Taormina & Law, 2000). Some participants in this study stated they were not always able to develop attachments or special feelings for each of their dying

clients. Some clients may not want to develop an intimate relationship with the home care nurse and prefer nursing care that focuses on physical management only. Participants in this study cited heavy workload as a major stressor that placed unrealistic expectations upon them. They were unable to become emotionally involved with all clients when their caseload of palliative clients was high. Depersonalization is the tendency to regard people objectively and can be a means of self-protection (Taormina & Law). Heavy workload may not only contribute to depersonalization but also a decreased feeling of personal accomplishment, the second dimension of burnout (Taormina & Law). Some participants in this study described thoughts and feelings similar to the dimensions of burnout; however, identifying burnout was not part of this study. Participants in this study reported that changes in the organization were affecting the delivery of care to their palliative clients and that less community supports and decreased hospital beds were resulting in dying clients, at times, not receiving adequate care in the home. Manageable workloads that ensure home care nurses' are able to provide adequate supportive care to clients may contribute to less feelings of depersonalization and decreased sense of accomplishment at work for home-based palliative care nurses.

Emotional exhaustion is a key component identified in burnout (Taormina & Law, 2000). Personal stress management skills have previously been identified as the conventional approach to lessen emotional exhaustion but appeared to have limitations and was entirely ineffective in preventing burnout in the participants in Taormina & Law's study. Personal coping strategies that include organizational support are more effective in alleviating the effects of burnout (Kulbe, 2001). Participants in this study described many personal coping strategies but few organizational strategies that were supportive in their delivery of palliative care.



Fletcher (2002) cites cutbacks in hospital budgets have resulted in reduced hiring of new Registered Nurses, high workloads, stressful working environments, and forced overtime. Participants in this study cited time away from work as a self-care strategy to combat the effects of burnout: emotional exhaustion, depersonalization and decreased sense of accomplishment at work. They reported strategies such as working casual or part-time instead of full time, going on vacation after a particularly difficult death, using booked overtime or vacation to travel, taking time off work for projects, and taking time off work for union work. When palliative care nursing became too stressful, some participants stated they were looking elsewhere for employment in nursing. Time away from work as a coping strategy is a temporary solution and alarming in view of the nursing shortage. Home care nurses' descriptions of emotional exhaustion, depersonalization, and decreased feelings of personal accomplishment become organizational problems to solve. The recruitment of new nursing staff to home care and the retention of experienced home-based palliative care nurses may be enhanced by improving the work environment.

### *Implications for Nursing Practice*

In the following section, I will discuss the implications of the study's findings for nursing practice, specifically in relation to palliative care. The delivery of home-based palliative care is complex and the current organization responsible for the delivery of home care is undergoing many changes in the present climate of redesign and fiscal constraints. A recent Canadian survey by Dunleavy, Shamian, & Thomson (2003) cites intensified workload as a major problem for Registered Nurses who are experiencing fatigue and burnout as they attempt to do more with less and struggle to maintain their

nursing standards of care; Registered Nurses report unsafe practice environments due to downsizing and restructuring of health care organizations.

Many participants in this study voiced similar concerns and reported they no longer had the tools to provide adequate supportive care to the dying. Further, they indicated that resources were not available in the community when needed. Participants described feelings of frustration when their dying clients received inadequate supportive care. Self-care strategies alone will not prevent emotional exhaustion and burnout in home-based palliative nursing care (Taormina & Law, 2000). Organizational strategies that ensures manageable workloads, adequate staffing, community resources, and clinical support staff to maintain home-based palliative care nurses' standards of practice with dying clients in the community are needed.

The current nursing shortage is driven by growing health care needs of an elderly population, insufficient seats in nursing programs, and a heavy workload forcing Registered Nurses to leave the profession (Fletcher, 2002). Further, Fletcher cites that the Canadian Nurses Association predicts 331,000 Registered Nurses will be needed by 2011 to cope with Canada's future health care needs. Canadian colleges have been graduating 1,000 to 2,000 fewer nurses annually than needed to maintain the current nursing workforce. The results of a recent survey of Canadian student nurses indicated that the current work environment is deteriorating and is a significant factor for future nurses' career choices (Rheume, Woodside, Gautreau, & DiTommaso, 2003). Improving working conditions could prove an organizational strategy for the recruitment of new nurses into home care nursing. In view of these alarming statistics, the recruitment of new nurses to home care nursing and as well as the retention of experienced home-based palliative care nurses is of the utmost importance to serve a growing population at home.

The findings of this study suggest that an organizational strategy to assist home care nurses would be to provide time each day for team members to support to each other through case conferencing, listening to each other's stories, and providing constructive feedback to home-based palliative care nursing practice. Home-based palliative care nurses require a safe place to examine nursing practice regularly and a work environment that supports them to manage the complex emotions associated with palliative care nursing. Further, the findings suggest that additional clinical supports to the current organizational structure may provide home-based palliative care nurses with the needed support to continue in their practice of supportive care for the dying.

The findings of this study add to the small but growing body of literature on home-based palliative care nursing. The findings relative to participant's coping strategies suggest that solutions to the challenges they face may not reside totally within the scope of their self-care behaviours. The findings suggest questions for further consideration regarding which coping strategies these home care nurses could use to become more effective in buffering the extreme tensions they experience in relation to their role. For example, focus groups at each of the health units at Vancouver Coastal Health would provide a larger sample size than the current study. Participatory action research may be an effective qualitative method to determine which organizational coping strategies would benefit home-based palliative care nurses.

Some participants in this study described the effects of burnout identified by Maslach (1982): depersonalization, emotional exhaustion, and a reduced sense of accomplishment at work. It is beyond the scope of this study to suggest that any of the participants were experiencing burnout to any degree. The importance of this study is in

the participant's descriptions of feelings similar to burnout which suggests that investigating burnout using the Maslach Burnout Inventory may prove enlightening providing an appropriate sample size was obtained. Determining the levels of burnout in home-based palliative care nurses may produce results that would support the identified organizational coping interventions for nurses.

Vancouver Coastal Health presently offers clinical and emotional support to home-based palliative care nurses through the Home Hospice Program. Research that evaluates the current program's effectiveness in meeting home care nurses' needs may be useful. At present, education regarding self-care for nurses or understanding the process of personal grieving is lacking. Questionnaires may be an appropriate method to obtain information regarding what is needed within the program to support nurses. The findings of the small sample of this study indicate there are mixed reports. Some participants found the Hospice program supportive while others did not. More research with a larger sample size is needed to determine the effectiveness of the current structure as well as to make recommendations for improvement, if needed.

### *Conclusion*

This study identified home care nurses' stories about coping with their experiences of grief and loss while providing supportive care to their dying clients. The methodology of narrative inquiry was selected for this project and uncovered participants' narratives: *balancing professional attachments*, *entering into suffering*, and *honoring the memories*. The findings of this study contribute to the growing body of literature on home care nurses' experiences with the dying. The emotional work of nursing often remains hidden and invisible, not easily measured. The difficult aspect of home-based palliative care nursing, psychological support during the death trajectory, is

becoming increasingly recognized as important. The personal coping strategies identified in this study that contributed to the participants' physical, emotional, and psychological well-being were effective for coping with the complex nature of working with the dying. Current organizational strategies to support home care nurses who care for the dying at home were found lacking by many participants. The future predictions of the growing nursing shortage within the context of an aging population at home, raises the recruitment and retention of home care nurses' issue to the forefront. Strategies that support home care nurses to continue in their supportive care of the dying are necessary. The findings of the study suggest that there may be more organization strategies required to assist home care nurses with the complex emotions that accompany working with dying clients and that further research in this area will assist decision makers by identifying appropriate interventions. This study is only a beginning step towards creating an environment that will provide home-based palliative care nurses with effective tools for their nursing practice.

## References

- Andrus, P. (2001). Loss, Grief, and Bereavement. In B. Poor & G. Poirrier (Eds.), *End of life nursing care*. (pp.39-57). Mississauga, ON: Bartlett Publisher, Inc.
- Barbour, R. (1994). The impact of working with people with HIV/AIDS: A review of the literature. *Social Science Medicine* 39, 221-232.
- Barthow, C. (1997). Negotiating realistic and mutually sustaining nurse-patient relationships in palliative care. *International Journal of Nursing Practice* 3, 206-210.
- Beck, C. (1998). Qualitative research: The evaluation of it's credibility, fittingness and auditability. *Western Journal of Nursing Research* 15, 263-265.
- Bennett, L. & Kelaher, M. (1994). Longitudinal predictors of burnout in HIV/AIDS health professionals. *Australian Journal of Public Health* 18, 334-336.
- Benoliel-Quint, J. (1997). Loss and bereavement: Perspectives, theories, challenges. *Canadian Journal of Nursing Research* 29, 11-20.
- Booth, K. (1995). Professional support within hospices. *International Journal of Palliative Nursing* 1, 206-210.
- Booth, K., Maguire, P., Butterworth, T., & Hillier, V. (1996). Perceived professional support and the use of blocking behaviours by hospice nurses. *Journal of Advanced Nursing* 24, 522-527.
- Bottorff, J., Johnson, J., Irwin, L., & Ratner, P. (2000). Narrative of smoking relapse: The stories of postpartum women. *Research in Nursing & Health* 23, 126-134.
- Bowlby, J. (1980). *Attachment and loss*. Vol. 3. New York: Basic Books.
- Boyle, D. (2000). Pathos in practice: Exploring the affective domain of oncology nursing. *ONF* 27, 915-919.

