NURTURING THE DYING AT HOME: THE EXPERIENCE OF SHIFT CARE NURSING

by

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Abstract

The purpose of this study was to develop a theoretical conceptualization that explains the experience of shift care nursing and how shift care nurses care for themselves so they can continue providing home palliative care to their clients. Shift care nurses are palliative care nurses who provide 12-hour shifts of care in a client's home. In this grounded theory study, the data was comprised of unstructured interviews and group discussions. Analysis included open, axial, and selective coding of the data using constant comparison as well as Strauss and Corbin's coding paradigm.

What shift care nurses do is conceptualized as a process of nurturing the dying at home. Nurturing the dying is composed of four dimensions: opening, witnessing, connecting and being present with the dying person and family. Being present forms the foundation for the other three dimensions. Strategies shift care nurses use to facilitate this process are positioning, becoming what the dying person and family need, teamworking, and tending the self. Characteristics of the shift care nurse, continuity, role expectations, knowledge base of team members, and family dynamics can be limiting or facilitating factors for the shift care nurses. The outcomes of nurturing the dying vary along a continuum of congruity to dissonance, which describes the degree of congruity between the shift care nurses' expectations for the experience and the reality of actual happenings.

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Dedication

This work is dedicated to
Tom Kenneth Wilkinson.

Chapter One

INTRODUCTION

Background to the Problem

The population of people needing palliative care is on the rise. Several factors contribute to this growth. The elderly population has increased due to the growing population and longer life expectancy (Lechky, 1991). Advances in medicine have found cures for acute illnesses that were once fatal and treatments have improved for other life-threatening illnesses to prolong life temporarily (Federal/ Provincial/ Territorial Working Group on Home Care, 1990). In addition, the increase in AIDS has contributed to the number of people who die of diseases that require palliative care (Lubin, 1992).

Not only have the rates and causes of mortality changed, but attitudes have also transformed. The Federal/ Provincial/ Territorial Working Group on Home Care (1990) note that palliative care has evolved as there has been a "growing resistance to heroic medical interventions at the last stages of life" (p. 27) so that many people are choosing to die in a more natural setting without high-end medical technology. In agreement with clients' wishes to die at home, the health care system is encouraging home as the setting for palliative care clients. This is evidenced in British Columbia by the resources transferred to community palliative care through "Closer to Home" initiatives.

These factors mean an increase in home palliative care such as that provided by the Vancouver Home Hospice Program (referred to as "Home hospice" from this point on). Home Hospice is part of the Vancouver/ Richmond Health Board (V/RHB). The V/RHB provides service to residents of Vancouver and Richmond at primary, secondary, and tertiary health care intervention levels, and at all ages and stages of life. Home Hospice is one of many programs within the V/RHB.

The Home Hospice team is comprised of the client's home care nurse, family physician, and other home care staff supported by a clinical nurse specialist, hospice physician, and social worker. If a palliative care client requires twelve or twenty-four hour

nursing care, a shift care nurse becomes part of the care team. Shift care nurses are registered nurses with a background in palliative care nursing who work for V/RHB. If a family cannot cope with the client's care needs or would benefit from some respite and the client's needs are such that a nurse is required, a shift care nurse comes to the home.

The shift care nursing program began in Vancouver in July 1992. Similar services are provided in Burnaby and on the North Shore (around Vancouver). This is in addition to some private agencies such as Paramed Health Services which also provide similar services. Shift care nursing is a growing trend for providing home palliative care. The number of clients who were provided service by the V/RHB in 1993 was 66 compared with 150 clients who were cared for by shift care nurses in 1997. Not only has the number of clients receiving shift care nursing become larger, the amount of shift care nursing received by each client has also increased. In 1993, clients who received shift care nursing received an average of 3.8 twelve hour shifts. In 1997, that number increased to 10.4 twelve hour shifts per client (personal communication, Della Roberts, June 18, 1998). Although the demand for shift care nursing during the day is increasing, currently these nurses are working mostly nights. It should also be noted that there are no full-time or permanent positions for shift care nurses in Home Hospice. All of the nurses have casual status positions.

Shift care nurses currently work twelve hour shifts. Although professional support is only a phone call away, these nurses do not physically work alongside other nurses, doctors, or support staff. Shift care nurses take their coffee breaks within the client's home, and have no nurses' desk to retreat to for a break, peer support, or shared problem solving. Hence, they may not have the same formal or informal professional support that nurses working in a hospital or community setting experience. Additionally, shift care nurses often assume roles that are usually completed by social work, rehabilitation, housekeeping, and dietary staff in other care settings. Most shifts are night shifts. Although hospice physicians and home care nurses can be accessed by phone, many situations are dealt with solely by shift care nurses as

they act with creativity, flexibility, and concern to accommodate a comfortable setting for the client and family.

Their situation seems, on the one hand, to be an opportunity for a very unencumbered environment for nursing as the nurse is alone and focused on the client. The nurse enters the client's home, and for twelve hours has the opportunity to provide intense care for the client. In other environments nurses have to contend with personal and professional conflicts, meetings, inservices, and the general "housekeeping" of the organizational environment. For shift care nurses, the environment *is* the client's environment. Shift care nurses go to where the client lives.

The organization of the Home Hospice currently employs several strategies to support shift care nurses. The clinical nurse specialist of the Home Hospice provides support for practice, responds when shift care nurses call to discuss a client, arranges case reviews with members of the hospice care team after difficult cases, and prepares educational inservices. The shift care nurse is also able to call the primary home care nurse to discuss the case and receive support. This does not often occur, however, as the home care nurses work during the day and the majority of shifts worked by shift care nurses are night shifts. While the home care nurses caring for these hospice clients receive informal support from their colleagues in community health centres, shift care nurses have limited opportunity to debrief. The educational inservices are the only organized times for these nurses to meet. The inservices are currently held four times a year.

I had the privilege of attending a recent inservice for the shift care nurses. The nurses spent some time sharing their most poignant or recent shift care experiences. I was touched by the quality and depth of their caring. The nurses spoke of experiences that had been rewarding and challenging. Sometimes they did not know what they were expected to do in such difficult situations, and wondered what they were capable of. For example, one of the nurses talked about coming into a home in the last days or weeks of a client's life and the

family expecting the nurse to help fix a lifetime of family issues in the short time that she was there.

One of the guests at the meeting encouraged the nurse to ask herself "Is that my job?". In light of the care setting of the shift care nurses' practice and the fact that they are alone with they client and family, I would propose that the "job" description of a shift care nurse can often seem nebulous. Therefore it may not be possible to define the boundaries of the job. Instead, the nurse may guide her work with questions such as: "What is helpful?", "What is possible?", and "What can I handle?". The latter question led me to wonder about how shift care nurses look after themselves.

The shift care nursing program has only been operating for six years. The uniqueness of the context of shift care nursing precludes it from being adequately described by the research and literature pertaining to palliative care nurses. There is currently no research on shift care nursing from any perspective. This research proposes to look at only a small part of the shift care nursing program, namely, the experiences of the nurses. While there are many other aspects of the program to explore (the experience of the client, family, etc.), studying the experiences of the shift care nurses may provide key strategies about supporting the nurses and enabling them to provide the best care to dying clients.

Statement of the Problem

The general problem to be addressed in this study originates from a lack of information about shift care nurses. Shift care nurses work with clients who are dying. The care is demanding on emotional, physical, and spiritual levels. Due to the organization of the shift care program, these nurses may not have access to the same amount of professional support as nurses in other settings. These nurses are at risk for stress and burnout. In addition, because they work alone, there are fewer opportunities for colleagues to be together to

provide support and notice signs of stress and burnout in each other. As the demand for shift care nurses increases, so does the need to understand the experience of shift care nursing.

Purpose

The purpose of this study is to develop a theoretical conceptualization that may contribute to a grounded theory that explains the experience of shift care nursing, what the demands and rewards of the work are, and how shift care nurses care for themselves so that they can continue to provide home palliative care to their clients.

Research Question

The research questions that will guide this study are:

What are the experiences of shift care nurses?

What are the aspects of shift care nursing that are rewarding and what aspects are demanding or stressful?

How do shift care nurses care for themselves so that they can continue to care for others?

Assumptions

The following assumptions are identified:

1. The work of caring for the dying can be demanding on the person of the nurse.
2. Shift care nurses attempt to care for, maintain, or replenish themselves.

Definition of Terms

The following definitions of major terms will be used:

Palliative Care A philosophy of care for the dying that values comfort as its goal (for the purposes of this paper, consider synonymous with hospice care).

Palliative Care Nurse	A registered nurse who works with persons who are dying in a variety of settings (e.g. hospital, community) (as above, consider synonymous with hospice nurse for this paper).
Shift care nurse	A palliative care nurse who works twelve-hour shifts for the Vancouver Home Hospice Program to provide palliative care for clients in their homes.

Chapter Two

REVIEW OF THE LITERATURE

The literature in this chapter provides background for the study through the identification of the existing knowledge and gaps that relate to the research project (Chenitz & Swanson, 1986). This provides a framework for the research by placing it in the context of the current knowledge in the area of interest. The literature reviewed here is based on nurses who care for terminally ill clients. There is currently no literature on the type of work that shift care nurses do within palliative care nursing. Both research- and experience-based literature have been critically examined. For the purpose of organization, the literature has been grouped into two categories: palliative care nursing, and the strain of palliative care nursing.

Palliative Care Nursing

> As the rawness of the struggle unfolds and hospice nurses engage intimately with patients, they commit deeply to helping that person. They give of their expertise and they give of themselves, not only as nurses, but intimately, person-to-person, and sometimes, soul-to-soul. Therein lies the glue that binds nurses to this work; that fosters their commitment and provides some of the exquisite rewards that can accompany this realm of nursing practice. (Hutchings, 1997, p. 112)

Overview of Palliative Care Nursing

Some of the literature presents an overview of palliative care nursing as perceived by researchers and practitioners. Cooke (1992) writes a belief paper based on her ten years of hospice experience. She articulates three beneficial opportunities for nurses doing hospice work: forming close relationships with the client and family, making a difference, and learning from the people they serve. Nurses are challenged on three levels: personal, professional, and community. The personal challenge is for spiritual development of the nurse. Professionally, the challenge is to identify the activities that promote or take away

from a peaceful death experience for the client and family. The third challenge lies in educating the community about preparation for death.

Nurses go through a process of adjustment as they move into the intimate role of palliative care nursing. Fisher (1988) cites Harper's (1977) "coping mechanism of the health professional" (p. 10) to describe this process. In the first stage, "intellectualization", nurses focus on professional knowledge and facts, distancing themselves from those who are dying. Next, nurses become emotionally involved as they recognize clients' suffering and relate it to their own self. In the third stage, coined as the "grow or go stage" (Fisher, p. 9), nurses feel the pain and mourn the dying process. "Emotional arrival" occurs at the fourth stage where nurses become empathetic rather than sympathetic. Finally, stage five is one of deep compassion which includes self-realization, self-awareness, and actualization. Nurses are "now able to relate compassionately to the dying in the light of the full acceptance of their impending death" (Fisher, p. 10). This model is intended to aid in assessing staff adjustment and the need for support.

The essence of Fisher's (1988) fifth stage is reflected in Dobratz's (1990) review of palliative care literature. Dobratz articulates four categories of palliative care nursing functions: intensive caring, collaborative sharing, continuous knowing, and continuous giving. Intensive caring involves managing the clients' physical, psychological, social, and spiritual needs. Collaborative sharing refers to the interdisciplinary teamwork that good palliative care requires. Continuous knowing refers to the skills and knowledge required by the palliative care nurse, and continuous giving speaks to "balancing the hospice nurse's own self-care needs to the complexities and intensities of repeated death encounters" (Dobratz, p. 117).

Preserving Integrity/Sustaining Oneself

The notion that palliative care nurses have needs that require attention and care has been studied by several researchers. Cohen, Haberman, Steeves, and Deatrick (1994) suggest that, "Perhaps, nurses will provide better nursing care when their own needs are met" (p. 9).

Davies and O'Berle (1990) also attend to the idea of nurses needing to care for themselves. This grounded theory study analyzed in-depth interviews with a supportive care nurse. A model of supportive care resulted which included the dimensions of valuing, connecting, empowering, doing for, finding meaning, and preserving own integrity. Valuing provides the context for the other dimensions; preserving own integrity is the core concept. Preserving own integrity is "the ability to maintain feelings of self-worth and self-esteem and to maintain energy levels" (Davies and O'Berle, p. 92). It includes looking inward, valuing self, and acknowledging one's own reaction. In a further work, Davies (1992) expands or clarifies the core concept "preserving own integrity" to "preserving integrity". This concept also recognizes the wholeness of the client, as the nurse cannot be removed from the context of the nurse-client relationship.

The supportive care model developed by Davies and O'Berle (1990) was used by McWilliam, Burdock, and Wamsley (1993) in their study of the experience of palliative care nursing as part of a multidisciplinary support team. While these authors began with the themes of connecting, doing for, empowering, and finding meaning, the results also indicated the addition of providing support for homecare professionals and coordinating and managing difficult problems. These components describe the "primary work effort" which takes place from a professional practice base. The primary work effort is impeded by: limitations of the health care system, intrapersonal conflict, interprofessional conflict, as well as some of the characteristics of palliative nursing such as family demands and death as the certain outcome. When impediments occur, "secondary work efforts" are necessary. These efforts are role adaptation, and intrapersonal and interprofessional conflict management.

McWilliam et al. (1993) provided a different interpretation of "preserving own integrity" than that described by Davies and O'Berle (1990). Preserving own integrity was described as an "active, concerted secondary work effort that consumed time and energy directed at ensuring that one's own needs, goals, and expectations of service to others were not jeopardized" (McWilliam et al., p. 784). Through categorizing "preserving own integrity" as a secondary work effort, the authors suggest that it this strategy is only necessary when impediments to the primary work effort occur. This is a contradiction to the model described by Davies and O'Berle where "preserving own integrity" is a basic, core concept. While McWilliam et al. continue to use Davies and O'Berle's conceptual labels in their adaptation of this model, they seem to have attempted to make the model more concrete. The authors have deductively applied and adapted this model to various hurdles of the work environment.

Regarding the latter two studies and their work done on "preserving integrity", Rasmussen, Sandman, and Norberg (1997) note:

> These studies point to the impossibility of separating the nurse as a professional from the nurse as a person. Of significance in this regard is that understanding patients' experiences and nursing care needs is likely to be limited if the nurses' own concerns and needs are not met. (p.331)

Preserving integrity as a concept also emerged in the phenomenological study done by Rasmussen et al. Eighteen palliative care nurses were asked to describe how they experienced the last year as a palliative care nurse. First, nurses pursued meaningful hospice care through giving good nursing care, good dying and death, a supportive working environment, as well as providing personal and professional confidence and growth. Second, nurses pursued spiritual integrity through keeping one's energy flowing, being cleansed, and finding/creating meaning. Tension in the nurses' stories reflects existential angst as nurses try to maintain wholeness in the context of death and dying. This tension is also explained as the conflict between striving for immortality for the client (through opening up the moment) and being constantly reminded of the nurse's own mortality due to caring for the dying.

In Zerwekh's (1995) family caregiving model for palliative care nursing, expert palliative care nurses identified 'Sustaining oneself' as the root of palliative care nursing. The work of palliative care nursing is metaphorically set in the template of a tree, illustrating that nurses sustaining themselves is key to all other nursing functions. The five roots of sustaining oneself are: giving and receiving, staying healthy and open, grieving, letting go of personal agenda, and replenishing oneself.

"What enables a caregiver to sustain quality involvement with individuals confronting life-threatening illness? How does one continue to encounter people whose lives are stripped to the essence?" (Sourkes, 1987, p. 28). Sourkes agrees with Zerwekh (1995) that the caregiver must be self-aware but adds that the caregivers must also have knowledge of their capacity or limits. This is further described as the ability to be introspective and acknowledge one's vulnerabilities. With regard to working with families, the caregiver must be able to enter the circle of the family while preserving one's own boundaries and have a high tolerance for ambiguity. Maeve (1998) describes this "tempering involvement" (p.1138).

In an attempt to sustain themselves, a group of palliative care nurses participated in a retreat to rekindle their spirits (Bailey, Carney, Grodski, & Turnbull, 1987). These nurses worked on clarifying the palliative care philosophy, evaluating emotional aspects of palliative care nursing, learning how to blend ideals with reality, maintaining motivation among staff to continue working with clients and family in a way that coincides with the palliative care philosophy, and teaching/learning from each other. Informal and formal evaluations revealed that the retreat was a success in that it improved the nurses' feelings about dealing with family situations as well as improving the effect their work had on the rest of their lives.

The above literature provides some valuable descriptions about how palliative care nurses care sustain themselves and identified that caring for self was important. The nurses studied work in a variety of environments: palliative care units, free-standing hospices, and oncology units. As none of the nurses studied work in the context of a shift care nurse, it

would be of interest to examine how shift care nurses sustain themselves. Does the difference in the care setting and support affect how these nurses attend to caring for themselves?

The Palliative Care Nurse - Client Relationship

Related to the idea of sustaining oneself is a section of the palliative care literature about the nurse-client relationship. Trygstad (1986) attempts to articulate how a nurse may integrate professional and personal roles. Seventeen oncology nurses were interviewed about their work experiences. Through grounded theory analysis, the author describes "the work of the professional friend" (p. 329). Participants speak of "exchange" in the relationship as they both give to and receive from the client. The role of the professional friend includes meaningful professional learning of technical skills, interpersonal skills, and holistic practice. It also means learning personal skills like being gentle, living in the present, and facing death without fear. The emphasis is on having a mix of personal and professional learning.

Rather than describing the nurse-client relationship as a friendship, Martocchio (1987) addresses the nurse's and the client's way of being in the relationship together through authenticity, belonging, emotional closeness, and self-representation. This differs from Trygstad's work (1986) as Martocchio stresses the difference between the intentional relationship of the nurse and client, and an intimate friendship, noting that a true friendship is marked by mutuality. So while the nurse does not distinguish personal from professional, the relationship is an "*atmosphere* for closeness, not a friendship" (Martocchio, p. 26).

Raudonis (1993) explored empathic relationships in palliative care nursing. The "empathic relationship developed through a process of reciprocal sharing and revealing of personhood within a context of caring and acceptance" (p. 304). The major category was "affirmation as a person". Raudonis suggests that nurses should examine their own personhood, values, and knowledge of the potential meaning and impact of their relationship with the terminally ill.

The nurses who participated in the study done by Raudonis (1993) were home hospice nurses. Home hospice nurses are similar to home care nurses at the V/RHB. They visit several clients a day. This differs from the work done by shift care nurses. A shift care nurse spends an entire shift (twelve hours) with one client. There may be some differences in the nurse-client relationship when it occurs in the intimate and intense context of shift care nursing: one nurse, one client, in the client's own home, for twelve hours.

