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The Experience of Oncology Nurses who Provide Bereavement Support

By Vicki Meyouhas

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Abstract

Background:

Oncology nurses are present in varying degrees in the lives of cancer patients and their families as they journey through the cancer trajectory. When the patient dies, it is common practice for the therapeutic relationship between the nurse and the family to end, leaving the bereaved individual without this relationship during the difficult bereavement period. Although bereavement has been acknowledged as a period of increased morbidity and overuse of health care system resources, nurse-led bereavement support programs are not commonplace in tertiary care settings. Currently, very little is known of the experience of oncology nurses who provide bereavement support, and scant research exists regarding the needs of nurses who take on bereavement support in addition to their main nursing role. This lack of knowledge and understanding of the role and experience of oncology nurses who provide bereavement support can impact on services provided to bereaved individuals.

Objectives:

The objectives of this study were:

- 1) To explore how oncology nurses perceive the benefits of providing bereavement support;
- 2) To explore how oncology nurses perceive the challenges of providing bereavement support;
- 3) To understand the support oncology nurses require to carry out the role of bereavement support providers.

Methods:

A qualitative approach was selected for this study as little is currently known on this topic. In this study, Interpretive Description methodology by Thorne (2008) was used to guide data collection and analysis. This method has been defined as “a qualitative inquiry into human health and illness experiences for the purpose of developing nursing knowledge”. Interpretive Description yields clinically useful knowledge that can change and enhance practice.

The study was conducted in a large teaching hospital in Montreal. Nine oncology nurses working in different oncology roles, and from in-patient and outpatient settings, were purposefully selected to participate in this study. The nurses’ experience in oncology varied from three years to over 30 years.

Results:

Oncology nurses’ experiences of the provision of bereavement support ranged from negative to positive and were influenced by factors such as; the use of primary nursing, unit culture, workload concerns, and perceived lack of knowledge and skills. The experience of these oncology nurses is reflected by the three main themes of this study “*Living the benefits of completing the circle of care*”, “*A professionally challenging opportunity*” and “*Navigating the unknown*”.

Conclusion:

This study provides new knowledge and understanding regarding the experience and role of oncology nurses who provide bereavement support. Findings of this study

revealed that nurses recognize the provision of bereavement support as an essential aspect of oncology nursing that allows for closure and for ensuring that the bereaved are coping well. Specific educational and administrative strategies and recommendations for nursing practice, research and education are suggested to enhance oncology nurses' ability to provide an optimal service to bereaved individuals.

Key terms:

Grief, bereavement support, primary nursing, oncology nursing.

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The cancer patients and families that I've met throughout my career as an oncology nurse inspired this research topic. I am indebted to all the patients and families I've encountered who made me a part of their difficult journeys, especially those who shined some light on the importance of bereavement support. It is those specific cases that inspired me to study the experience of oncology nurses in hopes of improving bereavement care.

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Chapter 1- Introduction

Oncology nurses are present in varying degrees in the lives of cancer patients and their families as they journey through the cancer trajectory. When the patient dies, it is common practice for the therapeutic relationship between the nurse and the family to end, thus leaving the bereaved individual without this relationship during the difficult bereavement period (Holtslander, 2006). Occasionally oncology nurses in various settings take on the role of bereavement support providers; however nurse-led bereavement support programs are not commonplace in tertiary care settings. Currently, very little is known of the experience of oncology nurses who provide bereavement support, and scant research exists regarding the needs of nurses who take on bereavement support in addition to their main nursing role.

1.1 Background

The incidence of cancer is expected to increase steadily over the coming years (Canadian Cancer Society, 2007). Health care professionals working with cancer patients are highly skilled and knowledgeable; offering expert care, attentive emotional support, and comprehensive education to patients and their families throughout the trajectory of the illness—from diagnosis to palliative and end-of-life care (Boyle, 2000). Yet, as the second leading cause of mortality in Canada (Canadian Cancer Society, 2007), cancer leaves behind a large number of bereaved families that may require additional support in coping with this loss. Occasionally, this support is provided by the same oncology nurses

who actively cared for the patient, and his or her family, throughout the course of the illness (Burke & Gerraughty, 1994).

1.2 Grief, Loss and Bereavement

Grief, loss, and bereavement are universal experiences that accompany the death of a loved one, and can trigger a wide variety of reactions and feelings—such as anger, despair, sadness and guilt (Ferrel & Coyle, 2001). Other effects of bereavement may include a decline in health status, the occurrence of depression, and an increased prevalence of substance abuse (Prigerson & Jacobs, 2001; Schaefer, Queensberry, & Wi, 1995), all of which can contribute to an over-reliance on the health care system (McHorney & Mor, 1988; Parkes, 1970, 1972; Parkes & Brown, 1972; Schultz, et al., 2001; Stroebe, Schut, & Stroebe, 2007). The range and extent of all the possible effects of bereavement indicate that bereaved individuals have specific needs and may require additional support during this significant time in their lives.

Many organizations, including Health Canada and the World Health Organization (WHO) believe that palliative and end-of-life care should also include bereavement care (Health Canada website, 2010; WHO website, 2010). They recognize the value of bereavement support programs that are providing continuity of care, screening of family members for high-risk situations, and for supporting individuals during their grief (Davies, et al., 2007; deJong-Berg & Kane, 2006; Stein, Peles-Borz, Buchval, Klein, & Yaniv, 2006). Consequently, for several years now, bereavement support programs have become more common within health care institutions and the community (Burke & Gerraughty, 1994; Jackson, 1996; Marquis, 1996).

1.3 Types of Bereavement Support

Bereavement support programs are multifaceted. They consist of a wide range of services offered in several types of institutions, and can be delivered by many different professionals (Burke & Gerraughty, 1994; Kojlack, Keenan, Giles-Fysh, & Sibbald, 1998; Marquis, 1996). Services can be as simple as a bereavement card, a personalized letter, a face-to-face meeting, a telephone call, or even attendance to a memorial service; but they can also be as complex as intensive therapy. Although bereavement support programs were mostly seen in hospice settings and were considered to be part of the overall care provided by these institutions (Marquis, 1996), they are increasingly emerging in tertiary care settings, including intensive care units and oncology departments (Burke & Gerraughty, 1994; Jackson, 1992). Despite financial and human resource constraints, neonatal and adult intensive care units, hospices as well as adult and pediatric oncology units have recognized the needs of bereaved family members. They gradually initiated and supported the development of nurse, or inter-professional team-led, bereavement support programs (Burke & Gerraughty, 1994; deJong-Berg & deVlaming, 2005; Jackson, 1992; Jansen, 2003; Maguire & Skoolicas, 1988; Marquis, 1996; Stein, et al., 2006).

1.4 Sources of Bereavement Support

Historically, bereavement counselors, members of clergy, and social workers provided bereavement support (Worden, 2002). However, some institutions are now recognizing the merit of using oncology nurses as providers of bereavement support to

deceased patients' family members (Burke & Gerraughty, 1994; Payne, 2004; Prigerson & Jacobs, 2001).

Oncology nurses in particular differ from other nurses and providers of bereavement support in that they usually have long-established relationships with, and extensive knowledge of, the deceased and their bereaved (Boyle, 2000). They have an understanding of the events that occurred throughout the disease trajectory and can respond to questions related to the patient's illness. Owing to the long-term nature of oncology care, these nurses often become emotionally involved with the patients and families they care for, which can contribute to their having a different experience from other providers of bereavement care.

1.5 Problem Statement

Although current literature and practice reflect that nurses, in a multitude of settings, are taking on the role of bereavement support providers, very little is actually known about the experience of these nurses (Burke & Gerraughty, 1994; Jackson, 1996; Kaunonen, Aalto, Tarkka, & Paunonen, 2000). The very few studies that were conducted examined nurses' perceptions of how their intervention was perceived by family members and focused on how nurses provided bereavement support. Results revealed that nurses felt bereaved family members appreciated the bereavement follow-up and that the practice of bereavement follow-up was not uniform. Indeed, they showed that nurses used several strategies or interventions that varied widely among settings and areas of practice (Burke & Gerraughty, 1994; Kaunonen et al., 2000).

Although knowledge of the patient, the family, and the specifics of the disease can be considered as facilitating factors for the oncology nurse who provides bereavement support, much remains unknown regarding this experience from the nurse's perspective. For instance, what challenges are associated with this role for oncology nurses, and how does contact with the bereaved affect nurses? Do nurses experience role strain while undertaking bereavement support? Do they consider themselves adequately prepared?

In order for oncology nurses to provide effective bereavement support to family members on an ongoing basis, it is important to gain an understanding of how nurses experience this aspect of their nursing role and what support they require to facilitate this role. Through a better understanding of oncology nurses' experiences in providing bereavement support—as well as a better understanding of the challenges and benefits they encounter during the operationalization of their role as bereavement support providers—specific interventions can be developed to provide nurses with the appropriate education, resources, and support they need, and to ultimately improve the supportive care they provide to bereaved family members.

1.6 Purpose of the Study

The purpose of this study is to better understand the experiences of oncology nurses who provide bereavement support. The specific objectives are: to explore how oncology nurses perceive the benefits of providing bereavement support, to explore how oncology nurses perceive the challenges of providing bereavement support, and to

identify the support oncology nurses require to carry out the role of bereavement support providers.

Chapter 2 - Literature Review

This chapter presents a literature review of the important concepts discussed in this thesis. It is divided into sections to reflect the context of oncology nursing and bereavement support. The review was conducted in the winter of 2008 and will begin with an overview of grief, complicated grief, and bereavement. Following sections will explore bereavement support, nurse-led bereavement support programs, and studies on the experience of nurses with bereavement support programs. Aspects of oncology nursing, such as primary nursing, will also be examined as they pertain to the experience and provision of bereavement support.

A review of the literature was conducted using the search engines Pubmed, Medline, and CINAHL. Keywords included “bereavement support”, “nursing”, “primary nursing” “oncology nursing”, “grief”, and “nurse-led programs”. No restrictions were placed on the publication dates. Articles on the role of the oncology nurse, the nursing scope of practice, and professional challenges were also reviewed as they are relevant to the context of the study.