- Bram, P. & Katz, L. (1989). A study of burnout in nurse working in hospice and hospital oncology settings *16*, 555-560.
- Clandinin, J. & Connelly, M. (2000). *Narrative inquiry*. San Francisco, CA: Jossey-Bass Publishers.
- Clark, D., Seymour, J., Douglas, H., Bath, P., Beech, N., Corner, J., Halliday, D., Hughes, P., Haviland, J., Normand, C., Marples, R., Skilbeck, J., & Webb, T. (2002). Clinical nurse specialists in palliative care. Part 2. Explaining diversity in the organization and costs of Macmillan nursing services. *Palliative Medicine 16*, 375-385.
- Coffey, A. & Atkinson, P. (1996). Narratives and stories. In *Making sense of qualitative data: Complementary research strategies*. (pp.54-82). Thousand Oaks: Sage.
- Coffman, S. (1997). Home-care nurses as strangers in the family. *Journal of Nursing Research 19*, 82-96.
- Cohen, M., Haberman, M., Steever, R., & Deatrck, J. (1994). Rewards and difficulties of oncology nursing. *ONF 21*, 9-17.
- Copp, G. & Dunn, V. (1993). Frequent and difficult problems perceived by nurses caring for the dying in community, hospice and acute care settings. *Palliative Medicine 7*, 19-25.
- Cornette, K. (1997). For whenever I am weak, I am strong. *International Journal of Palliative Nursing 3*, 6-13.
- Corr, C., Nabe, C., & Corr, D. (1997). *Death and dying, life and living*. (2<sup>nd</sup> ed.). Pacific Grove, CA: Brooks/Cole.
- Cortazzi, M. (1993). *Narrative analysis*. Bristol, PA: The Farmer Press.
- Costantini, A., Solano, L., Di Napoli, R., & Bosco, A. (1997). Relationship between

- hardiness and risk of burnout in a sample of 92 nurses working in oncology and AIDS wards. *Psychotherapy and Psychosomatics* 66, 78-82.
- Davies, B. & Oberle, K. (1990). Dimensions of the supportive role of the nurses in palliative care. *ONF* 17, 87-94.
- Dean, R. (1998). Occupational stress in hospice care: Causes and coping strategies. *The American Journal of Hospice and Palliative Care* 15, 151-154.
- DeConcini, B. (1990). *Narrative remembering*. Lanham, MD: University Press of America, Inc.
- De Conno, F., Caraceni, A., Groff, L., Brunelli, C., Donati, I., Tamburini, M., & Ventafridda, V. (1996). Effects of home care on the place of death of advanced cancer patients. *European Journal of Cancer* 32A, 1142-1147.
- Dolan, N. (1997). The relationship between burnout and job satisfaction in nurses. *Journal of Advanced Nursing* 12, 3-12.
- Donaldson, M. (1998). The importance of measuring quality of care at the end of life. *The Hospice Journal* 13, 117-138.
- Duffy, S. & Jackson, F. (1996). Stressors affecting hospice nurses. *Home Healthcare Nurse* 14, 54-59.
- Dunleavy, J., Shamian, J., & Thomson, D. (2003). Handcuffed by cutbacks. *Canadian Nurse* 99, 23-26.
- Duquette, A., Kerouac, S., Sandhu, B., & Beaudet, L. (1994). Factors related to nursing burnout: A review of empirical knowledge. *Mental Health Nursing* 15, 337-358.
- Durkin, N. (2000). The importance of setting boundaries in home care and hospice nursing. *Home Healthcare Nurse* 18, 478-481.
- Ellis, S. (1997). Patient and professional centred care in the hospice. *International*



- Journal of Palliative Nursing* 3, 197-202.
- Engel, G. (1961). Is grief a disease? A challenge for medical research. *Psychosomatic Medicine* 23, 18-23.
- Farrington, A. (1995). Stress and nursing. *British Journal of Nursing* 4, 574-578.
- Farrington, A. (1997). Strategies for reducing stress and burnout in nursing. *British Journal of Nursing* 6, 44-50.
- Fletcher, M. (2002). Nursing by the numbers. *Canadian Nurse* 98, 14-16.
- Florio, G., Donnelly, J., Zevon, M. (1998). The structure of work-related stress and coping among oncology nurses in high-stress medical settings: A transactional analysis. *Journal of Occupational Health Psychology* 3, 227-242.
- Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, systems and health* 16, 197-212.
- Freudenberger, H. (1983). Burnout: Contemporary issues, trends, and concerns. In B. Farber (Ed.), *Stress and burnout in the human service professions*. (pp.23-28). New York: Pergamon Press.
- Froggatt, K. (1998). The place of metaphor and language in exploring nurses' emotional work. *Journal of Advanced Nursing* 28, 332-338.
- Freud, S. (1957). Mourning and melancholia. In J. Rickman (Ed), *A general selection from the works of Sigmund Freud*. (pp.124-140). New York: Liveright Publishing Corporation.(Original work published in 1917).
- Gomas, J. (1993). Palliative care at home: A reality or 'mission impossible'? *Palliative Medicine* 7, 45-59.
- Goodman, C., Knight, D., Machen, I., & Hunt, B. (1998). Emphasizing terminal care as district nursing work: A helpful strategy in a purchasing environment? *Journal of*

- Advanced Nursing* 28, 491-498.
- Guba, E., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.) *Handbook of qualitative research*. (pp.105-117). Newbury Park: Sage.
- Guba, E., & Lincoln, Y. S. (1981). *Effective evaluation*. San Francisco: Jossey-Bass.
- Hardy, S. (1995). Promoting a healthy workforce: A clinical case presentation. *British Journal of Nursing* 4, 583-586.
- Hartrick, G. & Hills, M. (1993). Staff nurse perceptions of stressors and support needs in their workplace. *The Canadian Journal of Nursing Research* 25, 23-31.
- Hawkins, R. (1999). Care for the caregiver: Strategies for avoiding "compassion fatigue." *Clinical Journal of Oncology Nursing* 3, 183-184.
- Heyland, D., Lavery, J., Tranmer, J., Shortt, S., & Taylor, S. (2000). Dying in Canada: Is it an institutionalized, technologically supported experience? *Journal of Palliative Care* 16, 10-16.
- Higuchi, K., Christensen, A., & Terpstra, J. (2002). Challenges in home care practice: A decision-making perspective. *Journal of Community Health Nursing* 19, 225-236.
- Humphrey, G. & Zimpfer, D. (1996). *Counselling for grief and bereavement*. London, Eng.: SAGE Publications.
- Hutchings, D. (1997). The hardiness of hospice nurses. *The American Journal of Hospice & Palliative Care*. May/June, 110-113.
- Janssens, R., Zylicz, Z., & Ten Have, H. (1999). Articulating the concept of palliative care: Philosophical and theological perspectives. *Journal of Palliative Care* 15, 38-44.
- Jarrett, N., Payne, S., & Wiles, R. (1999). Terminally ill patients' and lay-carers'

- perceptions and experiences of community-based services. *Journal of Advanced Nursing* 29, 476-483.
- Joffrion, L. & Douglas, D. (1994). Grief resolution: Facilitating self-transcendence in the bereaved. *Journal of Psychosocial Nursing* 32, 13-19.
- Jones, A. (1999). A heavy and blessed experience: A psychoanalytic study of community Macmillan nurses and their roles in serious illness and palliative care. *Journal of Advance Nursing* 30, 1297-1303.
- Kash, K., Holland, J., Brietbart, W., Berenson, S., Dougherty, J., Ouellette-Kobasa, S., & Lesko, L. (2000). Stress and burnout in oncology. *Oncology* 14, 1621-1637.
- Krisman-Scott M., & McCorkle, R. (2002). The tapestry of hospice. *Holistic Nursing Practice* 16, 32-39.
- Kubler-Ross, E. (1969). *On death and dying*. Don Mills, Ont.: Maxwell Macmillan, Canada.
- Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). A new model for classification of approachers to reading, analysis, and interpretation. In *Narrative Research: Reading, analysis, & interpretation*. (pp.1-19). Thousand Oaks, CA: Sage Publications, Inc.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *The American Journal of Psychiatry* 101, 141-148.
- Loes van Staa, A., Visser, A., & van der Zouwe, N. (2000). Caring for caregivers: Experiences and evaluation of interventions for a palliative care team. *Patient Education and Counseling* 41, 93-105.
- Maeve, M. (1998). Weaving a fabric of moral meaning: How nurses live with suffering and death. *Journal of Advanced Nursing* 27, 1136-1142.