Palliative Care Nurse Characteristics

Researchers have explored the unique characteristics of palliative care nurses. Palliative care nurses were found to be significantly more assertive, forthright, imaginative, free-thinking and independent than nurses working in traditional hospital and community settings (Amenta, 1984). In addition, Brockopp, King, and Hamilton (1991) compared death anxiety and perceived personal control of nurses who care for the dying with nurses working in non-palliative settings: psychiatry and orthopedics. Palliative care nurses had more positive attitudes toward dying and experienced less death anxiety.

Hutchings (1997) asks, "What is [it] that draws nurses to such rigorous demands? What is it that keeps them there?" (p. 110). Applying the concept of hardiness to palliative care nurses, Hutchings draws on the work of Kobasa (1979), describing hardiness as a personality construct composed of control, challenges, and commitment. Hutchings reflects on how palliative care nurses may use these elements in their work and supports these claims through the existing literature. She states that the many challenges that palliative care nurses face "appear to mobilize the nurses' *commitment* by escalating their drive to serve others and exert *control* over the *challenge* facing them" (p. 111, italics added). Hutchings suggests that the characteristic of hardiness may strengthen palliative care nurses to do such demanding work. Sourkes (1987) concurs that commitment is a key characteristic of the those who care for the dying.

Spirituality is another characteristic of palliative care nurses. In a descriptive study by Millison and Dudley (1990), 120 hospice program directors indicated that many hospice professionals were affiliated with an organized religious group, perceived spirituality to be an important part of their lives and felt that spirituality was important to hospice work and the hospice team. The characteristic of perceiving themselves as spiritual was also indicated by a survey of 641 palliative care nurses (Taylor & Amenta, 1994).

Palliative Care Nurse Behaviours and Competencies

Palliative care nursing has been studied to identify some of the effective behaviours of palliative care nurses as noted by the clients' families, colleagues, or the nurses themselves. Families of dying clients identified 24-hour accessibility and availability, effective communication skills, caring and nonjudgmental attitudes, and competence in practice as the most caring behaviours of palliative care nurses (Hull, 1991).

In contrast to this list, expert palliative care nurses and educators identified the following critical nursing behaviours (from their observations of student and graduate nurses): responding during the death scene, providing comfort, responding to anger, enhancing personal growth, responding to colleagues, enhancing quality of life, and responding to the family. The category "enhancing personal growth" refers to some nurses who define a role for themselves in caring for the dying that enables growth and emotional rewards as a result (Degner, Gow, & Thompson, 1991). It should be noted that the identified behaviours indicated what expert nurses and educators expected from novices. Perhaps the behaviours would more aptly be labeled "critical nursing behaviours of the *novice* nurse caring for the dying".

In Zerwekh's qualitative study (1993), expert palliative care nurses reflected on their own practice and told anecdotes from which the following list of competencies was gleaned: personal grounding, identifying spiritual issues, being there, dialoguing, fostering

reconciliation, sharing nearing death mystical experiences, guiding the letting go of life itself, anticipating death, helping the family to prepare, and being present at death.

The discrepancies between the three lists are of interest. The families emphasize the importance of the nurse being competent and physically available (Hull, 1991), very basic requirements of a palliative care nurse. Degner et al. (1991) speak about the expectations of a novice palliative care nurse. The competencies identified by expert palliative care nurses (Zerwekh, 1993), highlight the deeper experience of palliative care and palliative care nursing. While some of the behaviours describe similar acts: effective communication skills (Hull), responding to family (Degner et al.) and dialoguing (Zerwekh), the language and level of conceptualization are very different. Further study and perhaps secondary analysis could be useful to explore, for example, whether families also found the expert-identified competencies to be caring and supportive.

In a shift care nurses' inservice attended by the author, shift care nurses expressed challenges of their work that were specific to working in shift care. These nurses have or still work as palliative care nurses in other settings. Perhaps the competencies that they developed as a palliative care nurse are not the same as those needed for shift care nursing. Further research is needed to articulate the demands of the work of shift care nurses.

The Strain of Palliative Care Nursing

It is a challenge to try to separate the literature that speaks about the stresses or strains of palliative care nursing from the previous section because, as Cohen et al. (1994) found in their research, many of the sources of difficulty identified by palliative care nurses are also identified by palliative care nurses as sources of reward. However, the following literature speaks more directly about stresses, difficulties, and coping strategies than the previous section.

Stress in Palliative Care Nursing and Other Specialties

Several researchers have pursued questions about the stress of palliative care nursing compared with nursing in other areas. Bené and Foxall (1991) compared death anxiety and job stress in palliative care and medical-surgical nurses. The death anxiety scores of both groups of nurses were within normal limits, although job stress was reported to be significantly higher in medical-surgical nurses. Palliative care nurses scored significantly higher with regard to stress related to death and dying. The authors suggest that this is due to the dissonance between the ideals that palliative care nurses uphold for supporting the dying and the reality of their work. The concept of discrepancy between ideals and reality is further explored by McNamara, Waddell, and Colvin (1995) in an ethnographic study of palliative care nurses in home and in-patient work settings. The nurses describe the value of a "good death" and indicate that threats to the "good death value system" are sources of stress (McNamara et al., p. 228).

The findings of a study by Bram and Katz (1989) differ. In a study comparing the degree of burnout experienced by nurses who work with the terminally ill in two different settings: hospice (29 nurses) and hospital oncology settings (28 nurses). The palliative care nurses scored significantly lower on the Staff Burnout Scale for Health Professionals. These authors suggest that the hospice is a less stressful environment in which to care for terminally ill clients. In contrast to previously mentioned studies, the researchers conclude that palliative care nurses experienced less discrepancy between their ideal and real work situations, suggesting that palliative care nurses "are reinforced by their work, rather than stressed by it" (Bram & Katz, p. 559). One must consider, however, the difference in the two client populations involved in this study. Palliative care nurses care for clients who they expect will die. Oncology nurses care for clients in a context where some will die and some will not. The difference in expectations could explain the decreased level of burnout in palliative care nurses.

Vachon (1986) interviewed 100 palliative caregivers regarding caregiver stress in working with the dying. Results of this study were discussed in terms of the common myths

about palliative care and coinciding statements about the realities. Findings reflect that palliative care workers' stress generally arises from the work environment and not the contact with dying persons. These stressors are similar to those experienced by caregivers in other areas of health care. While stress was not necessarily decreased in proportion to the number of available coping mechanisms, palliative care workers are healthy compared to caregivers in other areas as they report less stress and more coping mechanisms. In a more recent review of the research regarding stress for palliative care providers, Vachon suggests that stress and burnout occur less in palliative care than in other specialties. She proposes that this is due to support mechanisms initiated to prevent stress in palliative care settings.

As mentioned previously, shift care nurses do not work with their colleagues. They are alone with the client and family in the home. They do not even receive the support that their Home Hospice team mates, the home care nurses, receive. Home care nurses have an opportunity to support one another at the beginning and end of each shift. Shift care nurses may speak to the home care nurse on the phone during the day shift. As most of the shifts are night shifts, the shift care nurse often only communicates with the home care nurse through written or voice-recorded communications. Shift care nurses meet with one another four times a year. They also have the support of the Home Hospice clinical nurse specialist. What they may lack is the regular connection with their colleagues. The support mechanisms that Vachon (1997) cites as so valuable in palliative care are not, at this time, incorporated into the environment of shift care nursing. How, then, do these nurses compare on the issues of stress and burnout? The current research cannot answer this question.

Sources of Stress

Many different levels and areas of stress have been identified by nurses who care for the dying. Some stressors are organizational. Palliative care nurses who work in a hospice cite some of the staffing policies, admission policies, and physical characteristics of the hospice as sources of stress (Alexander, 1990). Home palliative nurses surveyed by Duffy

and Jackson (1996) find their paperwork excessive and have difficulties dealing with physicians who do not understand the palliative care philosophy. A study done by Hart, Yates, Clinton, and Windsor (1998) also indicates that organizational policies and practices can be a practice challenge for palliative care nurses, limiting their flexibility to provide effective care. Working in a team was also noted as stressful by palliative care nurses surveyed by Alexander.

Acute care nurses felt that the intensity of the relationship between the nurse and the dying client was stressful (Copp & Dunn, 1993). They had fears of losing control emotionally and watching clients die. Many palliative care nurses articulated emotional sources of stress such as the client and family's need for support (Alexander, 1990; Gray-Toft & Anderson, 1986) as well as caring for clients who have not yet come to terms with the fact that they are dying (Alexander; Copp & Dunn). Other stressors relating to the attributes of individual clients were clients with young children, and clients with psychiatric symptoms (Alexander). Duffy and Jackson (1996) found that home palliative nurses reported managing the client's physical symptoms as more difficult than providing emotional support. This finding was supported by Alexander (1990) and Dean (1998) as palliative care nurses noted the stress of dealing with clients who have uncontrollable pain.

As with the research done on palliative care nurse characteristics, much of the above research about sources of stress for palliative care nurses is quantitative. While using quantitative methods allows for a large sample and data base, it would be valuable to study in depth through qualitative methods what palliative care nurses might more fully describe as stressful and why.

Another stressor for palliative care nurses, repeated loss, has been studied by several researchers(Adams, Hershatter, & Moritz, 1991; Alexander, 1990; Duffy & Jackson, 1996; Killeen, 1993; Newlin & Wellisch, 1978). In particular, Adams et al. have identified this experience as "accumulated loss phenomenon". These researchers analyzed questionnaires filled out by 100 hospice caregivers. Five basic characteristics of accumulated loss were

identified: lack of closure, dying and death concerns, ideal versus reality incongruity, identification-distancing, and diminished boundaries. In addition to the losses articulated around death and dying, nurses also described loss of staff devoted to the hospice philosophy and loss of concepts and ideals of the hospice philosophy. Findings reflected that registered nurses expected too much of themselves and had feelings of inadequacy and guilt. Licensed practical nurses and nursing assistants did not report these same feelings. Palliative care nursing, nonetheless, is described as rewarding, especially when ideals are congruent with reality. Least rewarding aspects of the work of these palliative care nurses are the high acuity and rapid turnover of clients and the inability to control symptoms. Killeen did further work with the concept of accumulated loss phenomenon, applying it to the experience of caring for persons with AIDS. Findings suggested that the phenomenon encompasses physical, psychological, attitudinal and relational changes.

Although this work is done before the phenomenon "accumulated loss phenomenon" was labeled as such, Newlin and Wellisch (1978) explored the concept in their writings about oncology nurses. Oncology nurses are at risk of identifying with dying clients and feeling guilty for failing the dying client. Nurses are at risk of being inducted into the family emotionally due to their proximity, intensifying their experience of repeated losses. Emotional danger signs of this phenomenon are depression, certain dream topics, inability to detach from one's job, repetitive accidents, and guilt about taking time off from work.

Other researchers addressed the phenomenon of burnout as it applied to hospice caregivers. Korda (1987) reviews the literature on staff burnout and combines these findings with her clinical observations to identify stressors as exogenous (environment) or endogenous (individual). Korda refers to the basic "c's" of hospice burnout: conviction, compassion, and commitment. She argues that the very qualities that make palliative care nurses so suited to palliative care nursing also make them vulnerable to the phenomenon of burnout.

Price and Murphy (1984) emphasize burnout as a process, not a static end-product. The authors use Kavenaugh's grief theory to explore the process of adapting to high-stress

work which may eventuate in burnout. The phases of this framework (shock, disorganization, volatile emotions, guilt, loss and loneliness, relief, and re-establishment) illustrate how a staff member either adapts to the stressful work environment or experiences burnout.

Palliative care can occur over a long period of time, sometimes weeks, months, or even years. Palliative care nurses may care for a client for symptom management, to provide respite for informal caregivers, or to give end-of-life care. This care may be needed at any time in the clients' last weeks, months or years. Shift care nurses, however, care almost exclusively for clients who are in their last hours or days of life. There is a dearth of information regarding the effect that shift care nursing has on these nurses.

Alleviating Stress

Many studies which examine the stress of palliative care nursing also reveal stress-relieving strategies that palliative care nurses employ. McNamara et al. (1995) identify the following coping and support strategies: reversing the definitions of failure, utilizing reflexivity, relinquishing control, negotiating and validating support, and contextualizing death to "affirm their own 'living' status" (p. 240). This research emphasizes that nurses' ability to cope is not only due to personal strength but also to the value systems and support networks that they share within their work environment. The support of colleagues in the work environment is identified in several other studies as an effective strategy to alleviate stress (Adams et al., 1991; Alexander, 1990; Duffy & Jackson, 1996; Eakes, 1990). Some nurses emphasized that discussing work with family and friends was not valuable (Duffy & Jackson) while others found ventilating feelings with family a useful method of coping (Eakes).

Vachon (1997) expanded the idea of collegial support in her recent research literature review. More formalized support was identified through team work. Staff stated that they coped through adhering to the palliative care team philosophy, relying on team support, as well as administrative support. They also described seeking a sense of competence, control,

pleasure from one's work, and "sustaining oneself". The latter coping mechanism, sustaining oneself, recognizes that "it takes a 'total person' to respond day after day to the 'total needs' of other people" (p. 101) and warns caregivers against overwork and over involvement. The concept of the total person was also explored by Korda (1987). She stressed that "because the recipients of hospice care are so vulnerable and their need for genuine human involvement so acute, the providers of that care must be fully available - physically, intellectually, emotionally, and spiritually" (p. 40).

Chiriboga, Jenkins, and Bailey (1983) tested an analytic model of stress on 100 hospices nurses from 20 facilities. The model considers several factors that may impact the nurse's adaptive status: nurse's conditioning factors, environmental and internal demands, stress appraisal, coping strategies, and social resources.

Of the above factors, the nurse's appraisal of stress and coping strategies were found to have the greatest effect on adaptive status. This finding is of interest when hypothetically applied to the context of shift care nursing. The findings emphasize factors that may not be different between palliative care nurses and shift care nurses: their appraisal of stress and coping strategies. This factor is found to have more impact on nurses' adaptive status as opposed to social resources, which appear to be quite different for shift care nurses, especially with regard to collegial support resources. Conversely, McNamara et al. (1995) emphasize in their research that the nurses' ability to cope is not only due to personal strength but also to the value systems and support networks that they share within their work environment. Further research is needed to determine what resources and strategies shift care nurses employ to adapt in their environment.

Stiles (1990) describes nursing as an "infinite source of new meaning and spiritual growth that can revitalize nurses' professional lives, perhaps preventing burnout" (p. 245). Nurses who participated in this study about the nurse-family spiritual relationship recognized that they are vulnerable to burnout and described using self-protective strategies to protect themselves against burnout. Among these strategies was taking time for oneself. This strategy

is reflected in different ways throughout the research: exercise (Duffy & Jackson, 1996), spiritual practices and meditation (Duffy & Jackson; Adams et al., 1991) working part-time or taking time off (Duffy & Jackson; Killeen, 1993; Stiles). Humour was also recognized as a very effective way to cope with stress (Duffy & Jackson; Adams et al.).

Killeen (1993) emphasizes that stress is not avoidable in caring for terminally ill persons but must be dealt with in creative ways on an ongoing basis. She suggests that staff take responsibility for being healthy outside of work, set realistic goals for care, work through emotional responses by being self-aware, and participate in rituals for addressing the loss of the client. "The letting go creates space for healing and for reinvesting with another" (Killeen, p. 24).

The words of a participant reflects the relationship between palliative care nurses feeling rewarded through their work and feeling drained by it: "With full realization that the pain will come, I get close to people. I willingly accept that - that's the heavy part. I don't know where the spiritual growth is coming from and how long it will last, but I go with it" (Stiles, 1990,p. 243). The relationship between the rewards and demands of palliative care nursing is addressed throughout the literature in different ways. There are warnings of overinvolvement (Eakes, 1990) as well as descriptions of giving of oneself to clients: "If you've given a bit of yourself to them, you lose that something when they die" (McNamara et al., 1995, p. 233).

The prospective study done by Booth, Macguire, Butterworth, and Hillier (1996) explores nurses' behaviour that avoids intimacy. These researchers noticed a distancing technique that the nurses used when they were uncomfortable with the client. Blocking behaviours, actively moving the conversation away from the client's disclosure of concerns about illness and/or its impact, were used by the nurses with the majority of the dying clients who disclosed their feelings to them. The use of blocking behaviours decreased with an increased perception of practical and emotional support from the nurses' supervisors.

Summary

There is much value to the research done on palliative care nurses and their experiences. Although shift care nursing is a type of palliative care nursing, there are many factors that set shift care nurses apart. They work in the client's home like a home care nurse but, unlike home care nurses, shift care nurses are with the same client for twelve hours. They provide palliative care but, unlike palliative care nurses in other settings, they do not work in an environment with other nurses. Shift care nurses, like no other nurses, are employed almost exclusively for clients within the last hours or days of life. These nurses do unique work within an isolated care setting and there is, to date, no research reported in the literature which focuses on the experiences of shift care nurses.

Meaningful research has been done on palliative care nurses: their characteristics, their competencies, the demands of their work and how they cope with those demands. The unique factors that differentiate shift care nursing from palliative care nursing in other settings do not allow this knowledge to be assumed information about shift care nurses. Research is needed to explore the potentially unique experience of shift care nursing. The rich knowledge base regarding palliative care nursing provides a valuable arena for discussion about the similarities and differences between shift care nursing and palliative care nursing. As the need for shift care nurses grows, so does the need to understand their experiences, if they are coping, and how.

Chapter Three

METHODS

Study Design

The overall goal of this research is to describe the experiences of shift care nurses. The nature of this goal is conducive to qualitative research for two reasons. According to Strauss and Corbin (1990), qualitative research is an appropriate approach when little is known about the research topic. In addition, Strauss and Corbin put forward that qualitative research "lends itself to research that attempts to uncover the nature of persons' experience with a phenomenon" (p. 19). This study will attempt to explore the shift care nurses' experience of caring for themselves so that they can continue their work.

Grounded theory methods are used to develop theory that is derived inductively from the phenomenon it studies (Strauss & Corbin, 1990). Its primary purpose is to develop explanatory theories of human behaviour. Grounded theory suits this research problem as it allows the shift care nurses to describe their experiences, the demands and rewards of their work, and how they care for themselves. Grounded theory uses concurrent data collection and analysis, purposive sampling, and strategies to ensure validity so that the resulting theory is a direct conceptualization of the data. The theory is discovered, developed, and provisionally verified throughout the research process (Strauss & Corbin). The resulting theory represents the perspective of the shift care nurses, not the researcher.