2.1 Grief and Bereavement

Grief and bereavement are experiences that everyone eventually encounters. Although these terms are often used interchangeably, they are distinct and describe different phenomena. Grief is a highly personal, subjective, and individual set of responses that a person develops in response to a real, perceived, or anticipated loss (Despelder & Strickland, 1987). Grief is intense and painful. It is an inescapable

phenomenon that affects people of all socioeconomic status and cultures. It is a process of psychological, social, and somatic reactions to the perception of loss (Rando, 1984). There are several different types of grief; the process often begins with anticipatory grief whose onset is intensified with the delivery of a grim prognosis. After the actual loss, grief reactions can be described as complicated, or uncomplicated (Ferrell & Coyle, 2001).

Uncomplicated grief is experienced by most grieving individuals, and is manifested by symptoms of emotional lows that are followed by an adjustment to the loss and an eventual return to normal life (Worthington, 1994). In contrast, complicated grief, which occurs in a small subset of the population, is characterized by “intensive intrusive thoughts, pangs of severe emotion, distressing yearnings, feeling excessively alone and empty, excessively avoiding tasks reminiscent of the deceased, unusual sleep disturbances, and maladaptive levels of loss of interest in personal activities.” (p.904) (Horowitz, et al., 1997). In complicated grief, symptoms last longer than a year (Prigerson, et al., 1996). Some factors that may be predictive of complicated grief among bereaved individuals can include ambivalent or dependent relationship, multiple prior bereavements, previous mental illness (mainly depression), physical health problems, consumption of alcohol and drugs, perceived low levels of social support, and the professional’s intuition that the bereaved will have difficulties coping with the loss (Billings, 1999; Sheldon, 1998).

Bereavement is defined as the state of having experienced the death of a significant other (Warren, 1997). This can be greatly influenced by religion, culture, the nature of the relationship with the deceased, the age of the deceased, as well as the

manner in which the death occurred (Ferrell & Coyle, 2001). Bereavement is very closely related to concepts of loss, grief, and mourning. The process of bereavement encompasses physiological, somatic, affective, cognitive, social, and behavioral factors that are affected by loss. The goal for a bereaved individual is to transform his attachment to the deceased and establish new forms of relationships to the memory of that person. Bereavement involves adjusting to, and relearning, a world that does not include the deceased in a physical, social, or psychological manner (Ferrell & Coyle, 2001).

2.2 Bereavement Support

According to Worden (2002), bereavement support involves providing support to family members after the death of their loved one. Many authorities, including the World Health Organization, Health Canada, and the Canadian Hospice and Palliative Care Association, consider this care for bereaved individuals to be an important final step in the process of end-of-life care. The provision of bereavement support considers important factors such as identifying families who are at greater risk for complicated grief; it also allows organizations, such as hospitals, to fulfill the bereaved individuals' otherwise unmet needs for information and support to cope with their loss (Ferrell & Coyle, 2001).

Bereavement support interventions vary significantly based on the setting and the provider of this service. For instance, interventions can include a phone call, a bereavement card, a personalized letter to the bereaved, attendance of a funeral, a face-to-face meeting, as well as group and/or individual therapy (Burke & Gerraughty, 1994; Davies, et al., 2007; deJong-Berg & deVlaming, 2005; Jackson, 1996; Lewis, 1999; Marquis, 1996). The type of intervention and the extent of the involvement of the professional providing bereavement support depend greatly on who is providing this

service and what their mandate is. For example, many of the studies describing nursing-led bereavement support programs explained that the provision of bereavement support was an informal process that nurses engaged in as a courtesy to families (Burke & Gerraughty, 1994; Jackson 1992).

2.3 Nursing-led Bereavement Support

Historically, bereavement support has been offered by experienced professionals trained to meet the special needs of bereaved individuals, such as bereavement counselors, psychologists, social workers, clergy, and other religious figures (Worden 2002). Usually, these non-nursing professionals encounter the bereaved individual after the loved one has passed away, and as such, have no pre-established relationship or rapport with the bereaved. Although nurses receive training in the use of communication techniques, learning how to provide bereavement support is not part of their basic nursing education; thus most nurses undertake this role without specific training (Boyle, 2000; Burke & Gerraughty, 1994).

In fact, one of the most striking differences between oncology nurses and traditional providers of bereavement support lies in the pre-existing relationship developed with the bereaved. Oncology nurses typically know the families for extended periods of time and as a result, have more information about the support mechanisms, social networks, and coping skills needed to relate with the family in question (Mok & Pui Chi, 2004). In a study of hospice nurses and bereaved individuals, Marquis (1996) found that bereaved family members appreciated hearing from a nurse with whom they were close. In contrast, the bereaved family members identified that not knowing the follow-up bereavement nurse was a barrier to the bereavement support intervention.

Kaunonen and colleagues (2000) studied bereaved individuals who received a follow-up phone call for an oncology nurses, and also reported this barrier.

2.4 Bereavement Support within the Context of Primary Nursing in Oncology

Many oncology departments choose to function under a primary nursing model. Primary nursing is a philosophy and model of care that emerged in the 1960s which provides a framework for the development of a one-to-one, patient-centered nurse-patient relationship that promotes continuity of care for the course of the patient's disease whenever possible (Tiedeman & Lookinland, 2004).

In primary nursing, decision-making is decentralized and takes place at the bedside. During the patient's stay, the primary nurse has the authority to assess, plan, implement, and evaluate the plan of care (Tiedeman & Lookinland, 2004). This allows for continuity of care and the development of a close and therapeutic relationship between the nurse and the patient/family unit (McFarlane & Bennett, 2006; Olstrom & Albanese, 2006). The role of the oncology primary nurse also involves education sessions with the patient/family unit, the provision of emotional support, and knowledge of specific details regarding each patient's disease and treatment. Therefore, oncology primary nurses have the opportunity to gain a more comprehensive understanding of the patient and family during the illness.

Oncology nursing practiced within a primary care nursing model differs from other fields of nursing in several ways; the most important difference is in the length and nature of the relationship that is developed and maintained between the patient, family, and the nurse (Manthey, 2002; Manthey & Lewis-Hunstiger, 2006). Owing to the progress made in cancer treatments, patients may now live with their disease for months to years, thus

prolonging their contact with the oncology nurse. The extended relationship that nurses develop with their patients and families allows them to greatly impact the manner in which cancer is experienced. This is a well-documented source of professional and personal satisfaction for oncology nurses (Boyle, 2000; Mok & Pui Chi, 2004; Rittman, Paige, Rivera, Sutphin & Godow, 1997).

2.5 Oncology Nurses: Ideally Situated for Bereavement Support

Oncology nurses in a primary care environment are well-positioned to provide bereavement support for three reasons. First, owing to their extensive and prolonged exposure to patients and families in a primary care nursing environment, nurses are in an excellent position to evaluate families' coping mechanisms and to identify families that may be at risk for complicated bereavement, even before the patient's death (Cooley, 1992). This becomes important because individuals with altered coping mechanisms and poor social support networks are at risk for prolonged and complicated bereavement and may require additional sources of support during bereavement (Stroebe, et al., 2007).

Second, many authors emphasize the need for the bereaved to revisit the events surrounding the death, as well as to obtain information about the patient's disease course (Jackson, 1996; Kaunonen, et al., 2000; Rawlings & Glynn, 2002). In fact, several bereavement support programs allow families to discuss the patient's case with physicians and nurses, as well as encourage them to visit the unit if they feel the need to do so (Williams, et al., 2003; Jackson, 1996; Stein, et al., 2006). Nurses are ideal for this role as they are very familiar with the course of the patient's illness and are able to answer many of the questions families may have.

Third, the previously established rapport between nurse and family is a key asset in the procurement of bereavement support as it facilitates the discussion between the nurse and the survivor (Cooley, 1992; Glass, 1993; Jackson, 1992, 1996; Kaunonen, et al., 2000; Ruden, 1996; Skillbeck & Payne, 2003). Both nurses and family members have emphasized the importance of ‘knowing’ the other person when engaging in bereavement follow-up. Nurses expressed a sense of uneasiness when they had to contact a bereaved individual whom they did not recall extensively. Family members reported similar experiences and expressed disappointment when the nurse doing the follow-up was one that they did not know well (Jackson, 1996; Kaunonen, et al., 2000; Marquis, 1996).

2.6 Bereavement Support; the Health Care Professional’s Perspective

In a study conducted by the Canadian Association of Critical Care Nurses, an understanding of bereavement support was sought from the perspective of health care professionals and family members (Kojlak, Keenan, Giles-Fysh, & Sibbald, 1998). The self-administered questionnaire and semi-structured interviews administered to 117 health care professionals inquired about their self-perceived role in providing bereavement support, and the amount of experience and preparation they believed they required for this role. The questionnaire covered topics such as the providers’ comfort levels regarding death and their interactions with the bereaved after death. Overall, the results indicated that professionals had varying degrees of comfort while caring for the dying and subsequently interacting with their families. This study did not specifically address the experience of intensive care nurses in providing bereavement support; rather it expanded on the difficulties encountered in an environment where death is a regular

occurrence. Similar findings were reported in studies by Burke & Gerraughty (1994), Marquis (1996) and Lewis (1999).

In the study conducted by Kojlak and colleagues, surveys and interviews revealed that despite interacting with peers and reflecting on the events during personal time, health care workers were generally dissatisfied with their organization's available support. It was unclear whether the required support was related to their role as bereavement support providers or to the difficult nature of their job, excluding the bereavement support component. The study, although not exclusive to nursing, demonstrated that the interdisciplinary team would be willing to support the development of a more official bereavement support structure within the organization. However, it remained unclear whether the bereavement support they sought was for the families or for themselves.

Several of the studies on bereavement support in the nursing literature were conducted from the perspective of the bereaved and often in a pediatric program context (Davies, et al., 2007; deJong-Berg & deVlaming, 2005; deJong-Berg & Kane, 2006). These studies did make specific references to the nurses' experiences and indicated that nurses were initially fearful and reluctant to provide this type of support, but that their confidence in dealing with bereaved individuals grew with experience and exposure. Nurses reported feeling rewarded as they recognized this interaction as an extension of their care and felt it was an overall positive experience (Jackson, 1992, 1996; Ruden, 1996).