- Marino, P. (1998). The effects of cumulative grief in the nurse. *Journal of Intavenous Nursing* 21, 101-104.
- Maslach, C. (1982). *Burnout- The Cost of Caring*. Englewood-Cliffs, New Jersey: Prentice-Hall.
- Mathieson, C. & Barrie, C. (1998). Probing the prime narrative: Illness, interviewing, and identity. *Qualitative Health Research* 8, 581-601.
- Mazhindu, D. (1998). Emotional healing. *Nursing Times* 94, 26-28.
- McNamara, B., Waddell, C., & Colvin, M. (1995). Threats to the good death: The cultural context of stress and coping among hospice nurses. *Sociology of Health & Illness* 17, 222-244.
- McNeil, C. (1998). A good death. *Journal of Palliative Care* 14, 5-6.
- Merriam-Webster's collegiate dictionary* (10<sup>th</sup> ed.). (1993). Springfield, MA: Merriam-Webster.
- Miller, B. & McGown, A. (1997). Bereavement: Theoretical perspectives and adaptation. *The American Journal of Hospice & Palliative Care* 14, 156-161.
- Mishler, E. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Mishler, E. (1995). Models of narrative analysis: a typology. *Journal of Narrative and Life History* 5, 87-123.
- Morse, J. (1991). Strategies for sampling. In J. Morse (Ed.) *Qualitative nursing research: A contemporary dialogue*. (pp.127-145). Newbury Park: Sage.
- Morse, J. & Field, P. (1995). *Qualitative research methods for health professionals* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Murrant, G., Rykov, M., Amonite, D., & Loynd, M. (2000). Creativity and self-care for

- caregivers. *Journal of Palliative Care* 16, 44-49.
- O'Neill, B. & Rodway, A. (1998). ABC of palliative care : Care in the community. *BMJ* 316, 373-483.
- Payne, N. (2001). Occupational stressors and coping as determinants of burnout in female hospice nurses. *Journal of Advanced Nursing* 33, 396-405.
- Payne, S., Sheldon, F., Jarrett, N., Large, S., Smith, P., Davis, C., Turner, P., & George, S. (2002). Difference in understanding of specialist palliative care amongst service providers and commissioners in South London. *Palliative Medicine* 16, 395-402.
- Phillips, S. (1996). Labouring the emotions: Expanding the remit of nursing work? *Journal of Advanced Nursing* 24, 139-143.
- Pines, A. (1983). On burnout and the buffering effects of social support. In B. Farber (Ed) *Stress and burnout in the human service professions*. (pp.155-174). New York: Pergamon Press.
- Poirier, S. & Ayres, L. (1997). Endings, secrets, and silences: Overreading in narrative inquiry. *Research in Nursing & Health* 20, 551-557.
- Polkinghorne, D.E. (1997). Reporting qualitative research as practice. In W. G. Tierney & Y. S. Lincoln (Eds.), *Representation and the text: Re-framing the narrative voice*. (pp.3-21). Albany, NY: State University of New York Press.
- Power, L. & Sharp, B. (1988). A comparison of sources of nursing stress and job satisfaction among mental handicap and hospice nursing staff. *Journal of Advanced Nursing* 13, 726-732.
- Rando, T. (1984). *Grief, dying, and death: Clinical interventions for caregivers*. Champaign, Illinois: Research Press Co.

- Rando, T. (1986). A comprehensive analysis of anticipatory grief. Perspectives, processes, promises, and problems. In T. Rando (Ed), *Loss and anticipatory grief*. (pp.3-37). Lexington, Ma: D.C. Heath and Co.
- Rasmussen, B., Sandman, P., & Norberg, A. (1997). Stories of being a hospice nurse: A journey towards finding one's footing. *Cancer Nursing* 20, 330-341.
- Raudonis, B. (1993). The meaning and impact of empathetic relationships in hospice nursing. *Cancer Nursing* 16, 304-309.
- Raudonis, B. (1995). Empathetic nurse-patient relationships in hospice nursing. *The Hospice Journal* 10, 59-74.
- Redinbaugh, E., Schuerger, J., Weiss, L., Brufsky, A., & Arnold, R. (2001). Health care professionals' grief: A model based on occupational style and coping. *Psycho-Oncology* 10, 187-198.
- Rheume, A., Woodside, R., Gautreau, G., & DiTommaso, E. (2003). Why students choose nursing. *Canadian Nurse* 99, 25-29.
- Riessman, C. (1993). *Narrative analysis*. Newbury Park, CA: Sage Publications, Inc.
- Rittman, M., Paige, P., Rivera, J., Sutphin, L., & Godown, I. (1997). Phenomenological study of nurses caring for dying patients. *Cancer Nursing* 20, 115-119.
- Ruland C. & Moore, S. (1998). Theory construction based on standards of care: A proposed theory of the peaceful end of life. *Nursing Outlook* 46, 169-175.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science* 8, 27-37.
- Sandelowski, M. (1991). Telling stories: Narrative approaches in qualitative research. *IMAGE: Journal of Nursing Scholarship* 23, 161-166.
- Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. *Research in*

*Nursing and Health* 18, 371-375.

Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health* 18, 179-183.

Sandelowski, M. (1998). Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing & Health* 21, 375-382.

Saunders, J. & Valente, S. (1994). Nurses' grief. *Cancer Nursing* 17, 318-325.

Saunders, C. (1996). Into the valley of the shadow of death: A personal therapeutic journey. *BMJ* 313, 1599-1601.

Sprang, G. & McNeil, J. (1995). *The many faces of bereavement*. New York: Brummer/Mazel.

Seymour, J., Clark, D., Hughes, P., Bath, P., Beech, N., Corner, J., Douglas, H., Halliday, D., Haviland, J., Marples, R., Normand, C., Skilbeck, J., & Webb, T. (2002). Clinical nurse specialists in palliative care. Part 3. Issues for the Macmillan Nurse role. *Palliative Medicine* 16, 386-394.

Seymour, J. (1999). Revisiting medicalisation and 'natural' death. *Social Science & Medicine* 49, 691-704.

Skilbeck, J., Corner, J., Bath, P., Beech, N., Clark, D., Hughes, P., Douglas, H., Halliday, D., Haviland, J., Marples, R., Normand, C., Seymour, J., & Webb, T. (2002). Clinical nurse specialists in palliative care. Part 1. A description of the Macmillan Nurse caseload. *Palliative Medicine* 16, 285-296.

Stajduhar, K. & Davies, B. (1998). Death at home: Challenges for families and directions for the future. *Journal of Palliative Care* 14, 8-14.

Stordeur, S., D'hoore, W., & Vandenberghe, C. (2001). Leadership, organizational stress, and emotional exhaustion among hospital nursing staff. *Journal of Advanced*

- Nursing* 35, 526-532.
- Strickland, D. (1998). Balancing life's choices: All dressed up and too many places to go. *AORN Journal* 68, 634-641.
- Swift, G. (1994). A contextual model for holistic nursing practice. *Journal of Holistic Nursing* 12, 265-281.
- Taormina, R. & Law, C. (2000). Approaches to preventing burnout: The effects of personal stress management and organizational socialization. *Journal of Nursing Management* 8, 89-99.
- Taylor, E. & Amenta, M. (1994). Midwifery to the soul while the body dies: Spiritual care among hospice nurses. *The American Journal of Hospice & Palliative Care*, November/December, 28-35.
- Taylor, C. (2002). Professional boundaries: A matter of therapeutic integrity. *Journal of Psychosocial Nursing* 40, 23-28.
- Thulesius, H., Petersson, C., Petersson, K., & Hakasson, A. (2002). Learner-centred education in end-of-life care improved well being in home care staff: A prospective controlled study. *Palliative Medicine* 16, 347-354.
- Vachon, M. (1997). Psychological issues: Recent research into staff stress in palliative care. *European Journal of Palliative Care* 4, 99-103.
- Vachon, M. (1998). Caring for the caregiver in oncology and palliative care. *Seminars in Oncology Nursing* 14, 152-157.
- Vancouver/Richmond Health Board (2000) *Living well, dying well: Regional palliative care planning project report*. Vancouver, B.C.: Author.
- Vendlinski, S. & Kolcaba, K. (1997). Comfort care: A framework for hospice nursing.



*The American Journal of Hospice & Palliative Care*, November/December, 271-276.

Wilkes, L., Beale, B., Hall, E., Rees, E., Watts, B., & Denne, C. (1998). Community nurses' description of stress when caring in the home. *International Journal of Palliative Nursing* 4, 14-20.

Wilkinson, E., Salisbury, C., Bosanquet, N. Franks, P., Kite, S., Lorentzon, M., Naysmith, A. (1999). Patient and carer preference for, and satisfaction with, specialist models of palliative care: A systematic literature review. *Palliative Medicine* 13, 197-216.

Williams, M. & Wheeler, M. (2001). Palliative care: What is it? *Home Healthcare Nurse* 19, 551-556.

Worden, J. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer Publishing Company.

World Health Organization (WHO). (1990). *Cancer pain relief and palliative care*. Technical Report Series 804. Geneva: Author.

Wright, D. (2001). Hospice nursing: The specialty. *Cancer Nursing* 24, 20-27.

Zerwekh, J. (1995). A family caregiving model for hospice nursing. *The Hospice Journal* 10, 27-44.

## Appendix C: Demographic Data

## DEMOGRAPHIC DATA

Study: The experience of loss and grief by home care nurses who care for palliative clients.

1. How many years have you worked as a Registered Nurse? \_\_\_\_\_
2. How many of these years have you worked in home care? \_\_\_\_\_
3. Do you work full time \_\_\_\_\_ part time \_\_\_\_\_ casual \_\_\_\_\_?
4. Are you female \_\_\_\_\_ male \_\_\_\_\_?
5. What year were you born? \_\_\_\_\_
6. Do you have children? Yes \_\_\_ No \_\_\_
7. What is your educational background?