Sampling

Theoretical sampling guided recruitment of shift care nurses who could thoroughly articulate their experiences. Theoretical sampling is a non-probability sampling technique used to choose participants who can illuminate the phenomenon being studied (Sandelowski, Davis, & Harris, 1989). It is a concept developed by Glaser and Strauss (1967) whereby the researcher collects, codes, and analyzes the data and decides what data to collect next and from whom. Participants are chosen based on their ability to contribute to the evolving

theory. Theoretical sampling begins with the purpose of uncovering the varieties of the experience. This is described by Strauss and Corbin (1990) as open sampling. As the research progresses, the researcher chooses participants that will maximize opportunities for verification of categories, their relationships to one another, and filling in gaps in the findings: relational, variational, and discriminate sampling (Strauss & Corbin). The target population for this study were the shift care nurses hired by the Vancouver/Richmond Health Board's Home Hospice Program. Eligible participants were those currently working as shift care nurses.

It is the depth of the data rather than the greatness of its membership that determines sample size in qualitative research. Sampling continues until data saturation occurs. That is, no new information emerges from the data that indicates the need to form new categories or the expand existing categories (Morse & Field, 1995). The sample size for this research was six participants. There were also approximately four more participants who did not give interviews but were present for discussion at the shift care nursing meetings.

The sampling process begins with interviewing a homogeneous sample and then interviewing a heterogeneous sample to confirm or contradict parts of the theory (Creswell, 1998). Mindful of the need for sampling diversity to explore all aspects of the experience, the researcher investigated different factors as they became apparent in the analysis.

In the case of this research, the researcher presented the proposal for research to many of the shift care nurses at one of their meetings. Interested nurses notified their coordinator who gave a list to the researcher. The first participant was chosen because the researcher knew the participant and was aware that she worked many hours as a shift care nurse. The second participant did not work as many shift care nursing hours but worked more in the hospital palliative care unit. The data from this interview was less specific to shift care nursing so the next two participants were chosen because they worked many shift care nursing hours. The researcher was attempting to interview a homogeneous sample. After these four interviews the researcher approached a male participant to obtain potentially

heterogeneous data. The final primary interview was also with a male participant but one who did not work very many shift care nursing hours, like the second participant.

In combination with the data collected from four shift care nursing meetings, these primary interviews and two secondary interviews verified general consensus from the participants. That is, when presented with the various concepts that comprised the emerging process, all participants did agree that this conceptualization reflected their experiences. Consequently, sampling and data collection ended.

Data Collection

The researcher employed multiple approaches to data collection in an attempt to uncover the experience of shift care nursing. The identified methods of data collection were unstructured interviews, fieldnotes, participant observation, theoretical and process memoing, and using the literature. Shift care nurses were the sources of the information. The researcher was the instrument through which information was collected, interpreted, and analyzed.

The Research Officer of the Vancouver/Richmond Health Board granted approval for the research based on the research proposal. The researcher attended the shift care nurses' inservice (with the permission of Della Roberts, the Clinical Nurse Specialist for the Vancouver/Richmond Health Board Home hospice Program) to introduce the research project and give each shift care nurse a written notice about the research. Interested shift care nurses identified themselves to Ms. Roberts who, with the permission of the nurse, gave the researcher the potential participant's name and phone number. The researcher contacted the nurse to explain the research project further and inquire whether this person would like to participate. The researcher and nurse identified a mutually convenient time and location for the interview. Three interviews convened in the participant's home, four interview's at the researcher's home, and one at the Vancouver/Richmond Health Board Central Office. The four shift care nursing meetings were held at their usual location, Central Office. When the

researcher and participant met, the researcher obtained written consent and demographic data prior to starting the interview.

Table 1

Demographic Data	
Ages	34, 38, 43, 48, 52, 54
Nursing since:	1965, 1969, 1970, 1991, 1993, 1995
Other education:	DEGREES: nursing, social work, masters of arts in Canadian studies COURSES: palliative care, gerontology, administration, neonatology, psychoanalysis, psychosocial nursing, alternative health care, home care, case management
Other work experience:	Rehabilitation, Counseling, Professional gardening, Home support worker, Social work. Nursing : general medicine, geriatrics, obstetrics, oncology, psychogeriatrics, pediatrics, .
Any previous palliative care experience:	All participants had some.

The interviews were unstructured, using tracking to follow up on points so as to minimize the interference of the researcher in the person's relating of the information (Sandelowski et al., 1989). The opening question was: "What is it like to be a shift care nurse?". The researcher used silence as a strategy to allow the participants to express themselves fully before probes were employed. Examples of possible probes are: "What is challenging about shift care nursing? What is rewarding about shift care nursing? Can you tell me about a particular case that stands out in your memory?"

The interview was audio taped. The researcher wrote fieldnotes immediately following the interview that described the general mood of the interview, the participant's body language, facial expressions, etc. The researcher transcribed the interview and then read through while listening to the tape to ensure accuracy of the transcription and obtain a general impression of the interview as a whole.

In addition to interviews, the shift care nurses allowed the researcher to attend four of their inservices to listen to their discussions. This provided additional data for the research. For example, the senior management contact person for the shift care nurses also attended one meeting. The shift care nurses had a brainstorming session at this meeting to make a list regarding aspects of the shift care nursing program that make their job more difficult. This discussion included proposing possible solutions and was very valuable to the ongoing research. In addition, at each meeting the researcher presented the data analysis for validation and verification. Consent for this part of the research was verbal. If the shift care nurses wanted to participate, they stayed for that portion of the meeting. The shift care nurses meet every three months. Over a period of a year, they were presented with the research at its various stages of data collection and analysis. This had outcomes for all involved: 1) the research process was explained during each presentation, further educating shift care nurses about the process of conducting research, 2) the shift care nurses were fully informed of the findings, and 3) the shift care nurses helped to direct the research as they highlighted gaps in the emerging conceptualization and verified accurate, meaningful findings. The element of shift care nurses participating over time and directing development of the research is similar to participant action research. Participatory research is "a systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change" (Gallagher & Scott, 1997, p. 130). Shift care nurses expressed appreciation that this research was being done in hopes that shift care nursing would be better recognized by other health care providers and consumers.

The researcher kept theoretical and process memos throughout the research process. Theoretical or analytic memos are a record of the researcher's ongoing attempts to conceptualize and theorize about the data (Sandelowski et al., 1989). Process memos are journals that record the researcher's observations about interactions between researcher and participant as well as a record of the researcher's decision-making regarding the conduct of the study (Sandelowski et al.). In accordance with Strauss and Corbin (1990), memoing

began with the process of preparing the proposal and continues through the completion of the study.

Analysis was done on completion of each interview. Questions arising from the ongoing analysis were included in subsequent interviews and influenced purposive sampling so that emerging categories and themes could be verified, contrasted and/or expanded. Descriptions were presented to participants for purposes of validation and verification.

Data Analysis

In accordance with grounded theory procedures, analysis of the data occurred concurrently with data collection and sampling (Creswell, 1998). Analysis included open, axial, and selective coding of interviews and fieldnotes. Open coding is "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (Strauss and Corbin, 1990. p. 61). Open coding of the data involved conceptualizing the data line by line. Codes were written in the margin of the transcripts. Using "Microsoft Word version 5.1a" software, transcripts were "cut and pasted" according to codes and then grouped together into categories that reveal their similarities.

Axial coding is making connections between categories through using a coding paradigm that explores conditions, context, action/interactional strategies, and consequences (Strauss & Corbin, 1990). Strauss and Corbin's coding paradigm guided this phase of the analysis to explore the categories and determine causal conditions, phenomenon, context, intervening conditions, action and interactional strategies, and consequences. Analysis also included: the verification of those hypotheses (resulting from the coding paradigm) against the actual data, the continued search for the properties of categories and subcategories and the dimensional locations of the data, and the beginning exploration of variations in the phenomena (Strauss & Corbin).

The coding paradigm was presented to the shift care nurses for verification at one of their meetings. The shift care nurses discussed the conceptualization and made suggestions

for revision. Once the revisions were incorporated into the conceptualization, it was presented individually to the two primary participants not at the shift care meeting. Both participants agreed with the revisions and the final conceptualization.

Selective coding involved selecting the core category, articulating its relationship to the other categories, filling in categories that need refinement, and verifying findings (Strauss & Corbin, 1990). The researcher identified the core category with the technique of constant comparison. Sandelowski et al., (1989) further describes Strauss and Corbin's defining of the core category as that which "accounts for most of the variation in the data and that integrates the data, codes, and analytic and process memos accumulated during the course of the study" (Sandelowski et al., p. 82). Constant comparison is the method of identifying patterns and variations in the data, comparing them to other parts of the data set, as well as comparing them to the emerging categories (Creswell, 1998). Visual diagrams, questioning, and analyzing by word, phrase, or paragraph, Strauss and Corbin's conditional matrix, and theoretical memoing were some of the strategies used for analysis. Relevant literature was incorporated as the theory began to emerge. In addition, the analysis was regularly presented to the shift care nurses as a group or individually for feedback. All of these strategies were used as the conceptualization was honed into its present form. The grounded theory strategies helped to articulate the relationships between the concepts that form the process of the shift care nursing experience.

Ethical Considerations

The University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects granted ethical approval. Prior to each initial interview with a potential participant, the researcher explained the study and procedures to the participant, provided an information letter to take home, and obtained written consent to participate in the study. Opportunities were given for the participant to ask questions concerning the study prior to obtaining written consent.

Participants were informed both verbally and in writing that participation was entirely voluntary and that they could discontinue their participation at any time without any effect on them. Participants were informed that they were under no obligation to answer any question or to discuss any particular topics. Finally, the researcher explained to the participant that the purpose of the study is in no way evaluative of their practice.

If a participant needed counseling as a result of the effect of sharing their experiences or for other reasons, the researcher was prepared to provide information to the participant to aid him or her in accessing the employee assistance program counseling services for the Vancouver/Richmond Health Board.

Using code numbers rather than participants' names during analysis of the data ensured confidentiality and anonymity. The key which matched the clients names to the code numbers was kept in a secured drawer. Upon completion of the study, the key was destroyed and the audio tapes erased. Transcripts have been retained for further educational and research purposes, in accordance with the written consent from participants. Approval will be secured from appropriate university committees before commencing any further educational or research activities related to the data collected in this study.

Rigor

This study was guided by the factors outlined by Sandelowski (1986) to ensure rigor in qualitative research: credibility, fittingness, and auditability. A qualitative study is credible when the findings are so true to the experiences of the participants, that people having that experience would recognize it immediately as their own (Sandelowski). Credibility was enhanced by simultaneously collecting and analyzing the data. Data analysis shaped future interviews to validate findings and test for exceptions. Theoretical sampling also ensured credibility as participants were chosen for their ability to contribute to the emerging theory. Additional methods that promoted credibility were transcribing interviews verbatim to capture the exact words of the participants and other nuances that the tape cannot reveal, as

well as keeping fieldnotes. Grounding the emerging theory in such accurate records of the data increases its likelihood of reflecting the true experience of the participants. Shift care nurses verified the theory's credibility as it was presented to them throughout the research process at the interviews and at their shift care meetings.

Fittingness is achieved when "findings can fit into contexts outside the study situation and when its audience view its findings as meaningful and applicable in terms of their own experiences" (Sandelowski, 1986, p.32). Grounded theory must be grounded in the data directly provided by the participants. As a result, findings reflect the reported experiences and have more meaning to participants. Using unstructured interviews allowed the participants to describe their experience fully and increase the likelihood of the findings being meaningful. Although the majority of data came from 6 participants, the analysis was presented to a larger group of shift care nurses at their meetings where even those nurses who were not participants agreed with the conceptualizations that resulted from the interview data.

Auditability refers to the consistency of the findings (Sandelowski, 1986). Another researcher should be able to clearly follow the decision trail used by the investigator. Auditability was strived for through following the grounded theory methodology closely, as described by Strauss and Corbin (1990). Additional efforts aimed at methodological clarity involved theoretical and process memoing as well as reviewing decision-making with members of the thesis committee.

Chapter Four

FINDINGS

Overview Of The Grounded Theory

Causal Condition Initiation of Shift Care Nursing

Context Home
- Aspects
- Physical Care
- Needs and wishes of Dying Person and Family
- Immersion
- Intensity

Core Phenomenon Nurturing the Dying
- Dimensions
- Being Present (Foundational to other three dimensions)
- Opening
- Witnessing
- Connecting

Strategies
- Positioning
- Becoming what the Dying Person and Family needs
- Teamworking
- Tending self

Intervening Conditions
- Continuity
- Family dynamics

Consequences Congruity>>>>Dissonance

Introduction

What shift care nurses do is conceptualized as a process of *nurturing the dying.* The process begins when *shift care nursing is initiated,* and the shift care nurse enters the *home* to provide services. *Nurturing the dying* is composed of four dimensions: *opening, witnessing, connecting* and *being present* with the dying person and family. All dimensions are present throughout the process. *Being present,* one dimension of *nurturing the dying,* forms the foundation for the other three dimensions. Strategies shift care nurses use to facilitate this process are *positioning, becoming what the dying person and family need, teamworking,* and *tending the self. Characteristics of the shift care nurse, continuity, role expectations and the knowledge base of other team members, as well as family dynamics,* can be limiting or facilitating factors for the shift care nurses as they engage in this process. The consequences of *nurturing the dying* vary along a continuum of *congruity* to *dissonance*, which describes the perception of the experience from both the shift care nurses' and the families' perspective.

Initiation of Shift care nursing

Shift care nursing is initiated when three conditions are met: the client has a terminal illness, the situation needs the skill level of a shift care nurse, and the client and family have consented to shift care nursing.

Shift care nursing is only provided to those clients with terminal illness and generally is initiated in the last days or weeks of life. In addition, shift care nursing is initiated for clients receiving home care nursing when the client and family would benefit from the level of care that can be provided by a nurse or the consistent presence of a nurse. Sometimes terminally ill persons need no support beyond their family, friends, and family physician. Some families only need the assistance of a home support worker.

The dying person, family member, friend, home care nurse, or family physician identifies the need for shift care nursing. Shift care nursing requires the consent of the dying person and family to allow the shift care nurse into their home. The consent does not

guarantee how receptive family members will be to the shift care nurse's interventions, but, as a minimum, they have admitted the nurse into their home. Once *shift care nursing has been initiated*, the process of *nurturing the dying* begins.

Nurturing the dying

To *nurture* has been defined as: "to provide for growing things those conditions which are favourable to their healthy growth" (New Webster's dictionary, 1991). This term captures the dynamic, engaging relationships among the shift care nurse, the dying person, and the family. It encompasses the sensitivity, focus, and flexibility of shift care nurses as they accompany the dying person and family through the experience of dying.

The essence of the experience of shift care nursing is that the shift care nurse travels the journey of the dying process with the dying person and family. Shift care nurses are usually with a family until the person's death but sometimes they are present for only a portion of the journey, providing respite for the family and helping to sort out issues that will allow family members to manage on their own once again.

One shift care nurse used a metaphor of crossing a river to describe the dying experience and the shift care nurses' role. He described death as being on the other side of the river. The dying person crosses the river in a boat. The shift care nurse is the boatman who has crossed the river many times with other people and returns alone when the person dies. The river is familiar to the boatman, who knows the hazards and challenges of the river, as well as the smoothest routes. Sharing the dying person's journey, the boatman provides companionship and expertise for the dying person. The journey is the dying person's so the dying person guides the boat. This metaphor captures the process of *nurturing the dying* at *home*.

Home

Shift care occurs in the dying person's *home; home* therefore provides the context for *nurturing the dying.* Four aspects characterize the *home* context: physical care, the all-importance of the needs and wishes of the dying person and family, immersion, and intensity.

The physical care and support that shift care nurses provide in the *home* are often the background for shift care nursing activities. Providing physical care is a vehicle for the shift care nurses to gather information; exhibit skill, knowledge and confidence to the dying person and family; offer comfort and support; and, teach the dying person and family.

When palliative care is offered in the hospital setting, the dying person enters the nurses' domain. The bed, walls, linen, and pictures all belong to the hospital, not the dying person. Part of the *home* context refers to the dying person having a meaningful physical environment. However, *home* is much more than the physical structure. Shift care nursing occurs within the dying person's chosen context of family, friends, belongings, rhythm, and timing.

What differentiates the *home* context from palliative care in other settings is that the dying person and family's needs and desires are held as central. When the dying person receives shift care in the *home*, the dying person and family completely guide the journey. Their needs and wishes are paramount. Shift care nurses described the family's perceived value of receiving care in the *home*:

> Family really appreciates you being there ... I guess because you're coming to them, they feel that the service is somehow greater. I'm not too sure why. But the appreciation definitely seems to be greater there.

This shift care nurse remarks that he is "coming to them". This signals more than arriving at the proper address. Shift care nurses value the dying person's context and choose to work in a program that is set upon that value. They support people's desire to experience their dying at *home:*

> Being in people's homes is very rewarding ... they want you in there. People need to be in hospital and they're not necessarily wanting to be there. But if they're at home, it's by choice. They have to be very strong to be able to be true to that. The reward [for shift care nurses] is being part of the team to offer that to them.

> He would have been in hospital if it wasn't for the [shift care] program. He really didn't want to go to hospital. I love that spunkiness in people who just keep pushing and pushing and pushing and wanting their own way ... that's the way I want to do it, you know? (she laughs). It's just so admirable. I just admire those people that feel so strong and passionate about being at home. It's great.

Several shift care nurses referred to "immersion". Immersion refers to how the shift care nurse completely enters into the dying person's home and brings as little as possible of her own culture into the situation. Shift care nurses explain it as "holding their own egos" and being aware of the needs of the dying person and family compared to what they themselves may want. It again links to the very important belief that the dying person's needs and wishes have priority:

> Shift care, palliative shift care is about hearing... it's about listening. It's about staying behind your own boundaries. I would love to know a lot of things, but that's my need and not the relevant need. I go in with no expectations, absolutely nothing. I work from my soul.

Shift care nurses do have their own needs. They emphasize that they are not, could not, and would not want to be martyrs. Their needs, however, are minimal. For example, once at work in the *home*, shift care nurses say they need to eat, drink, void, and keep themselves safe. Beyond this, they become an "instrument" for the purpose of meeting the needs of the dying person:

Intensity is the fourth characteristic of *nurturing the dying*. The experience is intense due to immersion and the nature of the nurses' service. That is, shift care nursing usually begins during the last days of a person's life:

> I just found that being there for that length of time too, four or five days, you become very quickly very bonded to the family. Basically you're part of that family for that intense period of time.

The shift care nurses were all nurses with experience in other palliative care settings. When comparing settings, they perceived the intensity of shift care nursing experience as greater than in other settings.

DIMENSIONS OF NURTURING THE DYING

As outlined at the beginning of chapter four, *nurturing the dying* forms the core of shift care nursing. Four dimensions comprise *nurturing the dying*: *being present, opening, witnessing,* and *connecting. Being present* is the foundation for the other three dimensions. All dimensions are present throughout *nurturing the dying*.