2.7 Nurses' Experiences Providing Bereavement Support

Studies by Kaunonen and colleagues (2000), Marquis (1996) and Burke and Gerraughty (1994) give insight into the process nurses undertake to provide bereavement support, how this support is perceived by bereaved individuals, as well as some of the reasons nurses abstain from providing this service. For example, bereavement support interventions in these studies ranged from sending a generic card or personalized letter to the bereaved, to telephone follow-up, face-to-face meetings and semi-annual memorial services. However, there has been limited research related to bereavement support that focuses on the training and support required to best operationalize this role. Most striking is the lack of description of nurses' emotional reactions to the provision of bereavement support. It appears that nurses have a tendency to describe the process and not the details regarding their experiences. The following section reviews the few studies conducted with nurses who provide bereavement support.

The studies exploring nurses and bereavement support often reported issues relating to the work environment and workload. Several studies described an environment where the nurse must make special time for the intervention during the day (Jackson, 1992; Kaunonen, et al., 2000), while others reported that their current practice settings would not allow such interventions to take place (Burke & Gerraughty, 1994; Jackson, 1996). One of the main difficulties identified in studies on nurses and bereavement support was that nurses generally felt unprepared to provide bereavement support to family members as little time is allotted to this during their basic training (Boyle, 2000; Field, et al., 2007; Field & Kitson, 1988; Lloyd- Richards & Rees, 1996).

Using a phenomenological approach, Marquis (1996) explored the experience of Australian providers (hospice nurses and hospice volunteers) and recipients of bereavement support. The author conducted a total of 50 in-depth interviews with hospice nurses, volunteers, and bereaved individuals. Only the results of the hospice nurses' experiences are presented. The sample was comprised of ten nurses, from eight different sites, with a minimum of two years of service. They were randomly selected for face-to-face interviews. Interviews were transcribed verbatim and analyzed using the analysis framework developed by Colaizzi (1978). The author presented three themes: 1) Concluding care - Bridging life and death in partnership, 2) Resolving loss - Letting go and reinvesting, and 3) Developing confidence - Belief in knowledge and skills. The first theme expanded on the importance of concluding the relationship with the bereaved and how this relates to the nurses' job satisfaction and their belief that their services are valued. Nurses indicated that knowing the family for long periods of time facilitated the bereavement support intervention. Some nurses indicated that bereavement support was viewed as a part of their job and when not completed, they felt as if only part of their job was accomplished. The second theme pertained to the nurses' personal feelings of loss. Peer support was identified as an important factor in helping to cope with death and bereavement issues. The provision of bereavement support allowed nurses to conclude the relationship with the bereaved and reinvest themselves in relationships with their current patients and families. The third theme focused on developing confidence in the provision of bereavement support. Nurses identified that they required theoretical knowledge as well as experiential learning to better fill this role. Nurses described how experience and intuition allowed them to develop the skills required to evaluate the

bereaved's progress. Although this study explored nurses' experiences in providing bereavement support to individuals with whom they had an established professional relationship, it was not conducted in a Canadian setting and did not specifically target oncology nurses who, compared to hospice nurses, usually have lengthier relationships with the patients and their families.

Kaunonen and colleagues (2000) studied the perspective of oncology nurses after a bereavement phone call. Nurses on an in-patient oncology unit, who practiced within a primary nursing model, made a supportive telephone call to a family member four weeks after the death of a loved one. The goal of the intervention was to help the bereaved participants learn about grief reactions and become familiarized with available community resources. Another goal was to allow the survivor to ask questions regarding the patient's illness and death, as well as to revisit the events that occurred in the last days of life.

Data was collected over 18 months from 26 Registered Nurses and Registered Practical Nurses. Each nurse received a diary and was instructed to write her feelings regarding the call. Despite these instructions, nurses had a tendency to focus on the content of the telephone call and only briefly described their emotions. Although some nurses reported "feelings of inadequacy" and had a "difficult time concentrating", these barriers were not fully explored. The method of journaling employed in this study did not allow for exploration of the nurses' experience. In depth, individual interviews would have better captured the nurses' full experience.

The authors used the findings of this study to guide the practice of nurses who provide care to terminally ill patients and their families, as some of the feedback provided

by bereaved individuals related to the importance of quality end-of-life care and continued emotional support. The authors did not provide recommendations to improve the provision of bereavement or the support of nurses in this role. Although it was implied that the findings of this study were applied by the organization to improve care provided to families and patients during the anticipatory grief and end-of-life period, there was no mention of how information from this study would affect the provision of bereavement support on the unit, as it was not specified whether interventions were developed based on the results of the study. In fact, the authors did not discuss whether the nurse-led bereavement support program would continue, and if so, whether changes would be made based on the nurses' perceptions of their role.

2.8 Summary

Nurses who provide bereavement follow-ups to family members step outside the normal range of service to support the individuals who were under their care for a prolonged period of time. Understanding how nurses perceive their role as providers of bereavement support is important, as the nurse's role varies from that of a psychotherapist, social worker, and other trained bereavement counselors. While research has been conducted on the experiences of these professionals, it cannot be assumed that the findings can be extrapolated to the nursing profession. In addition, the few studies conducted on nurses' experiences with bereavement support provision focused on exploring the bereaved individual's perception of the nurse-led intervention. As nurse-led bereavement support programs are becoming increasingly common in the oncology setting, it is essential to expand our understanding of this emerging nursing role. This

knowledge is necessary to support the development of interventions that enhance the ability of nurses to provide this critical component of nursing care.

Chapter 3- Methods

This chapter presents the methodological components of the research. Attention is given to the design, sampling strategy, description of the sample, the data collection and analysis procedure and the means to ensure rigor and protect human rights.

3.1 Design

Because of the limited knowledge about the experience of oncology nurses who provide bereavement support, a qualitative design was used, as suggested by Morse and Field (1995) when little is known about a selected topic. Qualitative research is defined as a systematic, interactive, subjective approach used to describe life experiences and give them meaning (Leininger, 1985). Specifically, the Interpretive Description Method (Thorne et al., 2008), guided the design of this project.

The philosophical underpinnings of this method lie in developing a tentative truth claim about what is common in the clinical practice setting (Thorne, 2008). This research design differentiates itself from other frequently used qualitative designs in nursing studies as it yields “usable knowledge”. Thorne, the developer of the Interpretive Description method, stated that the nursing discipline was in need of “new knowledge pertaining to the subjective, experiential, tacit and patterned aspects of human health experience” (Thorne, 2008, p36). The purpose of Interpretive Description is to allow the discipline to gain ample understanding of such phenomena in order to guide future decisions that will impact peoples’ lives. This particular approach requires integrity of purpose, which is the justification for choosing a particular topic, deriving from two sources: first an actual practice goal, and second an understanding of what we do and do

not know based on the available empirical evidence. This allows for a “deconstruction of the angle of vision with which prior knowledge has been constructed and a generation of new insights that shape new inquiries and the application of evidence into practice” (Thorne, 2008, p. 35).

Interpretive Description methodology acknowledges that the clinical mind tends to be only partially satisfied with pure description, and seeks to discover associations, relationships and patterns within the phenomenon being described. Consequently, the use of Interpretive Description yields questions such as, “what is happening here?”, “what are the dimensions of the concept?”, “what variations exist?”, “how are phenomena different or similar from one another”, “how do they relate to one another”, and “what patterns exists?” The researcher must abstain from questions that attempt to determine causation or make predictions (Thorne, 2008, p50, 51). The aim of the research is to capture the themes and patterns of the subjective experience as it is lived by the individual. Although similarities exist between the methodologies of phenomenology and interpretive description, the latter was selected for the following reasons. Phenomenology is concerned with lived experiences and enables a better understanding of the social, cultural, political and historical context in which the experiences occur. It focuses on meaning and asks “what is the *essence* of this phenomenon and what does it mean?” (Polit & Beck, 2001). Interpretive Description requires integrity of purpose deriving from two sources: an actual clinical practice goal combined with an understanding of what is and is not known on the basis of the current empirical evidence (Thorne, 2008). Interpretive Description seeks to develop the type of knowledge that contributes to a

contextual understanding of a phenomenon that will subsequently guide future clinical decisions.

3.2 Methodological Assumptions

The naturalistic paradigm comprising qualitative inquiry believes that reality is not a fixed entity; instead, it exists within a specific context. There are numerous interpretations of reality that exist and no specific process can ultimately confirm or falsify a construct. With this type of inquiry, the interpretations of the study subjects are central in understanding the phenomenon. The interactions between researcher and participant result in the findings of the study. As such, the researcher interacts with those being researched and uses the knowledge that he or she has regarding the topic being studied. The subjectivity of the researcher is desired, and the researcher's values are expected to be a part of the research process. With the naturalistic paradigm, patterns—as opposed to generalizations—are sought (Polit & Beck, 2001).

As Interpretive Description seeks to develop workable knowledge, it considers the researcher's own experiences to be important in the conduction of research (Thorne, 2008). Although experience can sometimes be perceived as a bias in research and may blur the objectivity of the data, qualitative inquiry allows for this element based on the naturalistic paradigm, because for the naturalistic inquirer, reality is not a fixed entity. As a result of this unfixed entity, "many interpretations are possible and there is no process by which the ultimate truth is determined" (Polit & Beck, 2001, p.12). The naturalistic

inquirer seeks “patterns of experience from participants and considers subjectivity and values to be inevitable and also desired” (Polit & Beck, 2001, p.13).