Nursing Diploma \_\_\_\_\_

Bachelor's Degree in Nursing \_\_\_\_\_

Graduate Degree (please specify) \_\_\_\_\_

Other (please specify) \_\_\_\_\_

Thank you for completing this form.

All information will be kept confidential as part of this study.

## Appendix D: Interview Guide

### INTERVIEW GUIDE

Study: Home care nurses' experiences of loss and grief when caring for palliative clients.

#### *Questions*

1. Tell me about one of your experiences of loss or grief when one of your palliative clients was dying or died.
2. Was there anything that helped you during this time?
3. What were the things that made this time difficult for you?
4. Were you able to continue working?
5. What was it like for you to continue working while experiencing loss and grief?
6. How might things have been different?
7. Would you do anything differently if or when this experience happens again?
8. What effect has this experience had for you personally?
9. What effect has this experience had for you professionally?
10. In closing, is there anything else you would like to tell me that you haven't already said?
11. What name would you like me to use for your synopsis of your interview?
12. What has it been like for you to do this interview, to relate your experiences to me?

## Appendix E: Interview Synopsis

### *Hope*

Hope has been working in home care nursing for 22 years and 25 years as a Registered Nurse. Hope began her interview talking about a client, S., who was dying of pancreatic cancer. S. was socially isolated and had lived a wild life, leaving her husband and two children when they were young. S. had not wanted home help and as her condition deteriorated, Hope began to talk with her about going to the Palliative Care Unit. S. was a catholic and very upset that she felt she was not going to heaven because of her past life when she left her family and led a wild life. Hope arranged to have a nun visit S. when she went to PCU and that made an incredible difference to S. She stopped punishing herself and started accepting help and pain medication. Hope believed that S. had dealt with her unworthiness as she had previously been punishing herself. This client was significant and meaningful for Hope as she acknowledged the special connection with a person's humanness that comes in nursing. Providing care for S. could be a bit difficult because she would not accept the care she required. However, Hope developed a special fondness for her and found talking with her colleagues about her helpful. S. affected Hope deeply on a human level as she wanted the best for S., for things to be better, but knew that S. was the one in control.

For Hope, the professional boundaries can become blurred when you know someone over a long period of time. She has memories of clients and thinks about them when she drives by their house. She misses clients. She believes that when clients die it is their time to go and is better than struggling. Hope discussed a client, E., who was in her 90's and dying of cancer. She lived with her sister in the house they had both been born into. She had wanted to die in that home. E. had a colostomy and learned how to care for it. She fell and broke her hip and had to go to the hospital. E. was placed on a medical floor and not well cared for. Hope went to visit her and found she had not been fed and was dirty. Hope found the situation very hard and thought about E. at night. However, Hope did not know how the situation could have been different. She knew she could not give E. the care she needed in the hospital and tried to advocate for E. by encouraging the sister to talk with the Head Nurse. Hope went on vacation the week after E. died which helped, as Hope was upset about this situation. Talking with her colleagues was helpful as well as exercise and sleep. Hope likes to donate money to charity in a client's name that was special to her. She likes to go to the funerals of significant clients to hear stories about their lives, which feels like a completion. Prayer is important to Hope. Hope feels that she gets to know clients at such a small part of their journey.

Hope talked about the recent changes in the organization. People are falling through the loop, some family physicians do not know what they are doing for palliative care clients, and these clients are not getting the care they need. One difficult recent change is the limitation on how much help a client can have in their home. If things get

worse and clients cannot get the help they need in their home, Hope believes she could not stay in home care anymore even though she loves her job. She would find it too frustrating to see clients suffer when there is no need. Having the tools to do her job effectively makes a big difference. Hope is an advocate for her clients but thinks clients will be set up for a horrendous experience if the resources become too scarce.

Hope stressed the importance of relationship building with both the client and the family. When she builds trust and mutual respect with families' things can go smoother and are worked through together. If problems arise the family will talk about it and a difficult situation may be avoided. Working with team members keeps boundaries healthy and avoids families playing nurses off. She describes the process of dying as a very intimate moment of life similar to being born. She realizes she is not the only one providing care and will call upon others when needed such as the Hospice team.

Hope identifies Hospice case reviews and her manager as being supportive. However, Hospice case reviews are only once each month and Hope does not believe this is enough time to discuss concerns about palliative clients. Hope would like to see some guaranteed time when the nurses could get together and not be disturbed and share client situations and things they have learned. This time would be "sacred" time for dealing with bereavement and maintaining the health of the nurses. There is a place in her unit where they honor clients that have died. The name of a person is recorded in a book along with the names of the health care providers that cared for the client. She would like to see a candle lighting service where they could light a candle for someone and perhaps sing. With busy jobs things tend to get left or not talked about. Talking about her experiences with the dying is helpful, healthy, and a learning experience for Hope.

Hope concluded her interview describing a situation where a new nurse did not recognize that a client who was having pain was actively dying. The nurse thought it was radiation-related pain and the client went to the Cancer Agency and they sent her home. When Hope went to see the client the next day she sent her to the Palliative Care Unit and she died the following day. The nurse felt badly and Hope spent some time talking with her and told her if you learn something from this situation then you honor the client.

*Jane*

Jane has been a Registered Nurse for 30 years and worked in home care nursing for 20 years. She started the interview discussing three cases that were memorable for her. The first was a couple that she had cared for when she first started home care nursing. Both husband and wife were palliative. They were a difficult family to support because they were wealthy and expected a high level of support. The husband went to bed and expected to die. It took four months. He was angry when Jane came to visit because she represented the fact that he had not died yet. The wife died five months later. The second client was one that Jane had seen for a number of years who was not palliative. She fell and was hospitalized and died within two weeks. She just gave up and decided to let go. Jane was fond of this client and misses her. The last client was a gentleman who committed suicide. Jane had not been able to get him to plan around his death and one day she got a call from the client's wife and was told the client put a gun to his head, shot himself, but did not die. He died later in the hospital. Previously in home care, nurses routinely did bereavement visits with family up to 13 months after the death. At that time, bereavement was considered important but now bereavement visits with the family are only done if there is personal connection. Some bereavement visits are done informally on nurses' lunch break and that is one of many losses in the system now.

Jane described a fourth client who was dying of cancer of the lung. He had been a beer drinker for years. He carried on drinking beer along with his morphine for pain. He was quiet, gradually lost his functioning, and died quietly in bed. She was not present for his death and related that it is unusual for nurses to be there for the actual death. Nurses prepare people for it, describe it for clients, and help to anticipate it but are not often present in the home when it happens.

Talking to colleagues is mainly how Jane deals with feelings around working with palliative clients. Sometimes she asks not to have any more palliatives on her caseload for perhaps one week. However, she does not like to burden her colleagues with her palliatives and feels guilty if they are carrying her load. Sometimes she takes her colleagues palliatives for a while so they can have a break. The sharing of palliatives back and forth on the team helps her get a different perspective. Jane is a senior nurse and has lots of vacation. She takes two weeks off four times each year for a break.

Jane finds visiting palliatives on weekends or nights when she does not know them stressful. The visits are tough because she does not know how the family has been prepared or where they are in their process. There is often not enough time to read the whole chart. She feels unsure what advise to give and has to start at zero with these families. If the clients are her own then she understands the problems better.

Jane believes the current organizational structure does not allow the manager to be very involved. In the past, she could unburden herself with the coordinator. Now she believes the support systems are distant. The system is so big that people do not know one another anymore. The units are all divided. The loss of the respite bed at a local hospital impacts upon the care their clients receive in terms of diagnosis, symptom control, and rest. The Hospice doctors are wonderful but overworked and under-funded. Superb Nurse Clinicians that existed in the past have been pushed out. The system is the same now as it was 20 years ago when a nurse had to leave elderly clients alone in their

homes and did not know if anyone would come to visit or not. No one knew who would help them. Jane stresses the importance of maintaining the Hospice doctors for support, as they are one of the few supports left. With the cutbacks continuing, the doctors are at risk.

Jane describes entering into a client's pain the most difficult aspect of palliative care. Before she can talk with clients about the important things, she must apologize for the entire system. Clients have horrendous stories of neglect, delays, and bad decisions. The symptom management is not the hard part. It is the work of dying that is difficult. That is, preparing and getting ready for death and making sure clients understand what is going on without pushing them is hard. Sometimes there is time for this preparation and sometime there is no time at all. Sometimes their symptoms get worse and they go to the hospital and die. There is no completion.

Jane is feeling discouraged and sad about things. She recounts some personal family problems and her own health issues and how hard it is to work during this time.

Jane discussed the difficulties with her role working with palliative clients. Often clients are not prepared for the nurse and do not know how the nurse can help them. Clients can hardly grasp the fact that they have been given a terminal diagnosis. Jane thinks that she has a secret that she know what is going to happen to palliative clients. She knows how it will be with their fatigue, their loss of appetite, their losses and having to say good-bye. Sometimes she feels like a vulture with palliative clients who live a long time. One of her clients lived two years and she kept Jane at a distance because Jane brought a preparation for death that the client really did not want. She sometimes thinks she has been given a mission to inch her way in to people's lives when they are often not ready. It is frustrating when clients expect services that are no longer available.