Being present

Being present is a fundamental condition for how shift care nurses *nurture the dying* and is the foundational dimension for the other three dimensions of the phenomenon. It involves focusing on the dying person and family as well as expanding awareness to their needs. *Being present* is a continuous state for the shift care nurses and enables them to engage in *nurturing the dying* in a unique way with each family. It is a rewarding and challenging experience that may be difficult to maintain if the shift care nurse becomes out of balance.

First, in *being present*, the shift care nurse focuses completely on the dying person and family. Everything else is "shut out" so that, while with this family, the shift care nurse can absolutely attend to and focus on them:

> The being is just ... being present... sitting with people and not needing to talk. Being silent. I've said this to patients too: "We don't need to talk, I can just sit with you ... and you can go to sleep. Just know that I'm here". And when I'm with them, I'm a hundred per cent. I'm not thinking of anything else.

This focusing requires that shift care nurses set aside unnecessary concerns for self or things outside of work. *Being present* allows the shift care nurse to work uniquely with each family. It involves encapsulating the shift care nurse's self and using only those parts of the self that

are therapeutic for that particular dying person and family. It is an offering to them: "Here's what I am able to do, what can I do for you?"

Focusing requires the nurse to exclude factors not pertaining to the dying person and family. Within focusing, shift care nurses expand their awareness of the dying person and family to understand the breadth and depth of their needs. The awareness is expanded beyond the shift care nurses themselves to encompass the dying person and family. One shift care nurse highlights this aspect of *being present* through describing what happens when the nurse completes the shift:

> You're always this twelve hours of presence. It's sort of a relief to actually relax and let that presence go. Then your awareness isn't really out here (holding arms out in front of chest). It's not expanded really wide. It can fall back into its normal place, which is inside you. [Then you can] just worry about your own rhythm instead of the rhythm of the family, the rhythm of the house, the rhythm of the client.

As this shift care nurse mentions, another characteristic of *being present* is its continuous nature. When shift care nurses are working twelve-hour shifts with a dying person and family, they need to be "on" for that whole time. *Being present* is a state of anticipation and readiness:

> A lot of it is quiet time. I bring reading material with me. I do needlepoint a lot. And just be present, just sit there and feel what's going on. And be ready and anticipate what could go wrong or could change that I need to deal with before it happens.

The *presence* is physical, mental, and spiritual. Shift care nurses make all their "skills" available to the dying person and family.

Being present is both rewarding and challenging for shift care nurses. For some, it is a state that they practice in their own lives and feel privileged to be able to use it so much in their work:

> Above and beyond all the doing things, I'm really practicing just being there. So that's one of the bonuses for me, of the job. [It's] certainly one of the things I am really going to miss because, at [new place of work], there will be a lot more busy-ness and I won't ... I mean it's possible to still practice in that environment but it's not as easy, because, you're just dealing with so much more stimulus. So I'm going to really miss

> that part of shift care because it certainly is a wonderful opportunity to practice [being there].

Being present enables the shift care nurse to provide more meaningful opportunities for *opening* the experience, *witnessing* the dying process more deeply, and *connecting* more profoundly with the dying person and family. It *opens* the shift care nurse to the situation and removes the layers that normally exist between individuals. One shift care nurse describes *being present* as "living creatively and consciously" and "holding a point of serenity and stillness". It is a space, a time, and a rhythm that the shift care nurse enters. It calls the shift care nurses to trust themselves as they open up an inner part of themselves to engage in the intensely meaningful human experience of dying and of *nurturing the dying*:

> On one level clinically thinking, "This means that and that means that and I have to do this and that the next day". On another level being, "Isn't this beautiful? She's dying, it's going peacefully". Or "It's not. She's fighting and that's being true to herself". Or whatever. Just being there for it. Not being afraid of it. Not wanting it to not be what it is. And (pause) kind of knowing, verbally saying, "It's okay. It's okay".

Being present and focusing take time. Shift care nurses take time to assess the dying person and family's needs and pace so that they can *be present* effectively for them. When the shift care nurse is *being present*, clients know that someone is with them, attending to them, focusing on them:

> I've had people say, "Oh, you're going to be with me". And yes, I am going to be with you. Not only watching what they do but, in their mind, being with them when they do it. And that's hard work. I do a lot of needlepoint when I'm working but there are times when, although nothing's going on, I'm too busy to do needlework. Nothing is physically happening but I'm too busy being with this person to pay attention to the needle and thread. I guess, it's a very hard thing to describe and measure but, if it's that much work, I must be doing something.

Shift care nurses describe their work as very mentally challenging:

> You're not doing ... it's physically eight or nine hours of sitting. You shouldn't be tired except you are. You come home after three of four days and feel like, "I've run a marathon".

Being present for a dying person and family is challenging for shift care nurses in that they feel the drain of entering and holding themselves in that state. At times, *being present* can be

difficult to maintain. It requires energy and concentration. Shift care nurses recognize it as a necessary aspect of the work, regardless of how challenging it becomes.

Being present involves genuinely feeling what the dying person feels and acknowledging the meaning of the experience for the dying person and family. *Being present* is the first thing that has to be in place to *nurture the dying* and often, when the shift care nurse can do nothing else, *being present* is the one thing that can still be done:

> A lot of times there's nothing that we can do but be present. And it's so important that people have that presence. It's everything.

Being present is most of what the shift care nurses feel they do. The limits of language force the use of the word "do" but the nurses distinguish *being present* from doing, saying that it is on a different realm from doing:

> We come from a "doing" society. We always feel we have to do something to make somebody more comfortable ... Families hover around people, have to do, have to do, have to do, because it's the only way they know how to be, right? I used to do healing touch, I used to do all these things because I was used to doing all the time. Then one day I got a little message here. Who knows where it came from? Saying, "I don't need to do as many things".

Being present takes practice and effort. It also requires patience, stillness, and self-awareness. The shift care nurse needs a clear mind, having set aside some of the clutter of life outside of work. This involves a centering of the nurse's energy as she prepares to focus on the dying person and family:

> [The shift care nurses] care for patients and they give a hundred and ten percent. You don't get that in a lot of areas that I've worked in eighteen years. I really think that it's an amazing quality of care that people give ... physical care as well as emotional care ... But when we get together, when we did that ethical session ... you can connect to the energy of the shift care nurses because of that centering that they can do.

Confidence in one's own abilities to follow the information gleaned from *being present* is necessary. However, sometimes shift care nurses find they cannot *be present* and this affects their ability to engage meaningfully with the dying person and family, thus changing the experience:

> So there was a fine level going on which I just didn't clue into ... my soul was not on track. In a way [the client's husband] was right. If my soul couldn't pick it up, it was not the place for me to be.

If the shift care nurses don't care for self they feel run down and out of balance. Being out of balance means that the shift care nurse has not been giving enough attention to him or herself. Shift care nurses who are out of balance find that they can't *be present* with the dying person and family and lose their patience quickly. As *being present* is foundational to the other dimensions of *nurturing the dying*, being *out of balance* affects *opening, witnessing*, and *connecting* as well. Shift care nurses believe that looking after the self is the highest priority and allows them to do the work well:

> But I have to balance my life as well. I find I get too pulled in and forget about me ... I'm getting to the stage where I need more time for me. If I don't look after me it's pointless, right?

If they ignore this for too long, they may "shut down" after work and find they have nothing left for family and friends. They may need time off work to recharge:

> I waited too late. I wish I had somehow foreseen that a bit earlier and then took a month off. And then to be able to sort of regain my balance there. But I didn't. I waited too long and then I, not that I couldn't work, but every day [it] was just terrible to come in. And not to do with the patients but just, my feelings about work were just awful. So then I had to go for six months and I extended it cause I started traveling. That was wonderful. It was a great re-energizer. But I wish I had done it earlier. Now I recognize my stress much better because I've gone through it.

This is why the shift care nurses attempt to continue all of the activities that help them to *tend the self.* They know from experience that when they got *out of balance*, they cannot *be present* at work or enjoy their time away from work.

Shift care nurses recognize *being present* as an underlying state for what they do. They describe it as "everything", and sometimes the "only thing". They see that they are occasionally unable to *be present* and that this inability greatly impedes their ability for *nurturing the dying.*

Opening:

Opening is a dimension of *nurturing the dying* that entails showing options and opportunities to the dying person and family as well as removing the barriers that may prevent *opening*. It requires the shift care nurse to *be present*, to *have expertise*, and to evaluate continuously. The nurse offers an option or *opens* a door, which allows the family to see a new possibility:

> I do open possibilities for people. Part of being experienced with dying is that you can tell other people what it's going to be like or what it will be like if they choose a certain path. In that way, I guess you open other paths for people.

Another shift care nurse describes the dying process as a "unique story" where the shift care nurse is "not creating it ... merely facilitating the opportunity whereby [the dying person] can create it".

Shift care nurses also *open* the situation through taking away fears, and removing boundaries or limits for the dying person and family:

> For me as a helper in that situation, I try to soften some of the difficulties of [the dying experience] and to open some of the doors into places that allow people to really shine and for their hearts to open and for some healing to happen in those situations. I don't really do very much except for just be there ... I see myself as a sort of catalyst.

It is as though the shift care nurse can see walls or barriers that are constricting the dying person and family. The shift care nurse helps the dying person and family to remove the barriers so that they have space to move within the experience of one of the family members dying. One shift care nurse recounted an experience with a family in which the grandmother was dying:

> Grandkids were running everywhere and [the adults] were so upset. They were hushing up the kids and stuff. And I just said to them, "I can't imagine anything that she would rather hear than her grandchildren screaming and playing". Just a few words like that changed the whole experience for them. It became a less uptight experience. It became one where, they could be normal with her, around her dying. It changed it from something so somber into something so full of life.

The needs and wishes of the dying person and family are all-important. Using the strategy of *positioning*, the shift care nurses shift into the position that the family expresses need for. The nurses may watch and wait, or provide information about choosing various options, or provide even more guidance about making choices. The dying person and family's wishes and needs guide *opening*. Shift care nurses recognize that while these needs may provide guidance for *opening*, the potential for *opening* is not unlimited. *Nurturing the dying* occurs within the context of each unique family and can be limited by the family's patterns and history. Shift care nurses follow the family's lead and use *opening* within that context:

> The challenge in the death process is the family dynamics. People are coming to death and they've had so many years of life ... so many years of family dynamics. How do we as professionals allow them to die the way they live but help them? It's my job to do my best to make it easier. How much are they willing to be open to that?

Part of the shift care nurse's expertise is knowing what not to *open*. *Opening* is a gentle, hesitant process with the nurse watching closely to ensure that they are helping and not hindering the dying person and family. Some shift care nurses have had experiences where they gave options the family was not ready for. In other cases, shift care nurses tried to remove barriers the family intended to maintain as desired boundaries. In these cases, *opening* is not appropriate. The dying person and family may feel uncomfortable, thinking that they should choose a path or option just because it is offered to them. Shift care nurses were very sensitive to the appropriate time and way to *open* or give options to the dying person and their family:

> I'm very careful about how long the body stays at the home. I don't say [to the family], "You have to stay here for a while. You should finish this or you should do that". I would never say things like that. I would never forcefully open that pathway for them. It would be more in terms of, "Different families have different traditions and different needs. These are options you can choose from". I would never, I couldn't choose one path for them.

A shift care nurse will continuously evaluate the *opening*, watching the family's response to know whether to pull back or *open* further. Part of shift care nursing is accepting

each person's dying experience as unique. This applies to *opening* and the shift care nurse accepts families' responses to it. Acknowledging the uniqueness of each dying experience keeps the shift care nurse aware of the effectiveness of his or her attempts at *opening*, allowing for adjustments as appropriate:

> Sometimes I will try to open the door by talking about things myself and maybe teaching in some way. Again, waiting for the right moment to make this comment or that comment. Seeing how people react. If I see a little bit of a glimmer of something, then I'll say something else and if there's a total shutdown, then I'll back off. It's basically just being really, really sensitive and aware of where people are at with themselves and with each other and without being intrusive or trying to manipulate the situation according to what my ego wants. Looking for ways to bring more openness to the situation.

Opening has to do with the nurse reserving her own judgment and therefore *opening* without manipulating or intruding. The shift care nurse has to assess what the family needs and what they have experienced in the past. If it is not clear to the shift care nurse that the family is receptive to *opening*, the shift care nurse may ask their permission to *open* the situation:

> And on the first night of my second set of four, I brought in one of these candles ... I asked permission to light it ... just to remind us of spirit.

The shift care nurse can also *open* the situation for the family by being *open* herself. This allows the shift care nurse to be an example for the family:

> A lot of it is about just being there. And being there with an open mind and a clear mind, and an open heart ... That's easier said than done, believe me (laughs). But the more I can do that myself ... that helps other people in the space to tap into that place for themselves. I do what needs to be done. I change diapers, and I give medications and I make phone calls, and a lot of listening to people.

Opening is being open to possibilities and seeing them. It has to do with creating space and *opening* light in a situation, of being centered. More than just providing an example for the family, an *open* shift care nurse who is *being present*, can *connect* and *witness* more completely as he or she *nurtures the dying*.

Witnessing

Witnessing is another dimension of *nurturing the dying.* Shift care nurses *witness* many things, both positive and negative. Shift care nurses describe *witnessing* as more than observing. *Witnessing* comforts the dying person and family. Shift care nurses find that *witnessing* is an honour that can, at times, be difficult.

Shift care nurses describe many things that they *witness* with people who are dying. Sometimes they *witness* suffering and distress. One shift care nurse tells how difficult it can be to watch a person suffer. In this case, it is due to family traditions:

> I find it very difficult to watch the patient suffer at the hands of the family and me not able to do anything about it. If it's what the patient wants, then fine. People live as they die as the saying goes. And I suppose that even in the situations I've talked about, this person being part of that family will still be dying as they lived, within the confines of a controlling family or whatever. But, it's harder in these situations for me to just let go and accept.

Another shift care nurse points out that death can involve a great deal of physical pain that cannot or has not been overcome. Witnessing such pain can also be difficult for the shift care nurse, even described as an "anguishing death to look at". Several shift care nurses *witnessed* similar cases where the dying person's pain was uncontrollable. While their opinions differed on whether or not uncontrolled pain and suffering was avoidable, they agreed that this situation sometimes occurred. They also *witness* beauty in being, love, and sorrow:

> She had obviously seen the light as it were, and [the spouse] was so beautiful being in that situation. He was just able to be so real, with his love and his sorrow. And then the three of us as kind of witnesses to this. It was an amazing experience.

Shift care nurses *witness* extraordinary, unusual occurrences that are sometimes unexplainable to them and seem like miracles or magic:

> It was just after midnight on the Monday. And as she took her last breath, he reached out his hand and put it on hers. It was like a miracle. Yes, it was a miracle.

They *witness* the dying person and family's courage, bravery, strength, and wisdom as well as their relationships, tenderness, compassion both to and from the dying person, and being with

one another. One shift care nurse describes the pleasure of allowing the family to do more of the care and, as a result, being able to *witness* more of their love:

> I'm very willing to give up that standard [of basic bedside nursing care] if it means the family could do [the care]. And I've seen some lovely things that certainly wouldn't pass a nursing tutor (we laugh). But the love and the compassion that is allowed ... I [see] it manifested to the dying person or vice versa. That communication. That is so lovely and honest and redundant. I think that is bliss. That is real bliss.

They *witness* honour and integrity. They *witness* a person's life. Shift care nurses *witness* at the deepest level of their person and at the highest level of their expertise. *Witnessing* is more than just observing. One shift care nurse explained it as "watching from a place of knowing". *Witnessing* is bringing one's *expertise* to the situation. The dying person values knowing that the shift care nurse has gone through this before and knows or recognizes what they are *witnessing*. This area of *witnessing* includes the idea of validating and acknowledging the person's experience with his dying, that he is doing a good job:

> It is a delight and a pleasure for me to be able to witness [the dying person's] life. And, yeah, I guess that's a big part of being present for people who are able to respond is just witnessing. "Your dying ... this is part of your life and it's okay ... you're doing a great job, it's good". And genuinely [saying] those things, not just in platitudes. Genuinely feeling what's going on and what it means for them.

One nurse described the value to the dying person of *witnessing:*

> Taking away from this experience ... this person will know that someone watched them die and that someone is keeping this memory.

Witnessing is a cyclical experience. Shift care nurses bring expertise to *witnessing* that enables them to validate and acknowledge the dying person's experience. By so doing, nurses gain more experience which becomes part of the expertise they take to the next dying experience they are *witnessing*.

Shift care nurses talk about staying within their own boundaries and just enjoying or appreciating what happens. They are *witnessing* the dying person's and family's letting go. One shift care nurse describes how *witnessing* entails respecting the "dance" of the dying person and family and accepting how they choose to do it:

> She and her husband were doing a dance. And this is another thing you have to respect. You can read stories into people's lives and say, "Oh he's in denial because he's doing this and she's in denial because she's doing that". Come on guys, let them do their dance. Just guide them and [let them] say, "You can help me with this, you can help me with that".

At times, however, shift care nurses find it difficult to watch the dying person and family go through challenging situations:

> I was the first nurse in [the home] so I saw what he was like in total distress. We were just beginning to get the hang of calming his body down when it all went unraveled again. And that was his choice, he really needed to have the choice. But to watch it, and make no bones about it, it was really hard. It's hard, hard, hard to watch someone like that. That went on for twenty-four hours. So, although it sounds good that you listen and honour, it's not necessarily easy to do in practice. It's quite a challenge.

The shift care nurses regard *witnessing* as an honour:

> I feel very honoured to be part of that. There such magical moments that people have. It's not just necessarily the middle of the night. To be witness to those tender moments in people's lives ... it's magical. It changes you.

Witnessing changes shift care nurses, they learn, it enlarges their life experiences and their universe. They take away what they have seen ... holding, learning, and keeping it:

> There are lessons that we learn at the end of someone's life. And we are honoured in that way to be able to see [the lessons], and to be able to experience them with these people.

Shift care nurses feel they are a part of the dying person's experience, they are part of the dying process. *Witnessing* is being part of the person's dying experience, through both pleasant and unpleasant times. One of the shift care nurses described *witnessing* as enjoying your own soul:

> And that's a soul thing. That's just feeling a way in the soul. That's just letting the soul be and enjoying what comes out. But enjoying it on one level and watching it, the way I was trained in psychoanalysis, just watching it because that says something about your interaction with this family. There's a whole piece of information in that.

That is part of their expertise, knowing to let things be. Shift care nurses realize the meaning of the experience. They know when to intervene and when to let things flow.

Connecting

Connecting is the third dimension of *nurturing the dying. Connecting* refers to creating a bond between the shift care nurse and the dying person and family. Shift care nurses enhance *connecting* by using their strengths and finding similarities with the dying person and family. Sharing the dying experience with the dying person and family provides further opportunities for *connecting* as does *becoming what the dying person and family need. Connecting* occurs on many levels and occurs to varying degrees.