3.3 Sampling Procedure

Interpretive Description methodology seeks to produce useable knowledge (Thorne, 2008). Consequently, purposeful sampling was used in this study. This is a sampling technique in which the setting and specific individuals are recruited by the virtue of some angle of experience that they have (Thorne, 2008). This allows the researcher to better understand the phenomenon. Thorne (2008) explains that the ideal informant for an interpretive description study is one that has a particular affinity for observing and thinking about the situation he or she is in rather than simply living it. With the help of purposive sampling, a researcher can select participants that provide different types of experiences. The researcher must strive for a sample that will provide the most comprehensive understanding of the phenomenon of interest. Nonetheless, the research must stipulate that information redundancy was achieved.

Years of experience in nursing were also an important factor in choosing participants as it was anticipated that each nurse’s work and life experience would influence the bereavement support process. However, the researcher strove to select nurses with varying amounts of work experience in order to better understand how this influenced the nurses’ experiences with the provision of bereavement support. Nurses who worked in different settings were sought as the work environment was presumed to greatly affect the intervention and the experience of the intervention.

To participate in this study, nurses needed to meet the following criteria:

- 1) Worked as a registered nurse for a period of at least 6 months on the targeted oncology units. This criterion was established as a minimum of six months was usually required for the nurse to have had the opportunity to provide bereavement support.
- 2) Provided at least one bereavement phone call to a bereaved family member for which the nurse was the primary nurse of the deceased patient. No minimum amount of interventions was required as even one meaningful bereavement support intervention could be meaningful for the nurse.
- 3) Spoke English or French. The researcher who conducted and transcribed the interviews was proficient in both languages.

3.4 Setting

This study was conducted in a large university teaching hospital located in Montreal. A principal reason this hospital was selected for the study was due to its nursing bereavement phone call intervention program. Bereavement support programs are likely to be met with resistance by nurses at first (Burke & Gerraughty, 1994; Jackson, 1992). However, since the program had already been in place for a few years, it was anticipated that many of the preliminary issues related to the staff's comfort levels—with regards to undertaking the intervention as well as the logistical issues regarding time and staffing—were now resolved. Another reason for selecting this particular hospital was because the oncology nursing department had been using the framework of primary nursing for several years.

To better understand the experience of oncology nurses who provide bereavement support, two specific settings of care were selected; the in-patient and outpatient oncology departments. Both the in-patient and outpatient settings are considered to be

part of the same comprehensive oncology program and provide an informal, nurse-led bereavement support follow-up.

Within the two settings, there are three different types of nursing roles; nurses working in the in-patient oncology unit, nurses working in the outpatient oncology clinic, and nurses who hold the 'infirmière pivot en oncologie' (IPO) role and who work in the outpatient setting. In the in-patient department, nurses work in a fast-paced environment and spend countless hours with patients and their families during hospitalization. The care they provide ranges from basic physical care to complex wound care, pain and symptom management, chemotherapy delivery, teaching and providing emotional support. Nurses on the in-patient department work in a team that consists of registered nurses (RNs), physicians, social workers, physiotherapists, occupational therapists, dieticians and orderlies. There are two different nursing roles in the outpatient department: the oncology clinic nurses and the IPO. The clinic nurses see patients on a regular basis for short visits whereby patients, usually accompanied by a family member, come to the clinic (located within the hospital) to receive cancer treatments, blood transfusions and/or antibiotics. The IPOs are involved with the patient and family during the entire disease process but do not provide direct patient care, however they are instrumental in teaching patients and families about their disease, treatment course and side-effects. They also play an important role in liaising with other members of the health care team and often do a lot of trouble shooting over the phone. For a detailed account of the nursing roles, see Appendix I.

3.4 Sample

Based on an understanding of qualitative inquiry and appropriate sample sizes, nine nurses were interviewed for this study. With qualitative inquiry, no specific number is recommended for the actual sample size (Polit & Beck, 2001). Instead, sampling is evaluated based on adequacy, which means that the data is sufficient and of sound quality. The concept of saturation is important to consider when determining the appropriate amount of participants required for a qualitative study. Saturation is defined as “the process of collecting data to the point where a sense of closure is attained when new data yielded from participants is redundant” (Polit & Beck, 2001, p.470). In qualitative inquiry, a sample size of ten or fewer participants is generally considered appropriate, as the in-depth conversations with informants provide a rich data set (Polit & Beck, 2001). Appropriateness of the sample is also an important criterion, as it represents the selection of participants that can best inform the researcher of the phenomenon (Polit & Beck, 2001).

3.6 Recruitment

A letter of support for the study was received from the co-director of the oncology department. Applications were submitted to the hospital and the university’s research ethics boards, and approval was obtained. Contact with the nurse manager of the three units was established via telephone and email. The purpose of the study was explained and the researcher received permission to attend a nursing staff meeting held in the hospital’s cancer center in order to present the study. The researcher attended two

meetings, each held approximately one month apart. Attendees of the staff meetings were mainly infirmières pivot en oncology (IPOs) and clinic nurses. Recruitment posters were also placed in hospital-approved areas. An information letter explaining the study in more detail, along with the researcher's contact information, was left with the nursing teams of targeted areas in their staff room. Nurses interested in participating in the study were asked to contact the researcher directly.

A similar process was undertaken with the nurses who worked on the in-patient department. Since no official staff meeting was planned for the coming weeks, a short and informal information session on the study was provided at the nurse's station to the nurses on the in-patient department. In-patient nurses who met the eligibility criteria and who were interested contacted the researcher to arrange for an interview. During the presentation of the study at staff meetings, the researcher emphasized that all types of experiences were sought, both negative and positive.

3.7 Process of Data Collection

Data was collected by means of individual audio-recorded, semi-structured interviews conducted with nurses who had provided bereavement support. The interview is a widely used method of data collection in qualitative inquiry, particularly when the goal of the study is to describe a phenomenon (Polit & Beck, 2001). Interviews involve verbal communication between the researcher and the participant; it is a means of transmitting information to the researcher (Polit & Beck, 2001). The interviewer uses specific prompting questions that encourage participants to discuss their experiences in depth (Burns & Grove, 2005). The semi-structured interview format allows the

researcher to have more control over the content of the interview and to ask questions that are relevant to the study (Burns & Grove, 2005).

Interviews for this study were held at a time and location that were convenient for the participants (i.e. their work office, a restaurant, the staff lounge). Before beginning the interview, the researcher reviewed the consent form with the participant and the form was signed. In addition, participants were informed that the researcher would also write notes during the interview. The interviews lasted from 40 to 80 minutes and were conducted in the participant's language of choice (English or French). All participants agreed to be contacted for a second interview in order to validate the study's findings. The researcher transcribed the interviews within 24 hours in order to recall details about each nurse's experiences.

A pilot interview was conducted and transcribed by the researcher. The thesis supervisor reviewed the pilot interview to evaluate the researcher's interviewing skills and to determine the effectiveness of the interview questions in obtaining data that met the objectives of the study. Feedback regarding the researcher's interviewing style was provided and subsequent interviews were arranged. As only minor changes were suggested (i.e. avoiding the use of close-ended questions and allowing more time for participants to answer each question), data from the pilot interview was included in the study.

All interviews were conducted in a similar manner as the pilot interview. Participants were assured that the information they provided would remain confidential. All nurses consented to being contacted for a second interview as part of the data validation process. The consent form was reviewed and signed.

The interview began with the collection of general demographic data. The participants were asked about their years of nursing and oncology experience, their highest level of education and if they held a certification in oncology or palliative care.

The interviews were semi-structured to allow participants to share their experiences, yet allow the interviewer to maintain some control over the content and direction of the interview (Polit & Beck, 2001). As Interpretive Description strives to provide “workable knowledge” (Thorne, 2008), in this study it was important to ask the participants specific questions in order to understand their bereavement support experiences.

After acquiring demographic data, the participants were asked an open-ended question: “please describe your experience of providing bereavement support?” Prompting questions were employed as necessary to generate more specific data. These questions included:

- 1) What are some of the benefits involved in this role for you?
- 2) What are some of the challenges associated with this role for you?
- 3) Can you share some experiences that have been particularly significant for you?
- 4) What kind of support do you need to carry out this aspect of your nursing role?

Field notes were taken during the interviews, but this was kept to a minimum in order for the researcher to remain fully involved in the interviewing process. Field notes are the notes taken by the researcher that describe the observations seen in the field, along with the interpretation of observations. Field notes are seen as the interviewer’s efforts to record, synthesize, and understand the data (Polit & Beck, 2001). In this study, these field notes allowed the researcher to note the non-verbal behaviour of the participants and her initial understanding of the data. After each interview, the notes were reviewed and

additional thoughts on the content and process of the interviews were recorded in a journal. The researcher transcribed each interview within 24 hours of its completion. After interviewing nine nurses and reviewing the verbatim transcriptions, it was agreed with the thesis supervisor that no further interviews were required.

3.8 Data analysis

As Interpretive Description does not provide specific guidelines for data analysis, Diekelmann's seven-stage process of data analysis, which allows for an inductive reasoning approach, provided the framework for the analysis of the data (Diekelmann, Allen, & Tanner, 1989).

The stages include:

1) Reading all of the interviews or texts for an overall understanding

After having transcribed all the interviews, the researcher read the transcripts several times.

2) Preparation of interpretive summaries of each interview

After reviewing the transcripts, the interviews were described as positive, neutral or negative and key statements were highlighted to support the descriptions.

3) Analysis of selected transcribed interviews or texts by a team of researchers (in this study, the research team consisted of the thesis committee).

After reviewing the data, certain key words were used to by the researcher to develop 20 categories that recurred in the transcripts. Specific quotes were selected by the researcher from the interviews to reflect the content of the categories. After a subsequent review by the researcher and the thesis supervisor, the list was decreased to 15 categories by merging certain categories, removing

others, and adding new ones. Subsequently, the categories were organized into six specific themes that the researcher felt represented the essence of the categories. These categories and themes were reviewed with the thesis supervisor once more. Members of the thesis committee were then presented with the transcripts of three interviews and the themes developed by the researcher. The three interviews were selected as they best represented the continuum of the nurses' collective experience and also represented the three different oncology nursing roles: inpatient, outpatient and IPO. These three interviews represented the negative, neutral and positive experiences that nurses in different workplace settings experienced.