Jane talked about her feeling of satisfaction working with palliative clients. Some families are supportive and pleased with the care. There is a joy when a client's stability is maintained for a certain period of time. She described a client that she did routine tracheotomy care for and was able to give him little bits of information and maintain him for about six to eight months until he died. There was satisfaction in being able to perform the practical and physical care to maintain him. There is also satisfaction when clients do begin to ask questions about things they previously did not want to discuss. For Jane, there is still some frustration and bitterness.

Jane described dealing with the whole person in palliative nursing. She described a client who was dying of prostate cancer and his wife would not talk about death and dying at all. Jane was performing wound care and all the wife would talk about was the wound or the client's diet. Jane had to promise not to talk about anything sad if she was to stay involved with this client. So Jane agreed. When the client finally went to the hospital, the wife was angry because she was not prepared. Jane felt she had honored the client's decision and the wife's decision not to talk about preparation for dying. They had dealt with his dying in their own way even though a huge part of his care may have been neglected.

Clients have palliative diagnosis but are living longer now. The client and families get tired but you cannot have long discussions yet because it is not the right time. Jane concludes her interview stating that she feels a lack of support providing palliative care. She acknowledges the work her colleagues do and wants to try to acknowledge it within her which is harder.

*Louise*

Louise is an experienced home care nurse of 17 years and has been an RN for 34 years. She began her interview talking about her early career in palliative home care and that was in the later half of the AIDS epidemic in the West End. She has feelings of sadness around clients' death but a realization that it was their time to go. At that time there was a lot of support for staff as palliative care and bereavement were new concepts. The support that was offered focused on learning how to cope with the work and self care. Louise talked about strategies she has used in her work life such as walking between client visits. While walking she leaves the sadness from the previous visit, as she knows she cannot take it in with her to the next visit. She wants to give 100% to each of her clients and she cannot not do this if she is still feeling sad from the previous visit. Louise takes care of herself when she goes home at night, taking time to be alone to work things out. Then she owes it to her family to be there for them.

Louise discusses how a supportive team can help to have feelings validated and understood. The team shares the caseload and has a team-centered approach rather than a nurse-centered approach. Nurses on the team watch over each other and debrief with each other. Mentoring new nurses or preceptoring a student nurse helps her review practice and how she's looking at things. Humour can be a life preserver and help her to not take herself too seriously. She discusses professional boundaries and the importance of not becoming part of the family situation. The nurse's responsibility is to stay back a bit to offer professional help. If she feels she is becoming too close a team member can visit for a while. Louise describes the huge responsibility of nursing to not get too close in order to be able to give the professional care the family needs. The nurse needs to know her limits and give everything you can as a nurse. The nurse cannot be a sister or mother or family member to the client. Louise keeps watching that she is not doing too much and overstepping the bounds, but doing enough.

Louise described a palliative client who was educated, bright, and lived in an amazing apartment. He was in a particularly horrible situation with feces coming out of his catheter requiring constant irrigation. Two days before he died, Louise went to visit and the client's partner was barbecuing shrimp and the smell mixed with the odour from the catheter was horrible. Louise described the situation as absurd and beyond anything reasonable. She learned that she had to allow clients to make their own choices and support the client's choice if it was not harmful.

Louise talked about the sadness experienced with palliative clients. She mentioned a couple dying within hours of each other, some clients who killed themselves, and a client who suffered because he was resuscitated at home and sent to the hospital when his wishes were for a home death. When things are not in her control it contributes to sadness but also she cannot be accountable when it happens this way. Louise believes that she attempts to make things work as well as they can and if she knows she has done that then she can live with it and let it go. Having done a good job helps her to deal with the sadness in situations.

A second situation Louise described was a couple that had been labeled "dysfunctional" who seemed to hate each other. Because of the relationship problems the woman was not getting the care she required in the home. She ended up in the Palliative Care Unit and a case conference was held with the hospice physician and social worker. In the end, no one knew what to say or do with the tension and frustration between the



couple. The ending was very sad with so much suffering. Louise describes some deaths as harder to work around and came to the understanding that the suffering was not her doing and she did everything she could in the situation.

Louise stressed the importance of self-care when caring for palliative clients. She uses ongoing education and resources effectively. Providing the best possible care for clients was a means of self-care because if Louise feels she is not doing the best job she can then she will have a huge weight of responsibility on her shoulders. Louise stated that staff supports from the organization were available when she began palliative care quite a few years ago and so she learned self-care at that time. Now she said the supports are there but you have to be able to ask or even push for them. An example she gave was debriefing after a traumatic experience. In the past, debriefing would have happened automatically. At this time, a nurse would have to ask for a debriefing session.

Louise discussed her early nursing years as an ICU nurse and how the families of dying clients were treated. The supportive care to families of clients in ICU or Emergency were lacking. In community nursing, she learned to recognize patients as people and give emotional support. She describes community nursing as a privilege as clients let you into their homes and into their lives.

Keeping some sort of balance in life is important to Louise. Taking time to debrief and think about situations can help put things in their place. She thanks God for the blessings in her life. Her husband is supportive. She is sometimes a bit self-indulgent and has learned to not put things off because they might not happen. She stresses the need to look after herself when feeling sadness. Regarding self-care, Louise said it is about knowing who you are and acting on it.

To conclude the interview, Louise talked about the things nurses tell caregivers when caring for a loved one at home. Nurses tell the caregivers to take supports offered because if the caregiver gets sick then she or he isn't going to be able to look after the loved one. Louise believes the same holds true for nurses, emotionally and physically.

*Lynda*

Lynda is an experienced RN of 32 years with 8 years in home care nursing. Her interview was almost a continuous narrative with very little participation from the researcher. She described in detail four palliative clients she had cared for that had affected her deeply. The first, R., was 22 years old, married, and dying of a brain tumour. She was diagnosed when she was 4 months pregnant and subsequently lost the baby due to chemotherapy. She described how the client and her husband were not open to nursing visits and how she had to market herself to get in to visit. She solved this problem of trying to help a younger population group by bringing in lunch for the client and her husband. The client's mother was the same age as Lynda and had an affect on her, touched her emotionally, as she described losing her only grandchild. Lynda stated that she felt profound empathy for the client's mother who was open to nursing visits. Working with this family helped Lynda to put things in her own life in perspective as she had some personal painful issues of her own. She discussed how in the past this situation would have overwhelmed her and she would have struggled hard to make sense of it. R. was a client who Lynda continued to discuss throughout the interview, calling it a sad story.

The second client Lynda described, N., was similar to her own age, dying of cancer, and becoming ill quite quickly. Before she became ill, N. had a full time career in teaching, lots of friends, was well liked and respected. Her husband was caring and they had a blended family together. The treatment for her cancer had altered her appearance to the point that she no longer resembled earlier photographs. Lynda again described how earlier in her career she would have struggled to make sense out of something that didn't make sense and wasn't fair. In the past, she used to think about cases like these at home that she found hard to accept. She developed avenues of how to comfort herself such as listening to music. Lynda said she wanted to try to make her client's journey as comfortable as possible as she traveled with them.

The third client, J., was described as an unbelievable story. J. is 44 years old, palliative, lost her husband in an accident two years ago, and has a six-year-old son. Her husband had a previous daughter who is currently after the estate. J. has had difficulty with her cancer treatment in that her care has been fragmented at various institutions throughout the city. Also, J. does not always follow treatment according to plan, such as medication management. Again, Lynda stated how this client's situation would have overwhelmed her in the past. However, she stated she has learned that she can't change anything. Clients make choices and she can support those choices within limits. Lynda discussed the value of kindness as the most therapeutic in providing care to palliative clients. Although Lynda stressed the importance of proper nursing assessment and using resources she believed listening to clients and offering hope really made a difference.

Lynda discussed a recent personal experience of a friend, S., who was diagnosed with breast cancer that had metastasized to the colon, duodenum, and pancreas. S. was also a nurse and had taught Lynda valuable lessons about nursing early on in her career. She learned about the art of nursing through S. Now S. was a recipient of health care service and Lynda could see some of the care was lacking. Lynda discussed how some of the doctors and nurses did not recognize S. was suffering. One nurse who offered kindness to S. recognized that another human being was suffering. Lynda believes that the biggest challenge for nurses in palliative care is to respond to another's suffering. By

responding in kindness, nurses would treat the suffering. Lynda had learned from another health care professional the importance of being a vessel and not a channel.

Lynda discussed what she thought was important about nursing. She thought people wanted to feel emotionally safe and that concern and kindness would help people feel cared about. Excellent nurses really care about their standards of practice, about guidelines, the client, and the family. A new nurse has to master the basic techniques of nursing and then can focus on a personal interest in nursing. Lynda has learned and received so much more than she has given to palliative clients.

Lynda had some personal pain in her own life and realized how health care professional and friends can support someone in their suffering. Through this experience, she learned she couldn't absorb another's suffering, people need an advocate to navigate the health care system, and not to judge anything.

Lynda talked about the importance of a good working environment that includes clinical staff support, manageable workloads, supportive teams, ongoing education, and nursing mentors. Knowledge about available resources in health care and how to utilize them helps professionally. Personally, Lynda finds support with her family and doing things with friends.