The starting point for *connecting* is assessing the dying person and family's situation so that the shift care nurse can "join" them:

> And that's a skill to me. That's the necessity of the job is that I work with someone uniquely, with them in their moment in time.

This assessment involves being sensitive and aware of the situation. It entails that shift care nurses find the meaningful point of *connection* for the family and put themselves at that point. Shift care nurses make the *connection* by being accessible, and using their own strengths and experiences. As one shift care nurse describes, *connecting* can be accomplished by using skills to become more aware of the needs of the dying person:

> It's putting myself inside that person. So that, in many ways, trying to know exactly what they're feeling, physically and emotionally. It presents as things like, the person can't speak, they look at me and I know what they want.

Shift care nurses use their sense of timing so that once they discover the place to *connect* with the family, they wait for the right moment to connect with them.

Connections may be made on the basis on similar interests, backgrounds, or culture. Shift care nurses try to "enhance upon similarities and minimize differences". *Connections* may be made as a result of activities done together, remembering, or sharing history. *Connections* can also be achieved through shared modes of expression or appreciating the experience in a congruent way:

> We just all held hands and sang. It's lovely because it was one of those times when you come together and you're human, we're just human beings. If you ask me, I'd say,

> "No, I don't recall facilitating anything". I was part of something. Yes, they needed nursing expertise for symptom and pain management, sensible things. But they were really all on their way together so it was just a pleasure to be part of it. Part of the process.

Shift care nurses describe different levels of *connecting* ranging from "deep spiritual" *connections* to "more superficial" *connections*. They accept that families are capable of different levels and types of *connection*:

> It's amazing ... the connections. I always have some connection with people. If you're open to it, it's amazing the depth of the experience. On so many different levels because not everybody is on the same level. Some people want to be superficial with you and some people want to be spiritual and some people will be cold as ice and denying right until the end.

A *connection* does not have to be at the deeper spiritual level to be meaningful. Shift care nurses accept each family's level of *connecting* or enable them to make deeper *connections* as appropriate.

Connecting involves offering something of yourself as an individual to the dying person and family, something to *connect* with. One shift care nurse describes how her work with pottery has helped her to make connections:

> It really gives me a lot of joy and I love talking to people about it ... just making incredible connections with people with clay and my work - the strength that it gives.

Guiding and *connecting* interrelate as the shift care nurse recognizes the dying person and family's learning need. *Connecting* is a strategy used to discover what the learning needs are. *Guiding* relates as the shift care nurse offers information that the dying person and family want to receive. In another sense, teaching may allow for a deeper level of *connecting* as the nurse's teaching allows the family to get to a place where they understand and connect with the nurse and the experience in a different and sometimes deeper, more meaningful way:

> I feed back to them how I see that person and what I'm doing and why. I love it when they turn round and say, "We know that. Don't worry, we'll do that. We know how to do it". And you think, "Ah ha, isn't that wonderful?" This chain of communication has gone round completely. They've really heard and I've made myself redundant. And I feel that's done it. They've pulled in shift care because they needed extra help and now I'm redundant.

Related to the *home* context, some shift care nurses perceive that they *connect* more readily and deeply in shift care nursing than in other palliative care nursing contexts. Two reasons account for this perception: the intensity of the experience and the family's perception that the shift care nurse's role is so valuable:

> It's very interpersonal nursing. I think partly because of the nature of what's going on. People are at home dying. You get fairly involved with people very quickly. First shift, okay, you're kind of a stranger, then you go home. By the second shift, suddenly you're dealing with deep personal issues with these people, which I think is quite different from other nursing.

Shift care nurses *connect* with the dying person in the context of him/her being a whole person, more than a patient. They relate this to the *home* environment:

> It's really nice being in someone's home. You really get a total picture of a person, you know? ... all the senses are stimulated when you are in someone's home whereas in the hospital it's like the bedside table. [In the home,] you get a sense of the person's family background and supports, so many aspects of themselves ... the bed is the institution's bed whereas when you're in someone's home... it's, I find it very holistic.

Connecting can range from being easy to being difficult. Easy *connecting* is enjoyable, touching, and deep. Depending on personal beliefs, shift care nurses describe it as synchronicity or skill. Synchronicity is being in the right place at the right time, where you are meant to be:

> But that was just the synchronicity of walking in and instantly being at home. The daughter and I sat up. The mother looked and she [said], "I knew you'd be coming" or something. She said something like that ... So it's magic ... it really touches your heart when somebody says that to you. You know you're meant to be there. All your doubts and all your moaning just leave. All your "stuff" is left at the door.

The shift care nurses that explained *connecting* in the context of skill and expertise refer to knowing the right action, the right words, and the right time:

> I know which few words will affect the family which way ... because I've done this a lot. I like the feeling of being able to make the right intervention. I'm not just grasping in the dark [saying], "Oh don't worry about it". I'm not just giving them platitudes. I'm trying to give them the words that will help them be in the right place. And I feel that I have the expertise now to do that and to do it well. I really enjoy that.

When the shift care nurse has a similar background and culture as the dying person and family, *connecting* is less work. This *connection* is also satisfying because the shift care nurse knows what to do for this family and feels skilled. *Connecting* with a family that is culturally disparate from the shift care nurse can also be satisfying when the nurse successfully *becomes what the dying person and family need.*

If a dying person is in a "bad place", full of anger for example, it is hard to "join" with the person. These situations are often unpleasant for the shift care nurse. The shift care nurse still recognizes, however, that it is necessary to join the dying person where they are, whether it's a "good place" or a "bad place":

> Sometimes people are in a very unhappy place and it's hard to be with them in that place. Other times it's incredibly wonderful. People are having a good death and family are coping well with it and it's just wonderful to see.

Shift care nurses recognize that they cannot wait in a "good place" for the dying person to *connect* with them there. The dying person needs the shift care nurse to "join" him in his current situation and help him develop the situation he desires. For example, if the person who is dying is expressing intense anger, the shift care nurse has to engage with the angry person in order to help him or her resolve it. The shift care nurse cannot wait for the person to resolve the anger alone before *connecting,* it may not happen without the nurse's help. In fact, the anger may not resolve at all but the shift care nurse can still connect with the dying person.

Shift care nurses emphasize that in *connecting* with they dying person and family, it is not enough to "just be yourself". The shift care nurses have to be what the dying person and family needs. In this way, shift care nurses are aware of their own boundaries in making connections and talk about "holding yourself in". It means *connecting* with the dying person and family's need and fitting in. The focus is on the dying person and family, not the shift care nurse. *Becoming what the dying person and family needs* enhances this aspect of *connecting.*

Shift care nurses express amazement at some of the deep *connections* they make. They learn things from and about the dying person through these *connections* and find that through *connecting*, they can better empathize and anticipate upcoming possibilities for this dying person.

Having Expertise

The shift care nurse's level of *expertise* facilitates or limits the dimensions of *nurturing the dying*. Shift care nurses have a large and ever-growing repertoire of skills and experiences. Shift care nurses use their skills of assessment, intervention, and evaluation to gather information and understand its meaning within the context of the disease and dying process for the client. Shift care nurses rely on their knowledge and experience to recognize and implement the right intervention at the right time, to evaluate its effectiveness and revise their care in accordance with the dying person's needs. The shift care nurses' *expertise* is the foundation of knowledge that allows them to move among the dimensions of *witnessing*, *opening*, and *connecting* with sensitivity and skill.

Shift care nurses use this expertise to tell them what is occurring. Their past experiences with dying often inform them about the current experience. They recognize milestones in the dying process as they are happening. *Expertise* also helps the shift care nurses to anticipate what might be coming:

> Just be present. Just sit there and feel what's going on. And be ready and anticipate what could go wrong or could change that I need to deal with before it happens.

One shift care nurse described how not *having expertise* affected the level of care she could provide:

> The first time that I was in someone's home when they passed away, [I was] alone and everybody was asleep and the dog was underneath the bed. The wife was down the hallway and wanted to be there when he passed away. It was sudden. Looking back on it, I know the signs. But that first time I wasn't knowledgeable [enough] to be aware of them. There was a shift in the last half-hour. [But I was] wanting [the wife] to sleep because she hadn't slept. And she was upset about not being there at the time because

> I felt that it was important for her to get her rest. [Waking her up before he died] was one of the reasons I was there. I felt bad that I'd deprived her of that time with him.

The shift care nurse's lack of expertise can affect how well he or she is able to *nurture the dying*. Expertise is what gives the shift care nurse the wisdom to know what to do, how to do it, and when.

Shift care nurses spoke about both expertise and intuition. They identified intuition as a sense that they have which is part of their expertise. They referred to being "tuned in to" the dying person and family:

> For some reason, I was sitting with them in the middle of the night and I got the sense that she was going. There wasn't even a change in her breathing but I got a sense that something had shifted. So I got the daughter and the sister downstairs. And she died just within moments of seeing the daughter. The daughter said, "How did you know?" And I really, my intuition kicked in.

The clinical expertise is challenging and rewarding because of the shift care nurses' autonomy and the fact that they have to deal with the clinical issues, one on one with the dying person, for what is sometimes a very long twelve hour shift:

> Clinically, I find it very challenging because I have the luxury to stop and think and figure out, what is going on? What can I do about it? Often we're in there because things have gone wrong and it's become very complicated. There are symptoms whose etiology are really hard to define. So we're in there to make an analysis of what's going on. How can we control this pain or this nausea and where is it coming from? ... if it was obvious, it would have been dealt with already. So it's quite clinically complicated and I really enjoy that. I like the challenge of trying to figure out how to deal with someone's dyspnea in a way that will work for them.

The shift care nurses build upon their expertise. They find this rewarding and feel that it is very useful to the dying person and family, making the experience for them as easy as possible.

Shift care nurses gather expertise from past and concurrent palliative care nursing experiences in other settings, from their experiences as shift care nurses, from their colleagues, and from the literature. At their meetings, they share information about what they have read, heard, and experienced with each other to maximize their learning:

> You learn a lot of tricks from each other. A lot of little things. Making ear pillows, just learned that a little while ago. Taking a piece of foam and putting a hole in it. Making a special pillow for the ear because people get bed sores on their ears. One person learns that and they get to use it with someone. Then this passes around through the nurses eventually and we all have that as part our repertoire. That happens a lot, particularly in home care. It's not like the hospital where you [have a] standard availability of resources. It's like, what have you got to work with?

Developing and maintaining the expertise for palliative care and especially shift care nursing skills allows these nurses to work effectively in a very autonomous setting that requires hands-on skills as well as a high level of critical thinking. Having this level of expertise enables shift care nurses to know when they should take action in a situation and when they can just witness what is "unfolding" for the dying person and family throughout the dying process. In other words, it allows the nurse to engage in the process of *nurturing the dying* with the ease and confidence of an expert.

STRATEGIES

The strategies that shift care nurses use to facilitate the process of *nurturing the dying* are *positioning, becoming what the dying person and family needs, teamworking*, and *tending the self.* The shift care nurses use these strategies to facilitate *opening, witnessing,* and *connecting.*

Positioning

While the word "shift" in "shift care nursing" indicates that these nurses stay in the home for twelve hour shifts, shift care nurses also shift *positions* in order to *nurture the dying.* This is *positioning. Positioning* allows the shift care nurses to provide care that best suits the needs of the dying person and family. There are five identified *positions: 1) watching and waiting, 2) supporting from behind, 3) walking beside, 4) guiding,* and *5) taking over.*

Positioning involves, first of all, assessing the dying person and family's situation. As shift care nurses attempt to ascertain the position of this dying person and family, they discover the culture, rhythm, and style of the family:

> The challenge is going in fresh and getting as much information [as possible]. But once you ... set up rapport it's good ... You really have to gauge it when you go into a house. You're fresh into a situation. And how you be sets up for the whole, how you present yourself ... So it can be challenging. You can get a report from a home care nurse and have this overall picture and when you walk in, you might think that was something quite different. So I've got an idea of what is going to happen but without a preconceived idea of what's going to happen.

As they become more intimate with the dying person and family, shift care nurses are able to see what the needs and wants are and provide care to them in the most meaningful way. Once shift care nurses have ascertained the dying person and family's situation, they "join" them in their experience.

The shift care nurse then moves through the process with the dying person and family in many different *positions*. The different *positions* of shift care nursing are not mutually exclusive but do indicate different levels of interaction with the client and family. The needs of the dying person and family direct these changes in position. As the needs of the dying person and family shift, so do the positions of the shift care nurse.

At times, the shift care nurses' *position* is to *watch and wait*. This is a vigil with the purpose of preventing harm, discomfort, or unpleasant experiences for the dying person and family. It involves the shift care nurse using past experience and expertise to anticipate and recognize potential problems for the dying person. When the shift care nurse is *watching and waiting*, the focus is assessment and "letting the experience unfold" for the dying person and family, rather than interfering.

Sometimes, the dying person and family need support to continue what they are doing. In this case the shift care nurse assumes the *position* of *supporting from behind:*

> Then I have to work with the person and find out: "What is it you want?" and, "I hear you". I'm very grateful for the psychoanalysis because that trained me to work behind

> my boundaries. I really create a lot of space. So that I can hear. I can really hear and work with you. I work behind you. I'm only facilitating from behind.

In these situations, the dying person and family are still managing the situation but the shift care nurse's support may help to sustain their ability to manage.

When the dying person and family need the shift care nurse to be more visible in the experience, the shift care nurse moves to the position of *walking beside* the dying person and family. This *position* relates strongly *witnessing* as the family needs to see that the shift care nurse is going through the experience with them, *witnessing* their journey. The dying person and family do not need the shift care nurse to provide guidance and lead but want the shift care nurse to accompany them:

> I have to remember it's somebody's journey. It's not my journey and I can't change the journey. But I can walk beside them.

In other scenarios it may be appropriate for the shift care nurse to provide *guidance* to the dying person and family. *Guiding* occurs when the dying person and family have needs that require shift care nurses to share their expertise and teaching. This *position* relates to the dimension of *opening* as the shift care nurses show options and opportunities to the dying person and family.

At critical times, the shift care nurse may have to *take over* for a short time until the dying person and family can manage again. Even when the shift care nurse *takes over*, however, it is to fulfill the wishes and needs of the dying person and family and to give the lead back to the dying person and family as soon as they are able to receive it.

Shift care nurses have the wisdom to know when and how to move into these various *positions*. It is part of their skill set. They have experienced the dying process with others and can bring those experiences with them while remembering the absolute uniqueness of each individual's experience: "No death is the same". The needs of the dying person and family shift throughout the dying experience. The shift care nurse engages in the strategy of *positioning* to move with they dying and person and family. This enables the process of *nurturing the dying* through *opening*, *witnessing* and *connecting*.

Becoming what the Dying Person and Family need

As previously mentioned, the shift care nurse has to *become what the dying person and family need* in order to be able to *nurture* them through the dying experience. *Becoming what the dying person and family need* is a strategy used by shift care nurses to facilitate the dimensions of *being present, opening, witnessing,* and *connecting*. Consider the chameleon. A chameleon adapts to blend with its surroundings. As the environment changes, so does the chameleon. The chameleon's ability to adapt is not unlimited and most alterations in appearance are temporary. The chameleon is a metaphor for the strategy that shift care nurses use: *becoming what the dying person and family need.*

Becoming entails respect, caution, awareness, and assessing the family. It focuses on the dying person and family, and requires that shift care nurses value the importance of "joining" the dying person and family in their dying experience. This differs from a situation in which shift care nurses act based on their own plans or vision for the experience. In *becoming what the dying person and family need*, shift care nurses are molding themselves as much as they are able to fit the needs of the dying person and family.

In trying to *become* the kind of person that the dying person and family can relate to, the shift care nurse attempts to emphasize similarities and minimize differences between themselves and the dying person and family. When shift care nurses use the strategy of *becoming*, they are not changing themselves, but pushing and pulling aspects of themselves as needed by the family:

> I am more careful about how I present myself. I don't present a different person but I present a quieter aspect. I don't present a falseness because I'm me. Okay? And then actually I just gauge on who they are, how they be with me too.

Shift care nurses make this alteration in order to be more instrumental for the dying person and family as they go through the dying process. Shift care nurses sometimes have to emphasize an aspect of themselves that does not reflect how they would usually present themselves. They make the change to meet the current need:

> It is harder for me when I'm dealing with a more openly communicating family. I'm able to set aside my own cultural background and work with that family but it isn't natural for me. So it's like, "Okay, we'll talk about this stuff" and yadda dadda dadda da. And we'll all express how much we love each other and give each other permission to do what you have to do and all that stuff. But it's not my natural way of being.

Shift care nurses strive to *become what the dying person and family need.* This may differ from what the dying person and family ask for or say that they want. The shift care nurses use assessment and expertise to use *becoming* based on rhythm, wants, needs, and what will be most effective for the relationship between the shift care nurses and the dying person and family:

> I become a different person, depending on what they need. And, sometimes it's very big. When I'm with a Chinese family, I am much more polite, much more reserved than if I'm with a Caucasian family who are very working class. Then I am just down and dirty with them. I become a different person based on what I perceive, a little bit of their rhythm, but more of what I think they need. And more of what I think will make me accessible to them.

Like the chameleon, the adjustments that the shift care nurses make are temporary. The shift care nurses all describe a process of returning to self. Returning to self is a strategy that allows them to continue to be flexible for families:

> I really am in love with that family dynamic at that point in time. And when I leave, I'm upset to leave ... The next day it lingers with me. It can often take me a full day ... I'm unwinding myself from it. But sometimes I'll take a full day. But then I'm really glad. And I don't want to maintain association. Because, in fact, with many families I've nothing in common with them. Remove the dying person and I've nothing in common with most families.

Becoming what the dying person and family need does not always happen easily and, occasionally, it is not possible. Shift care nurses try to expand their ability to *become* but there are limits. Shift care nurses are aware of these boundaries and that they are unique to each situation. Sometimes the shift care nurses' level of comfort with a particular experience dictates these boundaries. For example, one shift care nurse felt that a particular family was trying to manipulate her to work against the other members of the health care team. In those

cases, shift care nurses do not always allow themselves to *become* what the dying person and family are indicating.

In other cases, shift care nurses are not successful in *becoming what the dying person and family need* regardless of how much they extend their boundaries. One shift care nurse explains:

> The family situations, the permutations are unlimited. It's really challenging sometimes. Sometimes I'm not successful. There are times when I don't get through. I just don't reach this family. It's not because they're unreachable necessarily. Sometimes, I'm not the right person. And I can't become the person that they need me to be. That is sometimes frustrating.