4) *Resolution of any disagreements on interpretation by going back to the text*

A meeting was arranged with the thesis committee to discuss the proposed themes. After extensive discussion, the thesis committee members reached agreement on three major themes, with categories and sub-categories. A document describing all three themes, categories, and sub-categories, which included quotes from the transcripts, was sent to the members of the committee for review. All members agreed that this description was representative of the data.

5) *Identification of common meanings by comparing and contrasting the text's shared practices and*

6) *Emergence of relationships among themes*

These two steps occurred during the initial meeting with the members of the thesis committee when common meanings within the categories were identified

by reviewing key aspects of the interviews, and the relationships among the themes were discussed.

3.9 Methods to Ensure Rigor

Rigor has been described as the “striving for excellence in research through the use of discipline, scrupulous adherence to detail and strict accuracy” (Burns & Grove, 2005). Rigor is a necessity in both qualitative and quantitative research, but the means of achieving it differ. Within qualitative inquiry, rigor is associated with openness, a strict adherence to the chosen philosophical perspective, and thoroughness in data collection (Burns & Grove, 2005). It is measured by means of credibility, transferability, dependability, and conformability of the data (Lincoln & Guba, 1985).

3.9.1 Member Checks

Member checks consist of returning to participants and verifying the data. It is a method of validating the data by means of debriefing sessions and discussions with the interviewees (Lincoln & Guba, 1985; Polit & Beck, 2001). It is believed that member checks are amongst the most important steps in establishing the credibility of qualitative data and are an appropriate way to assure validity (Burns & Grove, 2005).

Thorne, the author of *Interpretive Description*, describes member checks as mechanisms for confirmation, exploration, and clarification (Thorne, 2008). Thorne (2008) explains: “Researchers who use this design are more than just a vehicle through which study participants speak, but an interpretive instrument capable of making sense among cases to uncover insights that would not normally be accessible if the researcher is only

familiar with one case and that going back to the original source of data is a vital step in transforming data into findings” (p.159).

When returning to the participants, the researcher seeks a confirmation that the synthesized data presented resonated with their experience. In this study, member checks were included in the participants’ consent forms in order to receive permission to conduct a second interview at a later time. Although all participants agreed to the possibility of a second interview, only four were selected for this phase based on their experience, work setting, and availability. These nurses were contacted approximately six months after their initial interview—after an agreement on the themes was reached by the entire thesis committee. Participants had the opportunity to provide feedback to the researcher regarding the interpretation of the data. Despite the fact that the themes presented to the participants represented the collective experience (i.e. positive and negative), all the nurses who participated in the second interview were able to recognize that their experience was reflected in the themes. Nurses who had very positive experiences expressed an understanding for the nurses who had negative experiences. Nurses with generally negative experiences understood that some might perceive the bereavement support experience as positive.

3.9.2 Credibility

Credibility refers to the confidence in the truth value of qualitative data and is established through a prolonged engagement with the participants, peer debriefing, and member checks (Lincoln & Guba, 1985). In this study, a thesis committee was involved

during seminal points of the proposal development and analysis stages. Member checks were also included.

3.9.3 Transferability

Transferability is established when descriptions from one researcher can be applied in other contexts. Transferability is another criterion for evaluating the quality of qualitative data; it refers to the extent to which findings can be transferred to another setting or group (Polit & Beck, 2001). In this study, the nurses all worked in the same hospital, and although they did not work in the same setting, their specialty—oncology—was the same. Oncology nursing, regardless of setting or role (in-patient or outpatient) share many similarities and fundamental premises; they care for patients with cancer and their families from diagnosis until death, they provide differing levels of emotional support, teaching and complex physical care. Despite the differences in acuity, workload and the nature of the care provided to patients and their families between settings, it can be assumed that findings from one oncology setting may be transferable to others. See Appendix I for additional information on the roles and responsibilities of the nurses in the three settings.

3.9.4 Dependability

Dependability and confirmability are established through an audit trail whereby the researcher provides enough information to allow another researcher to arrive at similar conclusions when reading the study. An audit trail refers to the systematic collection and documentation of materials that allow an independent auditor to draw conclusions regarding the data (Polit & Beck, 2001, p. 457). In this case, a journal was

kept by the researcher to document the emotional reactions of the participants, member checks were undertaken, and the keywords and timelines used for the literature search were saved. Detailed minutes were taken at each meeting held with the thesis supervisor. In addition, the thesis committee meeting, which involved discussion and decisions regarding data analysis, was tape-recorded and reviewed by the researcher.

3.9.5 Validity

The assurance of validity within qualitative research is difficult to achieve as the researcher collects the data and is initially submerged in it alone. Consequently, the researcher's inherent biases may go undetected in this stage of the process and could influence the interpretation of the data (Burns & Grove, 2005). In this study, the thesis committee validated the themes and further validity was sought through member checks and data review.

3.10 Protection of human rights

This study received approval from the University of Ottawa and the Jewish General Hospital's research ethics boards. All participants received a letter of information describing the purpose of the study and the interview process. Participants read and signed a consent form before beginning the interview. As it was anticipated that the content of the interviews might cause strong emotions to surface, all participants received the number to their anonymous employee assistance program and were encouraged to use this service if they felt the need. To ensure their anonymity, all identifying information was removed from the transcripts and each interview was assigned a number and a brief description of the participant's role/setting (i.e. nurse 3, outpatient clinic). Files involved

in this study will be kept in a locked cabinet in the thesis supervisor's office for five years, as per the research ethics boards' requirements. Computer files were password protected and only members of the committee had access to the information.

Chapter 4- Findings

4.1 Introduction

This chapter describes the study's findings by presenting a description of themes and categories that reflect the experience of oncology nurses and their provision of bereavement support. Data was collected based on the study's following objectives:

(1) To explore how nurses perceive the benefits of providing bereavement support, (2) to explore how nurses perceive the challenges of providing bereavement support, and (3) to identify the support nurses require to carry out the role of bereavement support providers.

Each theme, category, and sub-category includes participants' quotes that support the findings of the study. To protect their anonymity, participants are referred to as nurse 1 through nurse 9.

4.2 Overview of the Findings

The nine nurses who participated in this study worked in three different settings and as a result, had different scopes of practice, support systems, and experiences. The findings revealed that the oncology nurses' experiences while providing bereavement support ranged from negative to very positive; although most nurses acknowledged the presence of both positive and negative aspects in the overall experience of this role.

Several differences in practice were observed and reported. For example, their understanding of the term "bereavement support" was not uniform amongst the participants. Some understood it to be the nurse's supportive role during anticipatory grief, whereas others became very involved and met frequently with the bereaved after the death.

4.2.1 Characteristics of the Participants

In total, nine nurses from three different settings participated in this study. Participants included nurses who represented the in-patient department, the outpatient clinic, and nurses who held the Infirmière Pivot en Oncology (IPO) role. Participants' education levels ranged from nursing diplomas (two nurses) to Bachelor's degrees (four nurses) to Master's degrees (three nurses). The two nurses with nursing diplomas were currently enrolled in a part-time Bachelor of Nursing program. Years of experience in nursing ranged from three to 31 years, with most of the nurses having spent their entire career working in the field of oncology. Of the nine nurses interviewed, two had additional oncology certification. None of the participants had a certification in palliative care. All nurses had provided a minimum of one bereavement intervention but did not specify the total amount they had been involved in.

4.3 Outline of the Findings

An outline of the themes, categories, and subcategories developed from this study is presented below.

- **LIVING THE BENEFITS OF COMPLETING THE CIRCLE OF CARE**
 - **Preparing for the Loss**
 - *Preparing the family*
 - *Being a confidant*
 - *Looking for red flags*

- **Moving Forward After the Death**
 - *Therapeutic use of self*
 - *Being a guide/Providing resources*
- **Trying to Make Sense**
 - *Clarifying the events, answering questions and detaching from the relationship*
 - *Feelings of professional and personal satisfaction*
- **A PROFESSIONALLY CHALLENGING OPPORTUNITY**
 - **Unclear Expectations**
 - *Unit culture*
 - *Lack of a defined protocol*
 - **The Difficult Nature of the Job**
 - *The emotional nature of the job*
 - *Working within the reality of their workplace settings*
 - **Competency Issues**
- **NAVIGATING THE UNKNOWN**
 - **Not Knowing What to Expect**
 - **Bereavement Support as a Creative Process**

4.4 Findings

This section describes in detail the findings from the nine interviews conducted with the oncology nurses and will be divided into three major themes with their accompanying categories and sub-categories.

4.4 Theme 1: Living the Benefits of Completing the Circle of Care

All nine nurses expressed how bereavement support was beneficial to complete their circle of care. The “circle of care” in the acute care setting is usually understood as

care provided from diagnosis until death. However, for these oncology nurses, the circle of care encompassed not only the care provided from diagnosis until death, but also the period of bereavement. The circle of care within the oncology context includes several aspects of care, which have been divided into the following categories: *Preparing for the Loss, Moving Forward After the Death, and Making Sense*.

4.5.1 Preparing for the Loss

Every nurse interviewed reported preparing the family for the loss, but they did it in their own unique way. The approaches used varied depending on the length of the relationship, the perceived closeness to the patient/family, and other factors such as the nurses' communication preferences and unit culture. Preparing for the loss was further divided into three subcategories: *Preparing the family, Being a confidant, and Looking for red flags*.

4.5.1.1 Preparing the family

One aspect of “preparing for the loss” includes the concept of anticipatory grief. Nurses in this study referred to anticipatory grief as the period of time whereby the patient and family are aware of the severity of the prognosis and begin to grieve the upcoming loss. The nurses explained that although the death of oncology patients occasionally occurs prematurely and unexpectedly, such deaths are usually anticipated and both the family and the patient are aware of its imminent nature.

Anticipatory grief is a difficult period for the patient and the family. All nine oncology nurses in the study recognized the hardship that both the patient and family were experiencing and reported providing them with support by attempting to meet their

emotional and informational needs. Nurses described the importance of dialogue during this period as a means of acknowledging the feelings that the patient and the family were experiencing. During this preparatory process, the nurses focused on the patient—as well as the family—by sensitively approaching the topic of the eventual death. The following quotes are examples of how the nurses considered ‘preparing’ the patient and the family for the death as part of their role.