The last client Lynda described was an elderly married woman who did not always welcome the nursing visits. Lynda realized that it was because her visits reminded the clients that she was ill and that she was not getting better. Having a lifestyle that allows flexibility helps when providing palliative care. She wondered how young nurses manage in this field as they have so many other commitments such as young children. She has also seen and heard many younger nurses struggles with issues that come up with palliative clients. Lynda wondered whether in fact young nurses should be providing palliative care, as she did not feel she was mature enough until she was 40 years old. One has to live through it and learn through it. If one does not, then one experiences burnout and leaves. She stressed the importance of being kind to yourself, each other, and clients.

In conclusion, Lynda discussed how palliative care has expanded her as a person. Spiritually, she has done some searching and learned that she had to discover the meaning of life for herself. She realized that she probably wouldn't have explored some questions if she had not been working in palliative care. Palliative care has helped her grow and think about what is really important. Working with palliative clients has encouraged her to examine the meaning of life. She describes working in palliative care as a privilege.

*Marsha*

Marsha has been a Registered Nurse for 31 years and worked in home care nursing for the past 22 years. Marsha began her interview recollecting her early experiences working with palliative clients in the early 1980's during the AIDS epidemic. They were young men, newly diagnosed, that were dead within a year. Many of the men were younger than she was at the time. The unit that she worked in was small and the AIDS epidemic was new so they all had to cope with learning as they went along. There was an 8-week program developed specifically on caregivers coping with AIDS. In order to cope, Marsha decided to take a 6-month leave of absence from work as she was feeling overloaded with dealing with all the losses. Support from her team members was helpful. Going to funerals resulted in some closure with clients where the experience had been intense and sad. Sharing palliative clients with team members makes her feel that she is not alone. Marsha described going away for a break to an island cottage important to her on weekends as well as focusing on keeping herself in good health through diet and exercise.

Marsha discussed breaks from working with palliative clients that she has taken during her career as a nurse. She was involved with union work that took her away from work for long periods. At another time, she was seconded for a hospital project that lasted about six months. Marsha finds working with palliative clients sad but finds much satisfaction in the work knowing that she has made a bad situation a bit easier for people to cope with. She has received personal feedback from people acknowledging the support that was given.

Working with palliative clients challenges Marsha in her beliefs about life after death. She is constantly learning about how people cope and why some people cope better than others. During a period of a few years, Marsha's father died suddenly, her husband had a heart attack, and her sister had heart surgery. At this time she found it much more difficult to cope at work. She realized her professional approach and personal approach are different. The experience made her a better nurse. Marsha learned that a person couldn't really prepare for the loss of a loved one. It is impossible for health care providers to be working with palliative clients when they are losing their own family members. During this time, Marsha was able to take her six-month leave for project work. Colleagues who are losing family members are given about five days off work and this is not enough time away to cope with the loss. She is considering another career change at present, perhaps one less stressful, as she plans to work another five to ten years in nursing. Marsha tries hard not to show her own feelings of loss in front of clients but finds she can burst into tears easily afterwards at home or cry her eyes out through a sad movie. Marsha has found support through her colleagues at work, the EAP Program, and courses on bereavement and loss. She does not want clients to feel that they need to support the nurse.

Marsha describes the connection she has with clients intense at times. She has kept in touch with some people for years. She feels a part of the community she works in and often meets people on the street that she has known in the past. The feedback that she receives from people who reinforce that she made a difference in their lives makes up for the sadness and the tragedy that she has experienced.

Marsha discusses some of the supports that have helped her while working with palliative clients. Her husband is supportive and she likes to fund raise to contribute to

the health of others who have not been fortunate. In the past, the nursing coordinator was supportive but that position was deleted. Debriefing sessions have been helpful and Marsha related the story about a client where there was debriefing afterwards. The daughters of the client were making decisions for their mother when the client was quite capable of making them herself. Marsha felt badly that she didn't ask the client what she wanted. The debriefing session was helpful as the complex family dynamics made this situation particularly difficult. Marsha believes the organization could be more supportive by being more flexible with work hours. For example, a nurse should be able to come in to work half an hour early and leave half an hour early for something important if all the work gets done. Marsha has experienced difficulty getting off work early even though she stays late at times due to workload.

Marsha finds family dynamics very difficult. She describes a client who had many family members present while she was trying to obtain a history during her first visit. She had not been given much information prior to the visit. She felt the family was critiquing her. Relationships with clients can be quite intense because you visit them in their home and may see them over a long period of time. The follow up after the death with the family is helpful. Marsha stressed that the relationship with clients and families is professional and believes it is important to keep limits on what she does. Some clients have asked her for a number other than her pager number to get in touch with her. She remembers working with another health care professional who did not believe there was such a thing as burnout. She was not a team player but a perfectionist and died in her early fifties of an autoimmune disease. Marsha has developed her own coping strategies and believes clients have amazing coping skills.

Marsha has learned a great deal from palliative clients. Some people have such feisty spirits and can cope with whatever is thrown their way. She has developed the ability to not think that she has to know it all. With the AIDS epidemic she learned that although she had the knowledge and skills, the client is the one in charge. Marsha is willing to listen to clients' strategies on how they are going to cope or what is important to them however different it is from what she may think. The approach is very different than the hospital, which is a controlled environment. She does not have the resources at her fingertips when she is in the home and the only health care provider present. When events are happening in the home she feels she has to deal with them. Marsha feels that some of her biggest losses have been with clients who have had a chronic condition that she may have been involved with over eight or nine years. She misses the clients that have been a part of her working life. Walking around the community can trigger memories of clients that she has lost and misses.

The physical stresses of the work can be stressful for Marsha and sometime more stressful than the emotional. She describes climbing onto the bed to do wound care and visiting homes that are particularly filthy. One client was extremely difficult and the staff found him impossible to work with. Marsha did not feel sad when he died because he was so unhappy and not enjoying his life. Her lack of sadness at his death made her wonder if she did need a change from working with the dying. Marsha concluded her interview stating that she tries to set up the ideal for clients but realized that may not be the way things are going to happen because it is not in her control.

*Mary*

Mary has been in home care nursing for 2 ½ years and an RN for 8 years. Her interview was mainly questions and answers as she stated that she likes to be asked questions during interviews. Mary focused her interview primarily on what it was like for her working with palliative clients, although she did refer to a client she had been attached to that was currently in the Palliative Care Unit.

Mary discussed how she began in home care nursing and how it was not at all what she expected. Palliative care nursing was not something she was initially interested in and believed that death is something that we, as human beings, don't want to think about. There was not a choice about easing into caring for palliative clients due to short staffing and often she would see complex palliative clients. Mary believes that a person's background will often tell you how they will react to palliative care and she recounted the story of her mother's death at an early age. Her early experience with death and dying as well as witnessing her father's grief gives her a different perspective on loss. As well as personal experience, other factors that influence palliative clients' impact upon her are family dynamics, the client, and other stressors.

Mary described a client, J., that she felt attached to who was currently in the palliative care unit. She felt she really knew this client well. The palliative care staff were trying hard to have this client discharged as they felt that was what the client wanted. However, the client only wanted to go home if her sister could manage. Mary felt she had to advocate for the sister and that it was okay if the client was not discharged home. The client's wishes were dependent on the ability of her sister and if that was not possible, the client preferred to remain in hospital. Mary was never quite sure if she was doing the right job with palliatives.

Mary talked about days when she cried because of things that have happened at work and people that have died. She believed that health care professionals have to protect themselves at work, "harden yourself", but does not think she has yet. She does not think she will get "hardened to this" because in palliative care you have to get to know someone both personally and professionally.

Mary talked about self-care and her goal was to learn to relax more perhaps through meditation. She likes to exercise everyday, get lots of rest, and eat right and finds this helpful with the stress of working. She discussed counseling as a means to figure things out both personally and professionally.

Her transition from acute to community nursing was a difficult transition that she described as "rough". At first she felt like she did not fit in. There were changes in management and support staff at the time and Mary did not feel there was much support for the staff. She tried to learn from busy colleagues who all had different ways of doing things. She had to learn to become more independent, trust her own knowledge, and realize that she could make her own client care plans. Personally, she had just moved and was away from her family, she ended a relationship with her boyfriend, and she started a new job. Personally and professionally it was a huge adjustment.

Mary discussed how she develops a strong bond with palliative clients. Her connection with clients comes from having something in common or reminding her of

someone. She loves talking to people and feels she really gets to know her clients. She feels sad at the loss of her clients, feels their pain, but tries to not take it home with her at night. She thinks that her experiences of loss with clients takes her back to her feelings of the loss of her mother. She thinks her tears about her palliative clients may also be tears about her mother.

Mary has dealt with a lot of loss throughout her career. She would like to see more opportunity for debriefing and sharing palliative clients. Taking a break from palliatives is beneficial as sometimes she feels she can work with them too much. The rotation at work ensures "forced breaks" as after two weeks of day shift the nurses do a wound clinic for a week and some evening shifts. She talks to her boyfriend and colleagues at work for support. When clients die, she does not think she does enough preparing. She thinks about them for a few days and then tries to forget. When her clients go to the Palliative Care Unit she begins her process and realization that they are probably not coming home. Sometimes she goes to the PCU to say good-bye to clients. Once clients have died she tried not to dwell upon it and wonders if she is being cruel. She tries to carry on and bring what worked well with this client to her care of the next client.