Many factors can limit the shift care nurse's capacity for *becoming.* Demographic characteristics that may affect *becoming* include but are not limited to the shift care nurse's ethnicity, gender, age, social status and sexual orientation. While some nurses expressed how much they value the richness of the various ethnic groups with whom they worked, there were also some difficulties due to different ethnic backgrounds and belief systems:

> ... there is often a language problem. Then there are the cultural differences and how they approach death and dying. Where I run into problems is that sometimes I have been in situations where the family is doing something to the patient that is causing the patient to suffer. And they're doing it because of their belief systems. For example, there's two basic things, they're the same every time usually. One is wanting to feed the person past the point that they can [eat], or give them water. And the other one is to keep them so warm.

Although shift care nurses are very sensitive to the needs of the dying person and family to *become* someone that the family can work with and respect, a family's expectations are sometimes beyond what is possible for the shift care nurse to *become*. In some situations, where shift care nurses were unable to *become what the dying person and family need,* they felt that it was best to remove themselves from the case:

> Sometimes there's a bit of stress about the gender thing. I'm obviously a male nurse and there are people who obviously are uncomfortable with male nurses ... A lot of people are polite about it [saying], "That's okay, dear. That's fine, dear". But it isn't. And that makes me stressed because I would rather not be there if that person is uncomfortable. They shouldn't have to work to make me feel comfortable when

> they're dying ... But there's not a lot I can do ... Can't change my gender, don't want to anyway ... So, I just try to be aware and bow out gracefully.

Other shift care nurses recognized that some situations were not optimal for them or the dying person but still needed to accept the work due to financial obligations.

Becoming is hard work and a challenge for shift care nurses. It relates to the strategy of *tending self* as the shift care nurses recover from the stress of *becoming*:

> I am what they need me to be to the best of my ability. I mean, there are things I can't be. And I constantly try to expand my range of what I can become for these people. That's tiring. That is really hard work. When I finish working with a family, it's like (big sigh). And that's part of the reason why I do things that are me on my time. Because I have to come back to myself.

Shift care nurses see *becoming what the dying person and family need* as an effort that is central to the work and demanding of the self:

> I recognize that part of the burden of the job is becoming what other people need [me] to be rather than what I want to be.

Like the chameleon, the shift care nurse blends with the environment and is prepared to change as the environment changes. It is one strategy used to facilitate *nurturing the dying.*

Teamworking

Although shift care nurses work their shift alone, they are part of a larger team. These team members have various positions: fellow shift care nurses, home care nurses, family physicians, and the Home Hospice consultation team. *Teamworking* is influenced by two factors: 1) role expectations, and 2) knowledge level of the team members.

> I really think [shift care nursing is] a specialty unto its own. And it's not being with someone who is dying. It's much more than that ... That's enough unto its own but to get there, and to get there with peace and dignity and comfort, there's a lot to look at. And that comes with knowledge and expertise and *teamwork.*

Teamworking is a valuable strategy for the very independent shift care nurses. They are part of a team that includes the dying person and family, the family physician, the home care nurse, and sometimes members of the home hospice consultative group. *Teamworking*

involves sharing information about a particular case as well as sharing expertise. It also includes supporting other members of the team and asking for help when needed.

Shift care nurses value their fellow shift care nurses. They are a group of experts who share common knowledge and experiences. Shift care nurses give support to one another. They know each other and balance their skills when working with the same dying person and family:

> For the last year, we've had a really stable group of people working [in shift care nursing] and the team has become more important. In the past, the changeovers in staff have been much more frequent ... It's really good to have ongoing relationships with people. To know that the person coming on after me is going to do exactly the right thing. Or to know what the person after me is not going to do and therefore I have to do more of to balance it. I mean, we all have our strengths and weaknesses.

Shift care nurses do not feel they see each other often enough and compensate by arranging social activities and creating personal relationships with one another. They follow through with a team mate by calling and giving information about a client they both cared for who has died or gone to hospital. They would like more structures in place to share information about what happens to clients and to remain connected to one another through a central system of communication.

At their staff meetings, they share information about their clients, but also discuss differences in their practice. Shift care nurses show a large tolerance and acceptance for their different philosophies and manner of providing care for their clients. Shift care meetings also provide a venue for sharing new clinical experiences and new literature, and for counseling each other to gain closure around some of the losses they experience and share. Such meetings are what the shift care nurses say they need more of. They would like more time with one another to gain additional support and knowledge, and to grow together around a common philosophy for care.

The differences between individual shift care nurses may affect their ability for *teamworking*. Shift care nurses identify that their methods and philosophies differ within

their group and that it sometimes affects their ability to work optimally together. A frequent area of concern both in the interviews and in the shift care nurses' meetings is the shift care nurses' beliefs about using medications. Some feel that medications are overused and sedate the dying person beyond the ability of having a "conscious death". Others express concern about their colleagues allowing the dying person to suffer because they did not give enough medications. One shift care nurse describes some of the difficulty that shift care nurses experience regarding their individual judgment in dispensing medications:

> That's where I come in. If I feel it's not effective [I change it]. I go home that night and [the previous shift care nurse] comes back thinking, "That (participant's name) is just terrible" (laughs). So, I'm sure we're both working off each other. You know, "(participant's name) uses too much medications, (participant's name) uses breakthroughs too often..."

Another issue for shift care nurses that perhaps contributes to the discrepancy is the lack of a common language and philosophy within shift care nursing:

> Working with other shift care [nurses] when we don't really have a defined philosophy ... We work on the assumption that we're all working on the same philosophy but I don't ever recall actually sitting down and discussing what it means in practice ... At a thinking level, what it means to be in palliative care? Then at a practice level, what does it mean? Then what sort of standards? I think that the challenge now is to actually identify what it is we're doing and why. And where are our standards and parameters? I think it would be of some usefulness to define that at a level other than just that particular patient level. So that's a big challenge.

These characteristics of the individual shift care nurse may also affect how well the shift care nurse is able to work with the other members of the team: the home care nurse, family physician, and the home hospice consultation team.

Despite not meeting as often as they would like, shift care nurses recognize that they are part of a larger team for the dying person and family:

> One thing I would like to say about shift care is that I appreciate the level of support. I can phone and talk to a [home care] nurse or doctor. This is a huge, huge relief to me. I never feel alone. I never have to think I'm working on the edge of my knowledge. I can work inside my boundaries so I can check and double check. And to this I attribute one of the big successes of palliative care shift care nurses. It's not [just] us. It's a very, very good team.

Teamworking also includes shift care nurses working with home care nurses. The implementation of shift care nursing changes the role of the involved home care nurse. The home care nurse generally stops providing hands-on care and becomes more of a care coordinator.

Each home care nurse envisions and carries out the role differently. Each shift care nurse has different expectations for the role of the home care nurse as well. The shift care nurses adjust themselves to work with the home care nurse in a unique way with each client. In some cases, however, the communication between the home care nurse and the shift care nurse is not optimal:

> I like working with the home care nurses ... Often it's not very "teamy". It's like, I do my job and I tell them what I've done, and they do their job and they don't tell me what they've done. I like problem solving with the home care nurses. That's really satisfying because I learn new things. I get to feel like I'm part of the team and we're working together on it.

Some home care nurses instruct the shift care nurses to leave their report on voice mail. This does not allow shift care nurses to discuss or debrief about their shift, increasing their isolation. It prevents the shift care nurse from learning from the home care nurse's experiences with the dying person and family. It also prevents the home care nurse from using the expertise of the shift care nurses to its fullest extent:

> I guess not being part of the information loop sometimes. The home care nurses are primary and they have a handle on the whole picture. They have a handle on so many aspects of the case. Possibly been seeing this person for years ... different home care nurses take on different roles sometimes with families. Some are more thorough or some are more inclined to give you that information. It's not your role in their opinion. Your role is to be giving physical care and giving that bed bath before they come in and get the list of supplies that you'll need for the next trip and get in touch with the doctor if you need anything. There's a wealth of knowledge and strength that shift care nurses have that is not necessarily accessed by the home care nurses.

When the home care nurse and shift care nurse have different role expectations of each other, *teamworking* may be limited.

Teamworking includes working with the family physician. The family physician is the primary medical care professional in the community and usually plays a large part in providing the needed medical support so that the dying person and family can remain at home. Shift care nurses have varying degrees of involvement with the family physician. This is usually arranged on a case-by-case basis with the primary home care nurse. One shift care nurse explains:

> A lot of times ... when I'm at the home, I phone the doctor myself. Some of the home care nurses seem like they phone the doctor. I know the primary team is home care nurse, physician, and, of course, client. But it seems like when I'm there, I have a lot more time than the home care nurse does to phone. So I'm almost always phoning.

Shift care nurses work with the family physician either directly or through the home care nurse to ensure that they have medical support to provide appropriate physical care. Family physicians vary greatly in their knowledge and experience in palliative care issues, their degree of involvement with the dying person, and their contact with the shift care nurses. Working with a family physician with very limited palliative care knowledge or understanding of the role of shift care nurses can affect *teamworking* and ultimately may limit *nurturing the dying.* Once again, shift care nurses adjust themselves to work uniquely within each situation but find that:

> When I'm swimming upstream against the doctors, it doesn't feel great at all ... that's difficult.

More specialized palliative care support is available through the Home Hospice consultative team. The Home Hospice consultative team includes the hospice physicians, clinical nurse specialist, and social worker. They are a resource for all members of the team. They are available to consult regarding any aspects of the care and are often accessed for complex issues. Shift care nurses did not express any concerns with their relationships with members of the home hospice consultative group. The broadness of the role of the consultative group and their advanced level of expertise regarding palliative care in the home

seems to allow them to adjust to meet the varied needs of all of the other members of the team.

The dying person and family are central members of the team. In optimal situations, the expectations, needs, and desires of the dying person and family guide the actions of the rest of the team. Due to the fact that several members make up the team, *teamworking* is a multi-faceted strategy. *Teamworking* may greatly facilitate *nurturing the dying.* It is also a challenging strategy that is complicated by the many team members, their knowledge level, and their expectations of each other.

Tending Self

Tending self is a strategy that shift care nurses use to be able to continue *nurturing the dying. Tending self* means that shift care nurses take time to focus on their own needs and wants. *Tending self* can entail: catharsis, refueling and/or letting go of losses and can refer to physical, social, solitary, and collegial needs. It involves balancing work with leisure, others with self, and loss with rewards.

Shift care nurses *tend the self* because they acknowledge the intensity and challenge of the work:

> I found that the work was totally consuming my life. I'm not ready for that. [I] thought, well this is the kind of thing that requires a Mother Theresa or somebody for whom this is 100 per cent of their focus. This is what they do. Period. But I need more of a balance in my life. I found that you're working twelve hours so there's not much time for anything else except for work, eat, sleep, and maybe throw in the laundry, or maybe grab a few groceries, or fill up the car with gas. Those basic things. And I am the kind of person who needs to exercise ... my body needs to move ... So, I found after four days or four nights that I really felt run down, and really out of balance.

Shift care nursing emphasizes the focus away from self and on to the dying person and family. Off work, however, the shift care nurse deliberately changes the focus:

> I like doing the twelve hours. I like doing an intense amount of work time. I'm not just talking about nursing itself but just getting it done so I can do something else ... Make

> the money that I need to make. I'm not Florence Nightingale. I am doing this as a means to get some money as well. I just so happen to like what I do as well.

Tending self serves three purposes, which may overlap. First, *tending self* is cathartic and serves to release the emotions and energies remaining from the work:

> There have been patients who I have worked with in a very difficult situation. I actually come home that day, or maybe the next day depending on what shift it is and how the energy is moving through me. I actually dance specifically for that particular person or as a release from the energy that I have taken on and need to let go of.

Second, *tending self* is refueling and rejuvenating the self by doing things that are enjoyable and just oneself:

> I very deliberately choose things that are creative and alive and involve other people who are living. They round my life. And I feel very much that if I didn't do them, my life would be not rounded. I would run down and not be able to do the work.

Loss is a large part of the shift care nursing experience. Shift care nurses express the need to "be conscious" of the difficulties that this ongoing loss can cause. One shift care nurse cautions against feeling "burdened by the sadness of losses":

> Debriefing is really important. Supporting your peers, and getting support, asking, reaching out. Because dealing with death after death, you have to take care of your heart. You have to take care of your resources and your energy. And you have to put closure on the number [of deaths] that you see over the course of [time]. You're constantly losing, seeing people's lives go. I think it's hard work. But emotionally, there's some real growth in going through it. So balance is really important and people undermine that [saying], "I'm coping well with it". But it catches up and I've seen that a lot. It catches up to people.

Tending self involves letting go of the many losses that shift care nurses experience. Another shift care nurse describes the experience of letting go:

> I don't have any leftovers at the end of the day now. When the day's over, I don't fret and fuss about people. I go home and go on with my life. When someone dies, it's like, "Okay, this is finished". And sometimes it's sweet and sometimes it's sad but not for very long. (whispering) It's just gone.

Tending self involves meeting one's physical needs through getting enough rest and eating well. Also, many shift care nurses needed physical exercise and to spend time outdoors. In addition to physical aspects, shift care nurses recognize the need for a social

network. They attend to their emotions regarding the need to see their friends as well as the need to have time alone to "process" the events of their work and "unwind":

> I think I learned to use my friends a bit more. I don't always tell them too much. I think just explaining to them what's been happening with an individual client and how it affects me, how I'm feeling about it ... it shares my burden a little bit. I do a lot of my stuff. I internalize a lot. As I get older I can do a lot more of that, I find. I'm a bit more introspective than I was. A lot of quiet time for me sort of smoothes out all the bumps. Not always but mostly. So, I do use friends a bit.

Several shift care nurses found meditating was helpful. Professionally, some of the shift care nurses maintain their self through social contact with colleagues. Some do several different nursing jobs and find that the variety in their work helps to preserve them.

Shift care nurses find this job more than demanding and challenging; it is also very rewarding. They balance the demanding experiences and losses with the rewarding aspects of the work. Nurses described the job as a "gift to the self", "giving rewards" and "opportunities to grow". Additionally, their shift care nursing experiences have helped them to deal with their personal experiences with dying, bringing closure to deaths in their past and giving them valuable experience to deal with deaths of loved ones in the future:

> I've had two girlfriends that passed away from breast cancer. That has changed me. I think that's why I continue to be drawn back to the work. It's the personal satisfaction of coming to terms with their deaths. Having dealt with seeing my own parents being ill, I think that gives you a more personal and humbling experience to offer. The empathy is different now than eighteen years ago. My sense of humour has changed over time. I can see the lightness of things.

The work brings perspective to their personal lives and they try to keep perspective in relation to their professional experiences:

> I try my best to do the best that I can at it because I know that it's really important for the people going through it. It's a very significant event in their lives. But it isn't a very significant event in my life. It's what I do.

The shift care nurses all described needing a balance in their life. It is a balance of work with non-work, with giving to others and giving to themselves. It is a constant readjustment to make sure shift care nurses are giving what they want to give to others

without depleting what they are and have for themselves. This is why the shift care nurses set limits, protect their priority for self. This is also why they bend or break those limits and set their priority for self aside:

> You don't want to let go of the wishes, respecting the family and the client to stay at home. If you didn't do that extra shift, well, literally it got down to that, they'd have to be transferred to hospital. I can do another shift, you know? So there's that. That's hard sometimes. I don't get the pressure from the office but I get the pressure from the family, with their wishes. And that pulls at the emotional strings sometimes. You have to take care of yourself but at the same time sometimes there's no other way of doing it. You have to work. You have to do it, I feel. That's my own ethic.

They deliberately and consciously decide about what they can, and want to give.

Tending self is a strategy that shift care nurses employ to allow them to continue with their work. When they get run down and *out of balance,* shift care nurses feel unable to engage in the process of *nurturing the dying* as they would like. Being aware of and responding to their own physical, social, and spiritual needs is regarded by shift care nurses as a high priority strategy that enhances their ability for *nurturing the dying.*

INTERVENING CONDITIONS

Several intervening conditions have already been mentioned: characteristics of the shift care nurse, being out of balance, and role expectations. The following intervening conditions also affect the overall process of *nurturing the dying. Continuity* is an factor that is results largely due to the organization of the shift care nursing program. The other intervening condition relates to the family: *family dynamics.*

Continuity

Continuity refers to both the length of time that a shift care nurse is able to work with a dying person and family as well as the frequency of the shifts the shift care nurse works with the dying person and family. Three factors may affect *continuity*: 1) how quickly the

person dies, 2) seniority call-in, and 3) the shift care nurse's ability or willingness to accept the shift.

The process of *nurturing the dying* describes the experience of shift care nursing. This process takes place over time. It is a relationship that develops and progresses between the dying person and family with the shift care nurses as a group and with the shift care nurses as individuals. If *continuity* is sparse and the encounters are short or infrequent, the relationship may not develop and grow as deep as desired. This may affect the shift care nurses' capacity for *becoming what the dying person and family need* and *positioning*. The influence on these strategies may in turn affect all dimensions of *nurturing the dying*.

There is no way to know for certain how long a person will live. This fact, and the fact that the shift care nursing program has limited financial resources, make it difficult to know when to initiate shift care nursing. A home care nurse initiates shift care nursing. Family, friends, home hospice consult team, or family physician may request shift care nursing. Sometimes shift care nursing begins when there is only a day or a few hours left before the person dies. Sometimes, in fact, shift care nursing has been arranged but the shift care nurse does not even get to the home before the person dies:

> You can get booked for four shifts, and then the day before or even the hour before you go, you get a phone call that the patient has died. And then you are left without any work.

It seems that some home care nurses refer to shift care nursing earlier in the dying person's progress than other home care nurses would. How long the person lives after shift care nursing is implemented is one of the factors that determines how much time shift care nurses will have to implement the strategies they use to facilitate the process of *nurturing the dying*.

Seniority call-in is one of the aspects of the Vancouver Home Hospice Shift Care Nursing program that may limit the shift care nurses' ability to do their work as well as they would like:

> You don't get a chance to follow someone through. I would really like it if [when] you start with somebody, that gives you seniority within that case. Not overall [seniority] but within that case and therefore you could see it through.

The provincial nurses' union has implemented the seniority call-in system. This system means that shift care nurses are offered work on the basis of hours of work accrued. The experience of shift care nursing has changed for some nurses due to seniority call-in:

> It really hinges on this seniority system. If I do four days and then by contract I have to stand down, the chances are I won't go back. So when patients tell you lack of continuity, they're damn right. Because they'll get two of us for four days and then probably another two for four days. But instead of getting the first two back, they might get another two. So it goes on. And if a senior person only has two days available, then they'll get two shifts in there. Even one shift, there are a couple who will only do one shift. They'll demand the shift.

The seniority call-in system has affected the morale of the shift care nurses and perhaps their ability for *teamworking* with each other. It is a system that does consider the *continuity* for the dying person and family as a priority. Seniority call-in is a change from the past. Before seniority booking was implemented, shifts were booked in larger blocks, offering more *continuity* for the dying person, the family, and the shift care nurse. Having more time and *continuity* with the dying person and family allowed the shift care nurse to more effectively work through the process of *nurturing the dying*. The issue of seniority booking has the largest impact on the shift care nurses with less seniority because they have less choice when booking shifts.