Nurse one, IPO said:

And I think that we have a role in the preparation of... I mean, we prepare people for each step of the trajectory; they've been diagnosed and we prepare them for surgery, and then we prepare them when they relapse, and progression and then you prepare them to the palliative stage. That's the thing, family members talk to you about it before the patient even dies... 'what will happen when the patient dies?' (...) I think it's important to prepare people. (...) and so it's to prepare them a little, so that they can face this, and I think it prepares them as well.

Some nurses spoke of the dying process with the patient and the family in order to demystify it, while others used specific strategies before the death that could help the bereaved after the death. For example, nurse two of the in-patient department, described how the primary nurses of a young girl dying of cancer provided her with a journal in which she freely wrote her feelings. Segments of the journal were read during her funeral and the message to the parents written by the young girl proved to be of immense importance to them during their bereavement.

Nurse 2 from the in-patient department said:

We really did prepare, we purposely took certain actions before the death that we knew would have a positive impact afterwards, during the grieving process. For example, we gave the patient a diary, we organized really special moments, individually for family members and collectively...pictures, we really took specific steps towards this grief that we knew was going to be difficult (...) I had given Sandra a diary, because we had determined that it was one of the ways that was non confrontational that she could express her thoughts and emotions and leave little tidbits for her family.

Some nurses also stressed the importance of reviewing common grief reactions with the family, as well as the type, nature and duration of support they might expect from others during this difficult time.

Nurse one, an IPO, explained:

I tell them, initially you will be surrounded by people, afterwards... well it's possible that you won't be living through grief at that time because you will be more likely to go out and occupy your mind. Other people will take care of you intensely, maybe even to the point where you won't have the opportunity to grieve at that time... but eventually, you will. Eventually you will be confronted by the solitude... by this hole. I think it's important to prepare people (...)

4.5.1.2 Being a confidant

Due to the extended and intense nature of the relationship which develops, and is maintained, between the nurse and the patient/family, the nurse becomes "special" to the family. Although none of the participants in the study used the term "special" to explain

how they perceived the family's view of them, it was clear from the transcripts that the nurses perceived themselves as being special for the family. Nurses from this study reported that with primary nursing, a sense of closeness and trust often developed between the nurse, the patient, and the family; this resulted in the nurse becoming a confidant to the patient and to the family. The role of "confidant" was present during the illness, as well as during bereavement when family members shared information with the nurse that they may have deemed too sensitive to share with others. Nurse three, IPO, recounted how one bereaved wife was only able to share the extent of her grief with the nurse as she felt her children would not fully comprehend:

It's not always easy to feel that you can talk about the last few moments. Or if it was a difficult death, if the patient had a lot of pain that wasn't well managed, hmm you need to let them verbalize that. (...) They feel they can express these emotions to you. And they may not be able to tell their son or their daughter how horrendous they felt.

The role of confidant allowed the nurses to comfort patients and family members before and after the death by answering their questions, sooth their fears, and acknowledge their feelings. Patients felt a certain level of trust that allowed them to share their stories and feelings with the nurse. The following quote from nurse three, IPO, reflected the trust that existed between a bereaved family member and the nurse:

And sometimes it's funny, I'll call them and they'll say: 'I haven't told this to anyone but I feel guilty about a certain thing.' And they feel like they can let you know because you're not going to judge them or you're not going to say 'hmm,

that's stupid, don't stay that.' You'll hear them and you'll rationalize how they are feeling. And if 'this and that happened' it's not because of something they didn't do. So it gives them permission to express emotions that they may not be able to share with even close loved ones. Sometimes there are strategies that we can provide them.

Another nurse described her perception of how sometimes it was easier for families to confide in the nurse, rather than their family, out of for fear of burdening or saddening them. Nurse eight of the outpatient department explained:

And I think it's important to let the patients feel like we are close to them because sometimes, even when the families are there, they need another person to help through what they are living. Sometimes the patients will tell me things that they won't tell their family members because it will make them too sad.

4.5.1.3 Looking for red flags

As the oncology nurses in this study reported being able to form strong and therapeutic relationships with their patients and their families, they also felt they were able to screen them for complicated signs of grief and assess their current and prospective support systems. Gaining knowledge on the family's coping strategies and social support network early during the course of the patient's disease enabled nurses to apply this knowledge to their provision of bereavement support. Nurses reported that based on their familiarity with the bereaved, they could determine who absolutely needed a bereavement

follow up, who could wait for one, and who did not require one at all. Nurse one, IPO explained this process:

And in the choices of people that I've called, I think it had something to do with the well being of the helper, the caregiver... either the husband or the wife who were very, very attached and that they found it very difficult to watch their close one die, I would call them. (...) Well it also depends, if I see that the person was very... um, or if she didn't have much support or if she had a hard time facing the death of that person, I will call her sooner. Criteria like that, more distress... that's when I call early. But otherwise...

Nurse two, of the in-patient department expanded:

It's certain that at the level of evaluating the social support network, there's a part that's very very nursing. (...) I've had enough contact with the family to know that. But, that comes from my psychosocial nursing knowledge. But I think it's good to re-assess in the context of grief, cause it's not everyone that will react the same way, and sometimes the support network shrinks after the death.

Nurse three, IPO added by saying:

You can really predict and you can put services in place to help the families through it. You know the trajectory is different for everyone and this is why I do my phone call from one month of the death for sure and then depending on the interaction I have with the family, it can be a weekly phone call, I've done that in the past. It can be involving the community more, cause you're more concerned with what's going on at home and you want the community to be your eyes and your ears as well. And sometimes it's one phone call and that's it. Families come

and see us often though, so already, you can start seeing how they are doing, where they're at and how supported they are.

4.5.2 Moving Forward After the Death

This sub-category describes how the nurses were able to help the bereaved move forward in their grieving process by providing bereavement support to family members. Provision of emotional support, information and resources were cited as interventions which enabled nurses to achieve this goal. This category is further divided into two sub-categories: *Therapeutic use of self*, and *Being a guide*.

4.5.2.1 The Therapeutic Use of Self

The subcategory “Therapeutic Use of Self” encompasses the emotional and practical aspects of providing bereavement support. These include assessing and normalizing grief, doing a life review, and providing resources and appropriate referrals. “Therapeutic use of self” is a term often used in nursing to demonstrate that the nurse himself or herself is a tool and becomes instrumental in the therapeutic process. One author explains that therapeutic use of self occurs when a nurse uses his or herself therapeutically he or she consciously makes use of his or her personality and knowledge in order to effect a change in the ill person. This change is considered therapeutic when it alleviates the individual’s stress (Travelbee, 1971).

In this study, the nurses normalized the grieving process for the family members, and when necessary, involved other members of the team such as social workers, community counselors, and *Hope and Cope* volunteers. *Hope and Cope* is a hospital

based cancer support group that is led by specially trained volunteers and professionals. The nurses acted as guides during the bereavement phase by involving themselves to the extent that the bereaved required. If the nurses felt the situation was beyond their scope of practice, or required additional expertise and/or time, they sought assistance from other multi-disciplinary professionals (i.e. nurses with more experience, social workers, and/or physicians). Nurses who provided bereavement support acknowledged that this was not their primary role and the expectations for this role were not the same as they would be for a professional bereavement counselor. For this reason, referrals were viewed as an important aspect of the nurse's role in this context.

Nurse one, an IPO, explained how she referred the bereaved to different sources depending on their needs and preference:

Yes, to social work or to 'hope and cope', or to go to a psychologists. But that also depends on people's beliefs, some people, you so much as mention 'psychologist'... I guess it depends on the generations and cultural beliefs. You know, any kind of taboo questions... not everyone is ok with that. Some people are more comfortable with their spiritual guides, like a priest or... yeah, sometimes I'll refer people to their priest.

Nurse seven, an IPO, speaks of involving other members of the team for complex cases:

I spoke to a few people to get their opinion on how I could help her. She was asking for the information, but she was really beyond that, that was just what she could focus on, she was really suffering and I wanted to see how I could help her.

That was something that I didn't feel equipped to do on my own. And then, I spoke with the social worker, but she didn't want to speak to the social worker, she agreed to go to a bereavement support group.

Throughout the course of the patient's illness, the nurse acted as a therapeutic tool and enhanced the well being of the patient and family by meeting their informational and emotional needs. This process was not standardized, and some nurses felt they were more successful than others at establishing and maintaining this level of closeness with their patients and the families. The therapeutic use of self that existed during the course of the disease was one that continued during the bereavement period.

When describing their actions to support bereaved family members, all nurses stressed the importance of normalizing the grief reactions of the bereaved. Nurse two of the in patient department said:

And as time went on, I would inquire about her grieving process and about how things were... and I really encouraged her; 'ok, today it's not going well, but tomorrow might go better'. I really wanted to plant that belief that... 'it takes time, give yourself time' ... I mean, that's a cliché, but it's true.

Furthermore, because of their previously established rapport with the family, nurses were able to recall special or memorable events that comforted the bereaved. Reviewing the caregiver's important role during the disease course was also viewed as being beneficial to the bereaved. By describing specific examples that were pertinent to

the bereaved, nurses sensed that the guilt and sadness felt by the family member was somehow diminished.

The nurses also reviewed the course of the disease with the family and answered any questions they had. A nurse's knowledge of the patient's history—as it relates to treatment and disease course—proved to be very valuable, as information regarding the disease and treatment was often sought by the bereaved. Nurse two, of the in-patient department explained:

So really, to assess their resources, to reminisce on positive experiences, and a lot of valuing of the role that they played. Because, one of the things I say to people... I mean, I'm not always being honest, but still, it's good, It's what they need to hear "I've never seen such an extra-ordinary support as the one you've provided your spouse with"...But they all do it, they all give the best support, the best support they are able to give at that time, the best support they know to give. It's not because it's not textbook perfect that it's not all that they could have given. I mean, we all have that question "did I do everything I could do? Was I really there for the person?" so I think that they need to hear from a professional person that they did ok. And to be recognized for the contribution they made, to be valued in the role they played, as the companion.