Support systems in the organization such as the Hospice Team are valuable and help to protect the staff. Hospice case reviews are good for debriefing and help with understanding difficult situations. Counseling is available for anyone to use. Ongoing education is helpful. Sharing information with experienced colleagues is supportive. Although the staff is busy, they all try to go out for lunch every Friday. Although support systems are in place, Mary stresses throughout her interview how busy the unit is and how it is difficult to access these support systems due to a heavy workload.

Mary discussed her nursing practice with palliatives and the amount of time she spends organizing her care plans so other team members can follow them. She likes to do everything she feels she can for her clients and provide a direct, honest, and realistic approach. One of her struggles working with palliative clients is that she is meeting her clients at the end of life rather than getting to know them a bit sooner. The most important aspect of palliative care nursing is to make their life as pleasant as possible for whatever remainder they have. Visiting clients in the home tells Mary so much about a person as she is able to see how that person really lives. Mary is starting to believe that a person chooses their time to die and caring for palliative clients that are working through issues of death and dying bring up personal spiritual issues that are not yet resolved. Mary has learned many lessons and become stronger by seeing a lot of suffering. Journal writing helps to try to find answers and meaning to questions. Learning to relax the mind would help everything come together.

To conclude, Mary thinks there is a lot of personal grief and loss working with palliatives that goes unrecognized. Perhaps a bad mood that occurs two days later is something to do with the stress at work. She has started being more aware of cues such as needing to go to sleep when she gets home after work. She believes talking about work situations helpful but thinks nurses do not listen to each other enough and do not listen enough to their clients. Most palliative clients just want to talk about things and nurses can make a big difference by listening.

*Holly*

Holly has been a registered nurse for 10 years and working in home care nursing for the past 7 years. She discussed a client and his family that had impacted her and this story was weaved throughout her entire interview. Holly had recently cared for a young client, L., dying of cancer, and his supportive wife, N., who were both planning a home death. The couple were independent and private and Holly was struck by their incredible love for each other. She felt inspired by them and hoped that one day she would experience that sort of bond with someone. They all became good friends. L. was incredibly sick and N. was providing most of the care for him. Holly focused on trying to find ways to help N. cope with the situation by looking at what supports were available in the community. Eventually, N. put her back out trying to care for her husband and she became bed-bound and could not walk. N. felt guilty because her husband eventually had to go to the Palliative Care Unit, as she was no longer able to care for him at home. At PCU, N. had a bed placed in L.'s room and that was a good compromise. The day L. went to PCU was very emotionally stressful. That day Holly had a car accident where she was at fault and believed the events of the day contributed to the fact that she did not see the car in front of her. She realized that caring for this particular family was impacting her, both physically and emotionally, more than she realized.

Holly discussed how caring for palliative clients was difficult for her when she first began in home care nursing. She was energetic with worry about some of her clients. Now she feels more experienced with pain and symptom management. She is more knowledgeable about resources for clients and how to access them. Holly has chosen to work part time and, therefore, has more balance in her life. Her biggest support was identified as her colleagues and she stressed the importance of being a team player.

Holly talked about recognizing her limitations in her work and how sometimes personal issues can make caring for palliative clients stressful. At one time she took three months off work and traveled due to some personal problems and feeling she was unable to work at that time in her life. At times she has asked not to have any more palliatives on her caseload but feels she can only do this for a short time, as she is aware she has to support her colleagues. Holly describes working with palliative clients can be overwhelming and can become too much if something personal becomes overwhelming as well. She stressed how important it is to recognize when things are becoming too much at work or one is likely to burn out.

Holly discussed how working in community has made her a better nurse. She reflected upon her years working in the hospital and how she felt she was always rushing. Hospital nursing was task-oriented, breaks were at a set time, and lacked the personal approach. Hospital nurses "run like mad dogs", "work so hard", "and don't have any job satisfaction because moral is low." She enjoys being a "guest" in her client's home. She believes palliative clients have a major life-altering event in their world and what they really want is someone to listen to what they are feeling. Some clients have a tough time coping with the reality of their situation and need someone to talk with about their fearful thoughts, anxieties, or regrets. Holly finds situations frustrating when clients do not talk about their thoughts and feelings and keep telling her everything is fine. Helping clients work through these issues is often dependent on what is going on with the rest of the family.



Holly continued to discuss at length the young couple she was involved with. Although she had developed a good connection with this couple, she felt she was getting too close and was becoming too drawn into the situation. She reminded herself she was not a family member although she felt she had become good friends with this couple and would have been great friends with them if they had met in a different environment. They would have discussions together about things not relating to L.'s health care at times and, therefore, started to develop a real relationship. Holly began to realize that she needed some distance as things were becoming too personal. She felt her relationship might not have been that healthy as things became a little too close for her. She discussed the situation with a colleague and decided to slowly phase herself out after the client was admitted to PCU. She did visit the couple a few times in the hospital but felt she went as a friend rather than as a nurse. She kept in touch with N. after L.'s death for some follow up support.

Holly discussed feeling more confident in her role in the community. She feels doing the best job that she can and recognizing her limitations are important. Areas of support she utilizes professionally are the assignment nurse, the educator, the clinician, the manager, and physicians. Personally she exercises and goes for regular massages. As she has become more experienced in home care, she recognizes the importance of stopping and looking after herself. She thinks sometimes it is an event that makes her realize that things are getting out of control. She needs to focus and take care of herself.

Holly discussed the importance of encouraging self-care with new nurses in home care so they will stay longer. She talked about a colleague who has just taken the summer off work because of stress leave. Sometimes colleagues need their load lightened and team members are able to provide this support. She talked about another team member who is experienced and knows when she has reached the point where she has had enough. She talked about feeling guilty when you have to sometimes say "no." The alternative is to get tired and sick and take time off work.

Holly concluded her interview saying that community nursing was not for everyone. However, she finds it easier than working in a hospital because in community, the nurses take care of each other.

*Irene*

Irene has been working as a registered nurse for 27 years; the last 8 years in home care nursing. Irene described, in detail, two experiences working with palliative clients as well as the personal loss of her father. Her first client, S., had end stage Chronic Obstructive Lung Disease and lived in the Downtown Eastside and had a very disadvantaged life. Irene was involved with S. for 2 1/2 years as her condition deteriorated. Irene state she "moved heaven and earth" for her and they went through "heaven and hell" together. Irene became very attached to S. who became very reliant upon her. Irene remembers trying to find some balance in the situation. She performed a function but she was not family. However, Irene was "entrenched" in S.'s life and S. was "entrenched" in Irene's work life. Irene began to realize that S.'s death was going to impact on her and she knew she would have to pay attention to the process. Irene had been through a great deal with S. and had a deep respect for her. Irene felt that S.'s death would "break her heart." S. had a deep fear of dying which triggered spiritual questions for Irene. After discussions with her colleagues, Irene realized she would need to begin the process of "disengaging" before S. died. She needed to allow S. to have her death process and that there were limits on what she could accomplish for S. before she died. When S. was admitted to Hospice three months prior to her death Irene was able to relax and reflect upon what was her professional responsibility and what was her personal attachment. For her unresolved spiritual issues, Irene was able to arrange for a chaplain to come and visit S. in Hospice. Irene was able to begin to let go and let the Hospice staff "pick up the ball" for her although she continued to visit.

For Irene, the support from her two colleagues was very beneficial. They would discuss cases in detail and offer suggestion to one another when the involvement with clients became overwhelming. At times, they would visit each other's clients so they could have needed breaks. Irene described her work environment when she first started caring for palliatives. There was little education at that time and most of the learning was from colleagues. There was a general social worker but no Hospice Team. The workload was intense with nurses caring for 6-7 palliative clients at a time and working overtime everyday. Irene's work with palliatives is very focused because she believes there is a finite amount of time left and it is the one time in a person's life when "we should do it right." Irene describes a sense of ownership with palliative clients and she tries to make things move, as there is a clock ticking. Even though she had previous hospital experiences with death and dying in her nursing career, she felt like a novice in an area where she had previously felt like an expert. Palliative care in clients' homes meant that Irene was really in their lives, not the controlled setting of a hospital. Often the client's home was a world Irene did not understand, the world of disenfranchised people living in the Downtown Eastside. Irene discussed how caring for palliatives made her grow personally as she was much younger when she had experiences with death and dying in the hospital. She was humbled as she learned to let go of the pride of being able to cope with something that a lot of people don't want to cope with. Irene remembered how intense the experience was for her and how much love and compassion she received from her colleagues. She also remembered that the volume of workload, the number of palliatives, and the overtime probably resulted in burnout. Irene decided to go traveling for 6 weeks and upon return she realized how much the work was impacting her.