The third factor affecting *continuity* is the shift care nurse's ability and willingness to accept a shift. The shift care nurses have varying levels of the need to accept shifts due to financial stability. The on-call and seniority call-in systems create pressure and uncertainty for the shift care nurses as they try to secure enough shifts each pay period:

> If I knew in a fortnight I'd be working four shifts, I'd be very productive for the other ten days. I'd get on with my other stuff. But in fact, I spend so much time hanging around and worrying. I feel the lack of certainty of A) work at all and B) which work there is ... Quite often we're booked now for now or for two hours ago ... I find that really trying on my system. It doesn't allow me to do time management the way I

> want. And ultimately will be one of the reasons for me leaving the program. Because I'm not using my time constructively.

If a nurse feels that he needs the work and is having difficulty getting shifts, he may take what shifts he can get while shifts are available. Sometimes this compromises the shift care nurse's ability for *tending self:*

> For me, because I'm low seniority, I need to take the shifts when I can. And the reason why I'm doing shift care is because I find the work very enjoyable. But I also need the money ... So, I just need to take the shifts when I can and sort of say, pick up the pieces later. And when you get sick like I just did now, I don't scratch my head and say why. I know why. It's because I killed myself to get the work in.

The need for shift care nursing fluctuates from one day to the next but shift care nurses have financial obligations that do not fluctuate. They need to take the work while there is work available so they can protect themselves financially. The on-call work of shift care nursing means that these nurses have none of the benefits of regular work: no paid sick leave and no vacation benefits. They may have to work even more to earn enough to take a vacation or have extra in case they become ill. Financial obligations related to shift care nursing are not the same for all of the nurses. Some of the shift care nurses have a second job that gives them some guaranteed income. Others have a partner who collects more predictable paychecks.

The time necessary to engage in the relationship that is part of *nurturing the dying* is valuable to the shift care nurses:

> I think its about ten days that we [need to] do very good work with families. If we're in and out in forty-eight hours - it's 'iffy'. And [in those cases] I don't think that we're so great that we've really made a difference. We've tended to tasks [but] I'm not so sure as to family dynamics how much we've actually psychologically helped people.

They express a depth of the experience that is achievable with *continuity* and is more likely to result in an outcome that is *congruous.*

Family dynamics

For convenience and clarity in this document, family is the term loosely used to include relatives, friends, and anyone the dying person identifies as important.

Shift care nurses become part of an experience that includes more than the dying person. The whole family takes the journey of dying:

> I don't differentiate between the one that's dying and the one that's not dying. I don't actually have a dying person, just someone who's a main client, who's living their dying. But also dying is a relationship with everyone around.

Considering the whole family increases the challenge for shift care nurses as they try to understand and support the different family members involved, as well as the web of relationships between family members and between family members with the dying person. Shift care nurses describe a couple of situations that may challenge their ability to give care and nurturing to the dying person and family.

One situation concerns the family's willingness to have the shift care nurse giving care in the home. The dying person and family have consented to having shift care nursing but may change their decision at any time. Shift care nurses recall families that refused shift care as the shift care nurse arrives for the shift, between shifts, or even during a shift. One nurse was even able to recall a situation where a family member asked her to leave. As she was walking down the street to her car, the family member ran after her and asked her to come back:

> In the home, it's wonderful. They can chuck you out ... And I think it's a right they have, and it's a right that I offer them. I tell them they can discharge me. They don't even have to go through the home care nurse. They can just tell me to go and I will pack my bags and go. And yes, I think some people need to know it's a definite option. And yes, I can put my hat and coat on and said, I'll go. And sometimes I'm half down the block and they'll call me back and say, "I was silly". You know? Some people like the spicy route.

Shift care nurses have also had experiences in which families are divided about whether or not they want shift care nursing. Sometimes the shift care nurses are able to continue their work but encounter hostility from the family member who does not want them there.

Another aspect of families has to do with their willingness to engage in some of the dimensions of *nurturing the dying*. If family members are not willing to *open* or *connect* with

shift care nurses, the shift care nurses must adjust their style of communication. Some of the nurses find the reverse; that it is a challenge for them to work with a family that is very *open* and *connects* very deeply. In either case, the shift care nurses are highly respectful of the family's preference for emotionally engaging with the nurse. They understand that this is the journey of the dying person and family, not the nurses'. With this constant focus, the shift care nurses meet the challenge to adjust their "natural" ways of being and communicating to meet the needs and way of being that the family is most comfortable with. As mentioned previously, some families and nurses are too dissimilar and unable to adapt their differences, affect the process of *nurturing the dying.*

While shift care nurses do face challenges with families at times, they acknowledge that these difficulties are part of their job, part of their experience:

> Clients and families are never a problem. They are never a difficulty. That's the whole reason why you are there. If it was all easy, you wouldn't be there. If someone is just dying peacefully and the family's coping so well ... I mean, they can be doing all the medication stuff themselves but the whole reason why you're there is to intercede for them. And if someone is having difficulty with it then that's not your difficulty, that's your job. That's what you need to do. That's why you're there.

Shift care nurses try very hard to deal with these difficulties without letting them interfere with the experience of *nurturing the dying*. They work through them on their own, or with colleagues, or with the home hospice consultation team.

Congruity and Dissonance

The concept *nurturing the dying* describes the experience of shift care nursing. It is a process that has three possible outcomes: 1) the person has died and shift care nursing stops; 2) the family can manage care on their own and shift care stops because the dying person and family no longer need it, or; 3) shift care nursing stops because the dying person or family no longer want it. Within these possible outcomes the experience may be described as *congruous* or *dissonant*.

The shift care nurses' aim in *nurturing the dying* is to make the experience as good as it can be for the dying person and family. When the shift care nurse hasn't done this, the experience is described as *dissonant*. *Dissonance* may also occur when the shift care nurse has done all she can and the family does not perceive that the experience has been as good as it can be. The *dissonance* in both cases is between the goal or expectations for the experience and the reality of what actually happened. If the expectations for the experience and the actual happenings match to create an experience that has been as good as it can be for the dying person and family, the experience is described as *congruous*:

> One of the most satisfying placements I ever had was [when] I worked with this family. Not a word was said about what was going on and what people felt and stuff. And just as I was leaving, after the wife died, the husband shook my hand and held my hand. I knew that was his way of saying, "Thank you. You did a good job". And I felt the congruence in communication. It's great when that happens.

Another shift care nurse had a case that left her with quite a strong feeling of *dissonance*:

> That man said he wouldn't have me back. He didn't think I cared enough about his wife. Not to my face, which is always a bit more galling ... So sometimes I can be very puzzled. That's one of the ones I've not resolved. I never will. It's good being able to phone the different nurses, the night nurses, next day nurse, home care nurses and talk it all out. No one had an explanation.

The concepts of *congruity* and *dissonance* can be visualized at either end of a continuum. The experience is not exclusively *congruous* or *dissonant.* The consequence is relative. For example, some experiences may have started out with much *dissonance* but become more *congruous* throughout the process:

> It's really, really rewarding to go in to a situation that is a mess and turn it around very quickly. Just because, I know what I'm doing...

Other experiences may have increased in *dissonance* throughout the process as, for example, new family members arrived and were not as willing to have shift care nursing:

> I was looking after a man in the West End who was all by himself. But he had a sister who ... liked to get up in the morning and start on her Vodka. She would come and by eleven o'clock in the morning was already totally soused. She was a total pain. [She was asking] constant question after question after question and always wanting to

> talk. If she wasn't asking questions to me or to [the client], she was talking about herself and all her problems or she was talking to [client] in a way that was totally inappropriate. I put up with it on the first day, because I just met her and I didn't know what it was going to be like. On the second I said, "I'm sorry [client's sister], but it's either me or you".

Shift care nurses learned from all types of experiences with congruous and dissonant outcomes. Dissonant experiences often caused them to explore "what went wrong" with their colleagues, other members of the health care team, family, and friends, through informal discussions and formal case reviews. Congruent experiences left the shift care nurses with a greater sense of satisfaction and success. They value all experiences as a contribution to their expertise in future cases.

In summary, the experience of nurturing the dying may be described by the shift care nurse along a continuum from congruity to dissonance based on the shift care nurse's perception of all involved: shift care nurse, client, and family. The congruity and dissonance refer to how closely the actual experience matches the aim of making the experience the best that it can be for the dying person and family.

Summary

The process of nurturing the dying characterizes the experience of shift care nursing. When *shift care nursing is initiated*, the shift care nurse enters the *home* of the dying person and family where he or she engages in this process. *Nurturing the dying* is comprised of four dimensions: *being present, opening, connecting,* and *witnessing.* Shift care nurses facilitate the process of *nurturing the dying* by *becoming what the dying person and family need, positioning, teamworking,* and *tending self.*

Characteristics of the shift care nurse, continuity, role expectations, and knowledge base of team members may affect the process. As well, *family dynamics* may complicate the process as the shift care nurse aims to include all of the family. *Congruity* and *dissonance* are the terms used to describe the outcome of shift care nursing.

Shift care nurses recognize the challenge of the work they have chosen. However, they feel honoured to *nurture the dying at home*. They are providing valuable care in a very meaningful setting as well as witnessing experiences that enrich their own experiences of living and dying:

> [Shift care nursing] is unique on every occasion. It's like living a moment of creativity. It's like living your soul very, very consciously ... on behalf of the patient and family. You're not living it for yourself. Me, I'm only here to survive. But [my soul] is a working tool on behalf of the patient and family. That's what makes it creative and soulful and spiritual and very satisfying. For me, to be working with a conscious soul all the time is immensely rewarding.

Chapter Five

DISCUSSION AND IMPLICATIONS

Introduction

When shift care nurses work with a dying person and family, they engage in a process that can be described as *nurturing the dying*. This study has explored the process of *nurturing the dying at home*. As each shift care nurse and researcher is unique, so are the results of this study - bringing some new ideas and perspectives to the body of palliative care research, as well as confirming some previous work.

Nurturing the dying and the dimensions that comprise it: *being present, opening, witnessing*, and *connecting* can be compared to some previous studies and palliative care essays. In addition, the concept that formed the initial research question, *tending self*, was found to be a strategy for *nurturing the dying* and has been well researched in palliative care. Quite a unique finding was the strategy of *positioning*. This strategy was very useful for shift care nurses who are *nurturing the dying* but has not been described elsewhere in the literature as such.

Immersion was an aspect of the home context of shift care nursing that the shift care nurses described, along with *intensity*, as differentiating shift care nursing from palliative care in other settings and for shorter visits (home care nurses). And finally, the outcomes of the process described in this study were *congruity* and *dissonance*. Palliative care outcomes have been the focus of several palliative care writings and research.

Nurturing the dying at home: The theoretical conceptualization

The grounded theory developed in this study is reminiscent of two other theories in palliative care nursing literature in recent years. Although *nurturing the dying at home* is not identical to either of these theories, there are a few similarities. One such work is the model: "The Supportive Role of the Nurse in Palliative Care", developed by Davies and O'Berle

(1990; O'Berle & Davies, 1992). In this model the components are preserving integrity, connecting, doing for, empowering , finding meaning, and valuing (O'Berle, & Davies, 1992).

It seems as though several of the concepts in this model coincide with the theory of shift care nursing. Preserving integrity relates to *tending self*, connecting obviously relates to *connecting,* empowering may indicate what the shift care nurses are doing when they are *opening*, and finding meaning and valuing may relate to the shift care nurses of the *home* context and holding the dying person and family's needs and wishes as paramount. While Davies and O'Berle's concept of doing for may relate to the shift care nurses strategy of *positioning*, their model does not reflect the movement between different positions as indicated by the shift care nurses.

Another theory of nursing in palliative care has been developed by Zerwekh (1995): "A Family Caregiving Model for Hospice Nursing". This model defined the process of palliative care nursing through the articulation of nurse competencies. As discussed in Chapter Two, the ten identified competencies were modeled into the form and functions of parts of a tree. Sustaining oneself was identified as the roots. This coincides with the shift care nurses' description of *tending self* and the notion that they must continue tending self to be able to do the work of shift care nursing. Zerwekh also uses connecting to describe the shift care nurses' *connecting* and encouraging choice which relates to the shift care nurses' dimension of *opening.* Collaborating would relate to the strategy of *teamworking* for the shift care nurses. Guiding letting go is a competency described by Zerwekh that may more closely relate to *positioning* than other concepts described in the literature as guiding implies using expertise. In *positioning*, the shift care nurses described knowing how and when to move into the different positions, using expertise. Zerwekh's model also notes the need to acknowledge the dynamics of the family in the competency, strengthening the family. The other two competencies cited by Zerwekh are comforting and caring spiritually. While neither were discussed explicitly by the shift care nurses, both may be implicit in the core phenomenon,

nurturing the dying. *Witnessing* is a concept in *nurturing the dying at home* that was not evident in Zerwekh (1995) or Davies and O'Berle's (1990) models. Another concept unique to this grounded theory is *becoming what the dying person and family need.* This concept may have emerged more strongly in this theory because of the *intensity* of and *immersion* into the *home* context. Nothing in the previous palliative care nursing literature comprehensively described the uniqueness of the shift care nursing experience. However, several of the concepts of *nurturing the dying at home* do relate to previous studies and writing on palliative care nursing.

Nurturing the dying

While describing the core phenomenon of shift care nursing was relatively easy to do, finding the appropriate word to reflect to reflect the concept presented a greater challenge. The shift care nurses were, as in many other aspects of the research process, very instrumental in finding the phrase that captured the phenomenon. It was a shift care nurse, in fact, who brought forward the idea of *nurturing* and suggested that label. *Nurturing* has not commonly been used in the palliative care literature. The phenomenon has, in some cases, been partially described elsewhere.

In general nursing theory, Watson's (1988) description of the "transpersonal caring relationship" contains aspects of *nurturing the dying*:

> A transpersonal caring relationship is ... a union with another person - high regard for the whole person and their being in the world... [Each] is able to detect the other person's condition of being (spirit, soul)... and responds to the condition... [through] an intersubjective flow between the nurse and patient. (p.63)

Watson's theory captures the holistic nature of shift care nursing and the respect and acceptance shift care nurses have for their client's "condition of being". The nurses' use of the word *nurturing*, however, is meant to convey the idea of having expertise to know when to intervene on the client's behalf as opposed to "letting things flow".

The shift care nurses related to one of their colleague's use of the metaphor of shift care nurse as boatman. Dying persons cross the river to death and the shift care nurse is the expert boatman accompanying them on their journey. Byock (1994), a palliative care physician, also employed the notion of navigation using the metaphor of water:

> Our task as clinicians is not to provide ultimate answers. Our task is to manifest ultimate commitment ... the unknowing can be the soul source of our clinical power. The ability to stand within and navigate within those cold, murky waters is what we can give to those persons whose suffering is not relieved by our protocols and our potions. (p. 10)

In agreement with Byock's description of navigating the unknown, shift care nurses felt they brought all of their expertise to each situation, used it to make the experience the "best that it could be" for the dying person and family. When there was nothing left "to do" or the shift care nurse had tried everything they could, the shift care nurse stayed with the client, being present for all of the situations, both known and unknown to him or her. The shift care nurses are proud of the expertise they have accumulated and pleased that it helps the dying person and family. They also value their own ability to accompany the dying person and family through aspects of the journey that are unknown to all. Hutchings (1998) refers to care of the dying as "the most intimate form of the self ... journeying with the most intimate form of the other" (p. 49). The journey that Hutchings refers to is similar to the nurses' boatman metaphor for *nurturing the dying*. It is a journey that is led by the needs and wishes of the dying person. The shift care nurse accompanies and offers expertise when it is invited or needed.

Dimensions of nurturing the dying

Nurturing the dying is comprised of four dimensions: *being present, opening, witnessing,* and *connecting*. *Being present* has been described elsewhere in palliative care and nursing literature (Benner, 1989; Maeve, 1998). These descriptions are consistent with the

shift care nurses' experience. The concept of *opening*, however, is not evident in other works. Byock's (1994) concept of generative imagination comes closest to what opening means to shift care nurses: Listen, watch, and wait for "any glimmer of possibility for relief and release" from suffering (p. 11). *Opening* is the label used to describe the aspect of *nurturing the dying* in which the shift care nurses offer possibilities and help to remove barriers that are making the dying person and family's experience more difficult. The shift care nurses described "giving space" for the dying person and family to move within this experience. It relates to the notion of control - showing the dying person and family more possible options and therefore more control and choice over how the experience "plays out". While control has been explored in the palliative care literature (Hutchings, 1997), it has not been connected to the action or process of *opening* as the shift care nurses have described it.

The shift care nurses' descriptions of *witnessing* reflected how they accompany the dying person. That is, knowing that the dying journey is not their journey but the client's journey, shift care nurses explore and explain their relationship to the dying person's journey. They describe not only what they contribute to the dying person but also what they receive from their experience with the dying person.

The literature confirms several aspects of *witnessing* as described by the shift care nurses. Part of *witnessing* is validating the dying person's experience. Validating has been described by Cooke (1992) as well as Gregory and English (1994) as something that nurses can still do when they cannot relieve the dying person's suffering. This concept seems to reflect the reality of palliative care nursing. The ideal is to alleviate all suffering; the reality is that some suffering is alleviated. The work of palliative care is to be with and accompany dying persons in their suffering.

The intimacy of *witnessing* is also reflected in the literature. Byock (1994) describes "receptive imagination" that entails looking at the world "from behind the eyes of the suffering patient" (p. 11). Gregory and English (1994) describe how palliative care nurses "come alongside and [are] allowed to see, to share, to touch, and to hear the brokenness,

vulnerability, and suffering of another" (p. 21). These descriptions coincide with the *witnessing* of the shift care nurses. They *witness* and they consider it an honour to do so.

Another aspect of the *witnessing* concept that has been confirmed elsewhere is its cyclical nature. *Witnessing*, as the shift care nurses describe it, involves bringing expertise to the individual's dying experience, *witnessing* his/her experience, which in turn contributes to the expertise you bring to the next experience. Maeve (1998) found that nurses "weave strands" of their practice with their everyday lives, personal and professional. The shift care nurses, however, also perceived that the dying person valued the knowledge that the shift care nurse is "taking away from this experience ... that someone watched them die and that someone is keeping this memory".