Nurse one, IPO, agreed:

I mean, there's this kind of peace, I acknowledge their feelings. I remark on what people say and what they have done, and I place emphasis on what they've done

that was helpful... and it can be quite touching, especially when the person dies... you see her go.

The nurses who felt most comfortable with the provision of bereavement support and were able to use themselves as therapeutic tools identified their own life, work, and personal experience with grief as assets. These nurses were able to recall several examples of positive bereavement support experiences.

4.5.2.2 Being a guide

Some nurses acknowledged that although they were not grief counselors or bereavement experts, they felt competent when it came to being a *guide* for bereaved family members. The nurses admitted to sometimes feeling as though they lacked the necessary skills to support certain individuals, but they felt comfortable in referring family members to their social work colleagues, psychologists, community support groups, the hospital support group (Hope & Cope) and occasionally, even psychiatrists. Nurse three, IPO, explained this process: “You get your social worker involved, your psychologist, the priest, or the rabbi or whoever in the community can be involved”.

“Being a guide”, a term used by some nurses to describe their role when providing bereavement support, was viewed as a “hands off” approach compared to their daily nursing practice. They mostly listened to and referred the family member to other resources if appropriate. One nurse warned of the downfalls of being perceived as the “go to” person for all problems. Nurse two, of the in-patient department, preferred bereaved individuals draw on their existing resources by providing them with encouragement and support:

But generally, it's good too, because at the same time, it allows them to realign themselves with their resources... to face their grief (...) so I think it's important to always bring back the person to her resources. (...) It's important to not give them solutions but to encourage the belief that they have their own solutions and that that's best. Cause often times, they are dismantled, and they come to see you for answers or they want you to do pave the way for them, and there are lots of unrealistic beliefs as well. So, instead of just giving them solutions... (...)The important thing is to not embark in it, and not to imagine that because they think you might have all the answers that you necessarily have to give them to them. That's not how it works, and I think that to do a good job as a 'companion' it's important to keep in mind that I don't have all the answers but that I trust that they will be able to find them. That I'm there for them, if they want to talk I will listen to them, I'm not going to disregard their grief.

4.5.3 Trying to Make Sense

Nurses described the patient's death as "an abrupt ending" to their therapeutic relationship with the patient and family. Consequently, the nurses perceived bereavement support as an opportunity to allow themselves to reflect on the situation and obtain closure.

The concept of "closure" often arose in the interviews. Nurses considered the process of obtaining closure to be beneficial to them and their practice. Bereavement support was a part of their job, as well as a more humane way of ending the relationship.

This category is further divided into two sub-categories: *Clarifying, Answering and Detaching*, which addresses the nurses' perceptions of how the intervention affected

the bereaved, and *Personal and Professional Satisfaction*, which addresses how the nurses perceived the effects of the intervention on themselves.

4.5.3.1 Clarifying, Answering and Detaching

Nurses in the study described the provision of bereavement support as a means to officially end the often-prolonged relationship with the family. The nurses described the process as a more humane and controlled manner to say their goodbyes. The following quote, by nurse two of the in-patient department, demonstrated how a follow-up with the bereaved family member impacted the nurse's practice and her sense of closure.

And by following up with these people, it helps to really tie that knot and to really end things, and to end them well. It brings...it completes the circle of care. It allows you to detach in a way that's much more serene than just wrapping a corpse and sending it to the morgue. It's more complete, it's more humane, it's much more... well, it just makes so much sense.

Other nurses insisted that their job was not complete until the follow up with the bereaved family member occurred. For them, completing the circle of care meant "going all the way;"ascertaining that the family was coping with the death and answering the family's questions in regards to the patient's disease course and treatment. Nurses reported that by doing so, families were better able to process their grief. Nurse three, an IPO, described the importance of such bereavement follow up for parents who had lost their 20-year-old son. Once their questions had been answered, their concerns heard, and their feedback considered, they were able to "move on":

I asked them to come in, I booked an appointment with the physician and they were able to express what they felt, what happened, they basically wanted to make sure that there was a follow up with what had happened so they could have closure to that difficult period. They expressed all that to the physician and myself and we said we were going to look into it and get back to them. And we did, we made them come back; let them know what the steps have been and that was a big part of what they needed to do in order to have a healthy grieving process.

Other nurses commented on the importance for some family members to return to the location where their loved one passed away or where they had spent much of their hospitalization. Nurse four of the outpatient department offered a bereaved husband the opportunity to go into the room where his wife had died after he had inquired about whether the room was currently occupied:

She was always in room 15 and she was so sweet. But her husband, when he came back, it was an isolation room so he couldn't go in. But I had the patient in that room, so I told him that we could gown up and we could go in together and the patient in the room didn't mind, so it wasn't even a problem... but he just wasn't able to.

The interviewed oncology nurses were familiar with the dying process, and thus were able to use this knowledge to support the bereaved by describing and explaining pertinent aspects of this process. One nurse described a family member's experience with death and how, by talking with him, she was able to provide him with a sense of having

been important in his wife's care. This, in turn, helped relieve the man's feelings of regret explained nurse three, an IPO, in this statement:

And letting them know that, 'if you were talking' you know, 'did you tell them what you were thinking?' "Well, yes I was" well then they likely knew because hearing is the last sense that goes away. Sometimes they say "I was there every single minute of the hour and when I went down to get a coffee, that's when it happened, why did she do that to me" and I say "well maybe she knew it would be too difficult for you to be around" so, as I said, normalizing, letting them express the sadness of their experience, permitting them to go through every single step of how it went, so they can go onto something else after.

Although the bereavement support follow-up was sometimes the official end to the nurse/family relationship, certain nurses admitted to always leaving the "door open" for further communication. Once they assessed that the bereaved were coping with the situation, the nurses stated they would no longer initiate contact, but would be available if the bereaved needed to talk. Nurses from all settings shared this practice. Nurses working in the in-patient department and oncology clinic gave the bereaved the unit's phone number or told them to return to the unit if they needed further support, whereas the IPOs gave them their business cards with instructions on how to contact them. Nurse four, of the outpatient department, recalled an event that occurred while she worked on the in-patient department:

I asked him if he wanted to sit at the nurses' station with us and to speak with the nurses, or 'did you need to go into the room', and sometimes they say no. 'Do you

need to speak to a physician?’ ‘Do you need to tell me something in particular?’

All the doors were open... and often they say no, they just need to come. That’s my experience.

Nurse five of the outpatient department shared a similar experience: “I left with that phone call, feeling that she had enough support. And I left it open for her to call back if she needed.”

Nurses described at length how the provision of bereavement support also allowed them to obtain a sense of closure. Several nurses stressed that a similar process occurred with the bereaved individuals. Nurse eight from the outpatient department explains: “We allow them to express themselves, they have the chance to put the period at the end of the...the illness. Everything that they’ve lived in our clinic, in our institution, it puts a ‘period’ to that I think”.

Follow-ups with bereaved family members allowed nurses to put their own minds at ease regarding the bereaved’s state. It enabled them to disengage from the relationship in a sensitive manner as described so emotionally by nurse five of the outpatient department:

Closure is definitely one of them.(...) but also doing an assessment of how the family is coping, to find out if there are other resources needed (...) If I hadn’t done the follow up phone call (voice cracks) I would have been like, I don’t know, left with this wondering feeling or a sad feeling, like nothing was resolved for me. But at least now, I touched base with her.

4.5.3.2 Feelings of Personal and Professional Satisfaction

All the participants in this study had engaged in the provision of bereavement support at one point in their career. Whether they had provided bereavement support on an as needed or regular basis, the oncology nurses who provided bereavement support spoke about the personal and professional satisfaction they received from this component of their work. Nurse two of the in-patient department explained:

Some of these moments are especially emotionally charged, specially when you're speaking about the last few moments of life or even the last few weeks. For people, it's almost as if it were more real, almost as if it were more intense. So it's very moving; the trust that these people are putting into us, the love that's expressed, the despair, the vulnerability. All those emotions that are very real, and very strong. It's not like talking about the weather or the Habs game. These are things that touch our very core, our identities, my worldview, so you know, it's really moving, it changes my state, and it enriches us.

Some nurses insisted that the provision of bereavement support was an integral part of their responsibility as an oncology nurse. Most nurses saw the provision of bereavement support as the natural extension of their practice, which allowed both parties (family and nurse) to detach from the relationship in a meaningful manner. Nurse one and three, both IPOs emphasized this by their respective statements: "And as for bereavement support, well if we follow the patient through the whole trajectory, and we follow the family, well it's only normal that we stretch it out into... into bereavement" and "I think

it's a CRITICAL, CRITICAL part of oncology nurses' responsibilities; the follow up calls with the family". Whereas, nurse five of the outpatient department said:

If I hadn't done the follow up phone call, I would have been like, I don't know, left with this wondering feeling or a sad feeling, like nothing was resolved for me. But at least now, I touched base with her and was able to convey to her that I cared for her and her husband. And it also gave her an opening, cause say like a month down the road, she has my card, she has my number. I told her, 'you can always call me if you're feeling sad or if you need to talk'...

Although certain nurses occasionally wondered if their bereavement follow-up was a source of pain for the bereaved, all the nurses acknowledged receiving some satisfaction from this aspect of their role. They felt it was important to ascertain that the bereaved were dealing with their grief; by contacting them after the death—as well as referring them to appropriate resources if required—the nurses received peace of mind. Nurses also felt satisfaction when the bereaved said they were glad they had made contact either by phone, in a face-to-face meeting, or at a funeral.

The nurses often mentioned how fortunate they were to be involved in such a role. Nurse two of the in-patient department in particular commented on how providing bereavement support was a privilege:

So that's really a special relationship. It's really an extra-ordinary opportunity to follow a bereaved person during this period, and to really see that person 'return to life'. It's beautiful. It's beautiful to see the resilience of people who have lived

such a terrible loss. It's really, really beautiful. [...] Well, it's like, it gives me an experience that I think are very useful in different aspects of life but mostly, it reminds me the importance of being there for the people I love and to say those things and to be real. It comforts me in what I do, people tell me I'm in the right place in my life, my work life, that I can make the difference.