The second client Irene discussed was P. who she originally met when she was caring for his partner who was dying of HIV/AIDS. P. who was very damaged from childhood and called Irene after the death of his partner. P. was an example of the clients Irene finds herself developing an attachment to; these clients have no social support systems, no real true friends to trust, and they have been damaged early in childhood. P. became Irene's client as his own HIV/AIDS condition advanced. Irene developed a deep personal attachment to P. and learned a huge lesson in that trusting for some people is a huge abyss that is almost insurmountable. Irene began to question from a professional and ethical point of view how much access to allow clients into her personal life. She crossed over some lines that earlier in her career she would not have. As P. began to near death, Irene began to question how his death would impact her. Irene related some of the details of her father's unexpected death and how there were things she was not able to do for him. Providing care for P., she felt, allowed her to do some of the things she wished she had been able to do for her father. Both her father and P. died on Thanksgiving Day, although in different years. Irene reflected upon the difference between death on a personal level and death on a professional level. On a professional level, 90% of what happens occurs before death, whereas, on a personal level, 90% of what happens occurs after the death. Some clients' memories stay with Irene even after they have died. Clients that particularly affect her are the ones that she has gone the distance with because there has been nobody else in their life. Or there may have been a very intimate and far-reaching personal communication around their death or dying. At different times she acknowledges them and then lets it go. She realizes how vulnerable she feels working in palliative care.

Irene concluded the interview by talking about her nursing practice with palliative clients and the importance of paying attention to yourself and finding ways of de-stressing. She describes palliative home care nursing as very rewarding and feels blessed, very privileged to engage with clients on their process of dying. She stressed the importance of management's understanding of how exposed and vulnerable nurses are in these situations and the need of support in terms of mental health days, in-services, and consultants.

*Anna*

Anna has been a Registered Nurse for the past 5 years and has worked in home care nursing for 3 years. Anna began her interview discussing that she does not always feel attached to clients or feel a sense of loss when they die. She would feel terrible, however, if the care she provided to the family was not good enough or was missing something. Anna told the story of a family that she was involved with where the client was having a difficult time with pain management. The client's daughter did not want her to have any pain medication but wanted her pain treated with massage and herbal medicine. The client died in pain and Anna felt responsible, not for the death, but because the client did not have comfort and relief from pain. Those that were involved with this client did education for the daughter regarding pain medication but the daughter would not give the client anything but herbal medicine. Anna went to pick up the medication herself and tried to give it to the client but the daughter yelled at her. Anna described this situation as a bad experience that upset her. A good death experience is when the client is comfortable, the family is happy with the care, and the client passes away peacefully. After the death, Anna and the staff that were involved with this client did a debriefing session because all the doctors and nurses involved were upset. When Anna called the daughter for follow up after the death, the daughter said she felt good about the death because the client died peacefully. Anna learned that clients and family dynamics are all different in each situation. Anna does not feel a sense of loss after the client dies if she has done the best that she could do for the client.

Anna discussed another client, J., who had skin cancer and his wife did not want to live with him anymore. Anna found this situation hard and felt angry. She did not want to judge the wife but at the same time felt bad for the client. She felt that the situation was not in her control and got the Clinical Social Worker involved, which helped. Using resources helped Anna to unload some of her feelings about this case. Anna has learned over the past three years not to take things personally so she will not get upset looking after palliative clients. She views families very differently now. If they do not manage the way she thinks they should, it does not have to be her way. Families know what is best for them even when they do not comply with what the nurses want. She does not do anything in particular to relieve stress.

Anna discussed how caring for the dying at home is challenging. There are many things to think about such as sufficient medication at home and who is going to give the medications. In the hospital, things were very straightforward when providing care to both the client and family. In the community, everything is slower and more difficult to access. The home is the family's territory and you cannot do anything without asking the family first. Anna feels she spends more time with the family when preparing for a home death and believes that clients are more comfortable when dying at home, although she would always support a client's wishes to die in hospital. Anna finds it comforting to do follow up bereavement with families after a death and wants to know how they felt about the whole process and if they were satisfied with the care.

Anna talked about boundaries with palliative clients. When she first started in palliative home care she would do "extras" for clients even if the families were able to do it for themselves. She would volunteer to pick up medications from the pharmacy just to be nice to clients. Now she does what she can to help them but does not do the extras because she feels like she is carrying a lot of weight with her. She would end up running

around and being all stressed out. She no longer gets involved with things she does not need to do and gives the family the responsibility. Doing the extras for clients does not solve the problem in the long run because if the person cannot do something, then arrangements need to be made for the client. Families can come to expect the nurse to do the extras when some days it is not possible. Anna realized that she would soon burn herself out if she continued doing the extras for clients. Once she started doing something for someone it was hard to withdraw so she finds it easier if she does not start.

Anna talked about what she has learned from working with palliative clients. Her involvement with clients going through the dying process and the family dynamics are interesting. The importance of pain management and the how clients respond to different medications was something new for her in community. Palliative care nursing is complex and changing all the time. At her place of work, there is an interest group that supports nurses interested in palliative care nursing. Anna finds support from colleagues beneficial. The paperwork consumes more time in her day than the time spent with clients. Anna described working with the family physician the worst part of the work. The family physician is the most central figure in the client's care and often unavailable. More paperwork is created when the family doctor is unavailable because the home care nurse has to call in the Hospice physician. Anna believes it is the responsibility of the family physician to talk with the family about their understanding of their illness. A lot of times clients and their families are not aware of their diagnosis. Some days Anna feels lost with a busy workload and many problems to solve that take time.

Anna concluded her interview with a story that had impacted her. She had been seeing a client, E., everyday for wound care who was also dying of breast cancer. One day the client ended up in the hospital and died soon afterwards. The day before E. went to the hospital she was sitting up and her quick demise was a shock for Anna. She was not prepared and felt there were many things she had not done. There were things she would have liked to have done if she knew E. was going to die so suddenly. When Anna was at a palliative conference and they were talking about grief and loss she started crying because she felt she had not done enough for her client. She thought there would be more time. Anna felt her client suffered because she did not have enough experience. When all the care has been provided and when everything has been done that can be done, Anna does not feel sad or badly about clients dying.

*Jess*

Jess has been working in home care nursing for 15 years and has been a registered nurse for 25 years. Jess discussed four different client situations during her interview. The first client, R., was a Philippine woman with three children. While Jess was away on vacation, the client died in Hospice. Jess found this situation very hard, as she was not able to get all the resources for the client when she needed to. Jess had provided care for R. for over a year and she cried when she found out R. had died. Jess had been disappointed in the care the family had provided. Two of the children and the husband did not seem to be very involved with the client's care. Only the 13-year-old son seemed to care about R. Jess finds it very difficult to maintain boundaries with clients because she is trying to give the family the best that she can. She felt that she may have been too involved with this case but found it hard because she was dealing with this family on a daily basis. The client had wanted to go to England to visit her sister before she died but the physician told her not to go. Jess told R. that if her pain was controlled it would probably be good for her to go. The client went and was happy to have seen her sister before she died.

Jess talked further about boundaries and the education provided by the Victoria Hospice Team. Although the theories are true, the practical is different. It is impossible not to get involved with palliative clients. There have been clients who have invited her to a birthday party and clients who have sent her cards. She becomes involved with clients as they begin to trust her and she does not want to hurt their feelings. The hospice counselor is supposed to be available to support staff but at this time the position is vacant and not filled. Home care nurses are seeing very young clients dying with complications and it is difficult to have a consultation. Jess described feeling frustrated that the resources are not available when they are needed. For her, work does not finish when the workday is completed as she still has all the responsibility in her mind. She feels concerned that she has not done all that she would like to have done for clients. If a client dies and she is away, she feels guilty. For a troubled situation there is a debriefing session offered afterwards if necessary, but Jess would like to see debriefing happen regularly.

Jess believes that the medical management of palliative clients can be addressed well but the psychological part of the client is the one that has to be addressed properly. The family dynamics are complicated. She recounts the story of a client, B., who was an educated man, a professor. Although he did not have any children, some relatives were caring for him. They began to clean out his house before he was dead. The client went into Hospice as the relatives were unable to care for him at home. The client was crying and upset because he wanted to die in his home and Jess supported his decision to be at home. The family was upset with Jess and she found this a difficult situation. When she tried to please the client, the family was against her.

Jess' spiritual faith helps her in her work with palliative clients. Discussing cases with colleagues is beneficial. Sometimes they call each other at night after work and sometimes they cry together. Nurses deal with families, family physicians, and different disciplines. At the beginning, Jess found palliative care difficult because she did not have the experience to plan someone's death at home. In her previous hospital experience, it was normal to die. In the community, you are trying to stabilize the client and prepare for death because you know the time is coming. The nurse has to find the best moment to share the client's feelings as well as the DNR (Do Not Resuscitate) and funeral

arrangements. Human beings want to have hope for more time and for things to get better.

Jess discussed a client who was upset and angry. When all her symptoms were under control, Jess talked to her about her feelings. The client was young and afraid to die. She encouraged the client to express her feelings and also talk to her son about her feelings. When clients are dying it is an opportunity to get to know them really well. Working in palliative care has taught Jess to appreciate life and not take for granted all the things we have such as good health. Palliative care nursing is rewarding for Jess as she tries to get the resources for clients to have the dignity to die in the way they would want to.

Jess remembered a client, aged 42, with a child of 7 years. One night the physician did a home visit with Jess and told the husband the client was in the last stages of death. The husband was upset because no one had told him earlier. The client died three days later. Jess stressed the importance of the psychological aspect of caring for dying clients. Having the resources available when clients need them is also important. The physical part is important but the spiritual aspect is also very important.

To conclude, Jess talked about her feelings working with palliative clients. Every death is different and she never gets used to having clients die even though she works with the dying everyday.