Connecting has been discussed in palliative care literature (Cooke, 1992; Hutchings, 1998; Liaschenko, 1994; Raudonis, 1995; Rittman, Paige, Rivera, Sutphin, & Godown, 1997) and in research focusing on the nurse-patient relationship (Morse, Anderson, & Bottorff, 1992; Raudonis, 1995). Several aspects of *connecting* for shift care nurses coincided with these previous writings. A very poignant description of the concept of *connecting* is given by Hutchings (1998) on "breathing the same air" (p. 49). Hutchings draws on descriptions of the *connection* between a conductor and his orchestra and finds meaning in this phrase for nurses who care for the dying. It connotes the deep *connection* that shift care nurses described with some of their clients. The shift care nurses also said that *connections* were at different levels with different clients. Rittman et al. put forward that palliative care nurses have different levels of *connecting* and intensity with their patients. These different levels help them manage the emotional demands in their practice. Shift care nurses claim that the level of *connection* is determined by the willingness of the dying person and family to *connect*. They did not identify benefits of having different levels of *connecting* and expressed acceptance for the dying person and family's level of engaging with them.

Liaschenko's (1994) results agreed with the findings in this study as the nurses in both studies did not speak of relationships but spoke of *connecting* with people. The shift care

nurses also stated that they very rarely keep contact with the family after the dying experience. Perhaps the brief, episodic nature of the *connection* between the family and the shift care nurse is why it is not referred to as a relationship. A very key aspect of the concept of *connecting* for the shift care nurses is "joining" the dying person and family. This respect for the dying person's "position" is reflected in Zerwekh's (1993) work on nursing hospice experts as nurses described "being where [the dying person] is at" and "I met here where she was at and didn't try to force my ideals on her" (p. 27).

Shift care nurses talked about clients in difficult "positions" as well as clients who were difficult to make a *connection* with. Shift care nurses used *connecting* strategies similar to Liaschenko's "making a bridge" as they looked for the point of *connection* with even the clients who were most disparate from them. The dimension of *connecting* was seen as critical. This importance is corroborated by Raudonis (1995) who claims that identifying and implementing palliative care interventions often depends on the nurse/patient rapport and relationship.

Positioning

While one may find reference in the palliative care literature to some aspects of *positioning* as described by the shift care nurses, the researcher was unable to find any discussions of the movement between the various *positions*. Hardiness (Hutchings, 1997) is a concept that relates to the concept of positioning. Bigbee (1985) summarizes hardiness as follows:

> When faced with a stressful event, the hardy person will attempt to change or modify that event (control) into a challenge consistent with his/her life purpose (commitment) which will result in learning and personal growth (challenge). (p. 53)

Understanding shift care nurses as having the personal characteristic of hardiness sheds light on the strategy of positioning. As shift care nurses are faced with the experience of caring for a dying person, the hardy shift care nurse engages in positioning to modify the event into a challenge. The challenge is consistent with his/her purpose (to make the experience the best

possible for the dying person and family) which results in learning and personal growth for the shift care nurse, the dying person, and the family.

Hardiness relates to positioning from the aspect of the shift care nurses' attitude to change. Hardy shift care nurses approach "change, rather than stability, as normal in life and frequently perceive change as incentive for growth rather than threats to growth" (Hutchings, 1997, p. 112). Hardiness explains the shift care nurses' ability to change readily with the changing needs of the dying person and family.

Work done by Rittman et al. (1997) describes nurses' being-towards-death as having a "situated understanding of self gained from being meaningfully engaged in caring" (p. 116). Perhaps it is the combination of the personal characteristic of hardiness with the perspective of the situated understanding that allows shift care nurses to engage in positioning in such a way that provides meaningful and appropriate care for dying persons and their families. In other words, first, the shift care nurse (who bears the characteristic of hardiness) is ready to change with the dying person and family. Second, through connecting and witnessing, the shift care nurse gains the situated understanding that gives him/her the knowledge of this unique situation. As a result, the shift care nurse is able to move smoothly with the dying person and family through the dying experience.

Tending Self

This research process began with a concern about how shift care nurses cared for themselves so they could continue to do their work. Tending self did arise as an important strategy in the process of nurturing the dying. Palliative care and other nursing literature includes extensive research and reports on the concepts of stress, burnout, coping, and self-protection (Adams et al., 1991; Alexander, 1990; Cooke, 1992; Duffy & Jackson, 1996; Froggatt, 1998; Hutchings, 1998; Killeen, 1993; Korda, 1987; Maeve, 1998; McNamara et al., 1995; Rasmussen et al, 1997; Rittman et al., 1997; Sourkes, 1987; Stiles, 1990; Vachon,

1986; Vachon, 1997). Several findings in these studies relate to the experiences of the shift care nurses.

Shift care nurses take deliberate action to tend the self. These activities can be divided into four categories: letting go, self awareness, social support, and indulging the self. Letting go was described by the shift care nurses as an action both during and after the dying experience. This is in agreement with the work of Rittman et al. (1997) who also described letting go as a strategy used by oncology nurses through whole process of dying, from admission to death. Shift care nurses engaged in letting go during the dying experience by letting go of the "energy" that they "take on" when working with some clients. They also let go of the experience when they are not working, doing things " that are very alive" in their time off, and "not having any leftovers at the end of the day". It is the notion of not letting emotions "build up" over time. After the person has died, shift care nurses describe "letting go of the losses" and not letting the losses "build up over time".

Letting go is a deliberate mental activity of closing experiences and not dwelling on them. Another thoughtful aspect of tending self relates to self awareness. The shift care nurses all discussed being aware of the effect the work has on them. Many described meditation as an effective component of tending the self. Others described their activity in this area as introspection - quiet time to "smooth out all the bumps". These strategies coincide with findings from Adams et al. (1991) and Sourkes (1987) who noted that self awareness and introspection were valuable and frequently used to alleviate sadness and assess one's own capacity for the ongoing losses associated with palliative care nursing.

While shift care nurses did receive social support from family and friends, some noted that they used these resources sparingly, preferring to access support from colleagues and other members of the health care team. All participants noted the high value of the shift care nursing team as well as the larger home hospice team. Support from colleagues is cited in previous research as a major coping strategy (Adams et al., 1991; Alexander, 1990; Vachon,

1997). Shift care nurses not only acknowledged its importance, but also highlighted the need for more mechanisms to connect with their team members.

Finally, shift care nurses talked about tending self through indulging their own needs and wants when they are not at work. This was evident in their descriptions of getting exercise, eating and resting well, meeting with friends, walking their dogs, square dancing, and making pottery. In a job where the needs of the client come first, shift care nurses know that when they are not working, they have to take time to put their needs first. One shift care nurse described that his friends understand when he indulges himself and doesn't return their calls, saying " so and so must have had a hard couple of days at work". Taking time out for self was also found to be a self-protective strategy by Stiles (1990) and a stress reducer by Duffy & Jackson (1996).

Both the shift care nurses and the palliative care literature highlighted the rewards of palliative care nursing (Cooke, 1992; Hutchings, 1998; Rittman et al., 1997; Stiles, 1990). My own experience in palliative care nursing, both in pediatric oncology and home care settings, is that the rich rewards of the work make the stressors easier to manage. In other words, the rewards make the difficult aspects of the work "worth it". Shift care nurses have to take deliberate action to tend the self but it is worthwhile to note that, because of the "gift" that the job is, tending self is not as difficult a task as one might think.

Immersion

Shift care nurses felt that one aspect of their work distinguished this nursing experience from other settings: immersion. In their shift care meetings, the nurses described becoming totally immersed in the dying person and family's intense dying experience. This concept has been touched upon elsewhere in palliative care literature. Byock (1994) describes surrendering and emptying oneself. Hutchings (1998) describes "entering the same sphere with a family" to concentrate, intuit, and "breathe the same air" (p. 49). Maeve (1998) uses the language of embodiment to describe nurses associating wholly with the experience of the

other. Shift care nurses, however, bring two aspects of themselves into the immersion experience. They bring their expertise to intervene when needed and they bring their person to draw boundaries to protect themselves. It is as if their immersion is not a total immersion - the shift care nurses are still people with present needs and past experiences as well as a future beyond and apart from this family. Yet, the shift care nurses do not only minimize this past, present, and future, they also perceive that they do it more with this work than with any other palliative care work they have ever done. Perhaps it is because the home context is comprised of the lives of the dying person and family that shift care nurses perceive immersion as more and intense than in other palliative care settings.

Outcomes

Outcomes for the shift care nursing experience are defined on a continuum that holds congruity at one extreme and dissonance at the other. Congruity and dissonance describe the degree to which the shift care nurse's expectations for the experience match with the reality of the situation. Palliative care outcomes have been explored broadly over the last ten to fifteen years (Adams et al., 1991; Bram & Katz, 1989; Byock, 1999; Cooke, 1992; Devery, Lennie, & Cooney, 1999; Donaldson, 1998; Eakes, 1990; Engle, 1998; Fakhoury, 1998; Gregory & English, 1994; Janssens, Zylicz, & Ten Have, 1999; Killeen, 1993; Korda, 1987; Martocchio, 1987; McNamara et al., 1995; Peruselli, Paci, Franceschi, Legori, & Mannucci, 1997; Rasmussen et al., 1997; Raudonis, 1993; Ruland & Moore, 1998; Vendlinski & Kolcaba, 1997). Palliative care outcomes are important because they guide development of standards of care (Byock), integrate current professional knowledge with desired health outcomes (Donaldson), and shift the focus from what a program does to what it is supposed to do (Devery et al.). There are several areas to discuss concerning this study and previous research. First, do palliative care outcomes measure endpoints or process as well? Also, what are appropriate measures for palliative care outcomes?

Shift care nurses continually evaluated how things were going. They evaluated throughout the experience and when it was over. Their assessment of how things were going often changed throughout the process and even after the experience was over, time changed their perspective as they integrated the experience with new ones. While not much attention is given to the issue of process over endpoint evaluation in the literature, McNamara et al. (1995) describe the outcome of "the good death" not as a fixed moment in time but as a process towards awareness, acceptance and preparation for death. Killeen (1993) suggests that focusing on the process instead of just the endpoint allows success throughout the experience. Cooke (1992) as well as Devery et al. (1999) state that outcomes are more than just endpoints - outcomes include the process that leads to the endpoint. These authors describe good outcomes even when, for example, the nurse is unable to relieve suffering but remains present with the dying person.

Traditional health intervention outcomes such as morbidity and mortality are insufficient for palliative care (Peruselli et al., 1997). Other suggested measurements for outcomes in palliative care are quality of life (Byock, 1999; Peruselli et al., 1997), quality of living-dying (Engle, 1998), a good death (McNamara et al., 1995; McNeil, 1998; Rasmussen et al., 1997), a peaceful death (Gregory & English, 1994), comfort (Eakes, 1990; Engle, 1998; Vendlinski & Kolcaba, 1997), or patient satisfaction (Devery et al., 1999; Fakhoury, 1998). Though these are all significant outcome indicators, the shift care nurses did not refer to most such outcomes. Rather, their experience more closely related to the literature that describes the outcome measurement of comparing ideals or expectations to reality (Bram & Katz, 1989; Devery et al., 1999; Donaldson, 1998; Fakhoury, 1998; Hershatter & Moritz, 1991; Korda, 1997; Martocchio, 1987; Rasmussen et al., 1997). It is the congruity or dissonance between expectations and reality that describe outcomes for shift care nursing experiences.

What is it, then, that shapes the shift care nurses' expectations for the experience with the dying person and family? Foremost, it is the dying person and family wishes that form the shift care nurses' expectations. The shift care nurses stated they followed what the family

wants. This is further enhanced by the shift care nurses' attitude of acceptance toward what the dying person and family want. They claim to enter each new case with "no expectations", "no judgments" and "no notion of how people *should* die".

As previously mentioned, shift care nursing is usually initiated during the last few days of the dying person's life. This may be a distinguishing aspect of shift care nursing, as it is not mentioned as a factor elsewhere in palliative care nursing literature. The short time that shift care nurses have with some families may affect the expectations of the shift care nurses. Some shift care nurses describe "turning a mess around *quickly*" and "making a big difference in a *short time*", inferring that time is a factor in achieving their expected outcomes with a family.

Therefore, guided by the dying person and family's goals, shift care nurses form expectations for the experience. The expectations are not just for the endpoint but more accurately, they describe the "colour" or "flavour" of the experience during and after the experience. Some perceive that one of the difficulties in palliative care is the fact that it is an idealistic movement (Korda, 1987). As some of the shift care nurses discussed, suffering is not always relieved and a peaceful death is not always attainable. Shift care nurses, however, seem to have overcome the discrepancies between the ideal palliative care philosophy and the reality of some dying experiences. While they acknowledge the difficulty they have witnessing suffering, they realize that, in some situations, it cannot be alleviated. In those cases, the shift care nurses describe "just being there for it. Not being afraid of it. Not wanting it to not be what it is". There is a deep respect for the dying person's journey. The shift care nurses' expectations are rooted in that unique journey and are therefore unique to each case.

Some shift care nurses did discuss "softening difficulties", "making it easier", and "giving peace". What is not clear from the data is how or if shift care nurses use any philosophy or vision in combination with the dying person and family's goals to form their expectations. For example, Ruland and Moore (1998) propose a theory for a peaceful end of

life. One shift care nurse expressed the need for a common philosophy among the shift care nurses. It is unknown whether the shift care nurses use their own individual palliative care philosophies or ideals to currently form their expectations.

Implications for Practice and Research

Some shift care nurses articulated the need for the development of a common philosophy. A common working philosophy has the potential to guide the development of standards, core competencies, and criteria for use in case reviews. It may also aid professional development (Hart et al., 1998). This shared value system would be related to what the shift care nurses consider important as it relates to their collective goals and feelings of efficacy (McNamara et al., 1995). Shift care nurses develop this philosophy informally as they share stories of their experiences at shift care meetings and over the phone but some are calling for a more formal process to develop it further.

All shift care nurses identified the need for more frequent meetings with each other. Consistent with previous palliative care research (Vachon, 1997; Dean, 1998), colleagues were sources of both stress and support for shift care nurses. The stress was attributed to different philosophies and opinions about client care. More frequent shift care nursing meetings may allow for discussion to find common understanding, thereby reducing this source of stress and increasing feelings of collegial support. The findings of this study clearly suggest that more frequent shift care meetings are needed.

Palliative care may be negatively affected by lack of continuity of care providers (Hutchings, 1998; Jarrett, Payne, & Wiles, 1999; Raudonis, 1995). Shift care nurses all had concerns with the continuity that they were able to provide to clients under the constraints of their current staff booking system. There is little room for change as the nurses' union has control over this booking system and the only way that the system could operate differently is to give the nurses regular working status instead of their current casual on-call status. This seems an unlikely possibility due to the uncertainty regarding availability of work. Immediate

and senior management are aware of these difficulties for the shift care nurses and have met several times to discuss the issue but no changes have yet been made.

The booking system is also the cause of much discontent among the shift care nurses regarding waiting for shifts and having shifts canceled at the last minute. Several shift care nurses have left the program since the beginning of this research project and others have stated that the booking system may eventually force them to leave for more stable work hours. At this time, there are often insufficient shift care nurses to meet the demands. It may be necessary to adjust how shift care nurses are booked in order to retain these nurses and provide the best continuity to shift care clients. A good booking system may help to reduce stress for shift care nurses and support them in their work.

Shift care nursing is an area of palliative care that has not been researched widely. The nurses in this study indicate that their work in the home setting and for the duration of twelve-hour shifts is markedly different from their experiences with palliative care in other settings. This preliminary examination of the experience of shift care nursing highlights many aspects that would benefit from further inquiry. Different perspectives, such as those of the family or other hospice team members working with shift care nurses, would enrich this beginning conceptualization of shift care nursing.

Nurse-client relationships have been researched in the past. The concepts of therapeutic and non-therapeutic nurse-client relationships have been explored (Forchuk, Jewell, Schofield, Sircelj, & Valledor, 1998). Further inquiry is indicated to determine how these findings relate to shift care nursing. Are shift care nurses able to form therapeutic relationships with their clients in such a brief period of time? Although the time is brief, it is intense. What effect does this have on the nurse-client relationship? What strategies do shift care nurses use to manage non-therapeutic nurse-client relationships?

Shift care nursing provides an alternative to many people in this geographic region to care for their dying loved ones at home. With this level of home hospice support, what are the effects on informal caregivers during and after their loved one's death? Research done by

McCorkle, Robinson, Nuamah, Lev, & Benoliel (1998) indicates that bereaved families who have had hospice nursing in their home experience less psychological distress. Further research is needed to articulate the emotional, physical, and financial cost of care at home with home hospice and shift care nursing. This information may help to secure resources for the home setting to support care of the dying at home.

Conclusion

The study was initiated in an attempt to explore shift care nurses' experience of caring for themselves so that they can continue their work. Through individual interviews and group discussions with the shift care nurses a theoretical conceptualization emerged. *Nurturing the dying at home* is the process that describes the experience of shift care nursing.

N*urturing the dying* occurs in the *home* and is comprised of *opening, witnessing, connecting* and *being present* with the dying person and family. This process may be facilitated by *positioning, becoming what the dying person and family need, teamworking,* and *tending the self. Characteristics of the shift care nurse, continuity, role expectations* and *the knowledge base of other team members,* as well as *family dynamics* may limit *nurturing the dying.* The consequences of *nurturing the dying* vary along a continuum of *congruity* to *dissonance* between the shift care nurses' expectations for the experience and the actual happenings.

While components of *nurturing the dying at home* have been described elsewhere in palliative care literature, the theory as a whole is distinct, reflecting the uniqueness of the shift care nursing experience. Several opportunities for further research arise from this study, including inquiry into the experience of receiving shift care nursing as a dying person or family member. The theory may be useful to shift care nurses as they discuss their practice with colleagues and other members of the home hospice team.

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Appendix A

PARTICIPANT CONSENT FORM FOR INTERVIEWS
The Experience of Shift Care Nursing

Principle Investigator:
Betty Davies, School of Nursing, UBC

Graduate Student:
Carolyn Knill, School of Nursing, UBC

The purpose of this study is to explore the experiences of shift care nurses, what the rewards and difficulties of their work are, and how shift care nurses care for themselves so that they can continue to care for others. I understand that while I may not receive any immediate benefit by participating, the study is being done to improve the understanding and support of the work of shift care nurses with the ultimate goal of providing the best home palliative care. This study is part of a Master's Thesis project by a student from the University of British Columbia.

I agree to take part in a tape-recorded interview that will last about 60 to 90 minutes. I understand that this interview will happen at a convenient time and place that is mutually agreed upon.

I understand that the notes, the tape, and the typed pages of the interview will have all information that can identify me removed and that my name will not be used in the research reports. I also give permission for the information obtained to be used for research that involves secondary analysis of the interviews, with the understanding that any additional research projects that use the interviews will be approved by the appropriate university committees.

I understand that I am free to refuse to participate in this study, to refuse to answer any questions, to end an interview at any time, and to withdraw from the study at any time, without any effect on me. I also understand that the purpose of the study is in no way evaluative of me or my work. I have had the opportunity to ask questions and these questions have been answered to my satisfaction. I have received a copy of this form to keep.

This is to certify that I,_____, agree to participate as a volunteer in this project.

_____	_____
Participant	Witness
_____	_____
Date	Date