4.6 Theme 2: A PROFESSIONALLY CHALLENGING OPPORTUNITY

The provision of bereavement support was considered both rewarding and challenging by all the oncology nurses interviewed. This theme will expand on the issues that contributed to the challenging nature of bereavement support for the nurses and will explore the complexity of providing this service in various care settings.

The nurses in this study described bereavement support as a demanding aspect of oncology nursing; it is influenced by factors such as organizational issues, lack of managerial support, lack of consistency in the provision of bereavement support and lack of a defined protocol for the provision of bereavement follow up. Nurses found themselves trying to offer bereavement support in clinical situations that were plagued by staffing shortages, lack of time, and competing demands. Several nurses indicated they did not have the necessary education or training to provide this type of support. Furthermore, depending on where these nurses worked, the unit culture influenced how colleagues perceived them, and how they perceived themselves, in the role of bereavement support provider. Nurses described either going 'with the grain' in a setting

where bereavement support was encouraged and expected, or ‘against the grain’ where bereavement support was seen as outside of their scope and a blurring of professional boundaries. This theme is divided into three categories: *Unclear expectations*, *Difficult nature of the job*, and *Competency issues*.

4.6.1 Unit Culture

The concept of “culture”, as it applied to the individual units, was mentioned by some of the nurses. Nurses that felt most supported in their role (i.e. IPOs), stated the provision of bereavement support was in fact part of their unit culture. As a result, nurses seemed to fully engage in and develop this aspect of their practice. Some ambivalence was noticed amongst the participants from the outpatient oncology clinic. This setting acknowledged that some nurses performed follow-ups, but that none of the nurses felt pressured to provide this service or were reprimanded for choosing to disregard bereavement support in their practice.

The nurses in the in-patient department seemed most conflicted. They described how although certain nurses chose not to engage in bereavement support, most colleagues were very supportive of the nurses who did. These nurses explained that the nurse manager was against the idea, but only speculated as to the reasons behind this. Opposing statements came from two of the in-patient department participants. One participant stated that her colleagues always respected and encouraged her bereavement support endeavors, while the other participant recalled an event whereby nurses commented about the unprofessional nature and inappropriate level of involvement nurses engage in while providing bereavement support.

The following quotes from nurses working in different settings represent the discrepancies and different expectations regarding the provision of bereavement support. This statement by nurse four of the outpatient department referred to her experience on the in-patient department:

Well, it's simply not part of the culture on the unit. Not at all. On the contrary, you become marginalized if you do it. Remember the girl who went to the restaurant with the wife of the patient who died, I thought that she crossed her boundaries, I and I wasn't the only one who thought so. Now I'm giving you a pretty neutral view of this, but there are some girls that spoke of this for a year. It was the gossip of the year: Nurse X had dinner with Mrs. Y, how could she do such a thing, it's not her job!

Nurse eight of the outpatient department and nurse two of the in-patient department seemed to have had different experiences as perceived by their respective comments: "I've never felt it was something we weren't supposed to do. Or something that wasn't valued. Within our team, it's something that's quite important" and "I haven't met a single nurse who was against this... except the head nurse. There are certain nurses that will do it less or that won't do it for different reasons, but generally they respect the fact that you do it".

Nurses who had reservations about the provision of bereavement support mentioned feelings that indicated that they were "crossing boundaries" and becoming "too involved". Some described it as a "slippery slope" whereby it became difficult to separate their professional life from their personal life. Nurse six of the in-patient department explained:

I mean, you could offer your help but to what point? You also have to be able to... I mean, you can't take care of them for the rest of their lives. I mean I care about them, but they aren't my family. I'm not going to try and put myself in their shoes. I want to know how they are doing, but I don't want to have to take care of them. I hope that they have support and that they have the tools to get through this but I don't have the intention to... I mean I have my family too, I have my life, my boyfriend, and I start allowing all this in... at one point there might not be a limit. I can't... well I don't think I can allow myself to become the family's private nurse after death.

Nurse four, of the outpatient department, explained how her job was already draining for her to invest any more energy into it:

It's certain that we get close to our patients and families...I know some of the girls go to the funerals, shivas and other things... but I didn't. I consider it my time... I would give so much of my time and energy to the unit that when it's over, it's over! There has to be a limit and I put the limit there.

Nurse two, of the in-patient department described an intervention that went badly. An elderly man who was experiencing complicated grief saw this nurse as his only lifeline, thus putting the nurse in a difficult position:

I didn't do this during work hours, I did it at home. And I found myself on the phone for two hours with someone that was convinced I was the only person that was able to help him. (...) And I had to tell this person that I was ending the

relationship that we had because it wasn't what was appropriate for him or for me.

It wasn't very good.

4.6.1.2 Lack of a Defined Protocol

The interviews revealed very different conceptualizations of “bereavement follow-up” amongst the nurses. Interventions in the in-patient department were often described as “haphazard” and “inopportune”, thus leaving nurses to struggle with meeting the bereaved's needs, their current patients' needs, and dealing with their own emotional reactions to the intervention. Although the nurses admitted to personally benefiting from the intervention on some level, they also recounted that this aspect of their work added to their already stressful and busy nursing practice. Nonetheless, despite the lack of a clear bereavement support protocol, the nurses supported bereaved individuals by reminiscing about their loved ones, reinforcing the important role the family member played as a caregiver, and normalizing their grief.

The in-patient nurses' practice was similar to that of the nurses who worked in the oncology clinic. Differences in practice were most evident with the IPOs, who had a more formal approach and more time and resources to assist with the intervention. One of the IPOs explained that her bereavement phone calls lasted thirty minutes on average; a luxury nurses in the in-patient department or the oncology clinic do not have due to their heavy workloads. Another IPO (nurse three) described how she usually calls the family member a week after the death for the initial bereavement phone call:

I usually call a week after the death, that's usually when the families leave and the wife of the husband you know, are starting to be more alone, because you know, a lot of the intensity of that first week, people leave, they have other commitments.

Some nurses—mainly those who felt uneasy regarding this aspect of their practice—singled out the lack of a protocol as one of the main issues. The lack of a defined protocol appeared to cause some of the nurses to doubt their therapeutic abilities in this process as described by nurse five of the outpatient department:

I think that... I feel like I'm kind of going into it blindly, if we had an in-service or were given a bit of guidance, like you know, a bit of advice as to how to do a proper thorough assessment just to get some advice from people who've done it a lot, I think that would be a big help.

Nurse four of the outpatient department explained that despite having knowledge about grief, she wanted to ensure she was on the “right track” before engaging in bereavement support. “You just want to know that you're on the right track... you just kind of go at it blindly. I mean, you feel that this is what you're supposed to do but you're unsure”.

4.6.2 The Difficult Nature of the Job

The oncology nurses described the provision of bereavement support as a very rewarding, yet challenging area of nursing. This section will discuss what the nurses have identified or alluded to as “difficult”. Due to the high mortality rate of cancer patients, nurses working in oncology are subject to several losses. These losses become more difficult when primary nursing is practiced, since the patient's death results in the loss of a relationship that was often lengthy and meaningful for both parties. This category has been divided into two sub-categories: *The emotional nature of the job* and *Working within the reality of the workplace*.

4.6.2.1 The Emotional Nature of the Job

Aside from witnessing the difficulties experienced by patients and their families throughout the cancer journey, nurses who expanded their role to include bereavement support amplified the level of hardship they encountered; witnessing somebody's grief was described as an emotionally taxing experience. This experience was especially difficult if ties to the patient and the bereaved were strong; nurse four of the outpatient department had to deal with her own feelings of loss while simultaneously being therapeutic and a source of comfort for the bereaved: "You know, sometimes it's like that in oncology, the patients you know them so well, I think we miss them."

Nurses admitted to occasionally requiring some additional time after the intervention to deal with their own emotions prior to returning to their work. Debriefing with nursing colleagues—both formally and informally—was identified by several of the nurses as an important aspect in contributing to their emotional well-being. They explained that no formal mechanisms were in place for debriefing, but that they benefited from such a process after an especially difficult death. This sentiment is reflected by nurse two's statement: "So it's happened to me to feel dismantled by this situation... and we don't exactly have resources person either". Nurse four of the outpatient department described an event where she debriefed:

Because just the fact that you can talk about it with people who are living similar experiences really helps: 'I spoke to Mrs. X and they could reply 'oh really, you ended up calling, tell me how it went' 'it went terrible, we both bawled!'

4.6.2.2 Working within the reality of their workplace settings

In addition to the emotional hardship they experienced, the nurses acknowledged that providing bereavement support was also challenging due to the realities of their workplace. Constraints such as lack of time, staffing shortages, and the lack of managerial support contributed to their feelings of uncertainty regarding the role. Despite these shortcomings, nurses often described teamwork as a useful tool in helping them fulfill their role of bereavement support provider.

Although “lack of time” was often identified as a primary constraint, the nurses rarely turned down a phone call or refused to talk to a bereaved individual who dropped by the unit to visit. The nurses who held more administrative roles (i.e. IPOs) indicated that they occasionally had to delay the phone call by a few days if their week was especially busy. This sometimes resulted in the phone call not being made at all as the nurses assumed too much time had passed and their phone call was no longer pertinent. Nurse one, an IPO, explained how bereavement support is not always a priority, due to the realities of the job:

The difficulties associated... well the lack of time (laughs). The lack of time, that's a difficulty. I mean, you see that you need to do it, but because of time, it gets delayed sometimes. People I would have liked to have called within a month, two months have passed and you know, sometimes the time passes and well I just don't call.

Some nurses shared their frustrations regarding their colleagues' opposing views about the provision of bereavement support. At times, nurses who enjoyed and believed in the importance of providing bereavement support felt their colleagues failed to see their perspective, and as a result, were reluctant to 'pick up the slack'. Nurse five of the outpatient department explained:

Well the clinic is really busy, we don't have enough staff for the patients that we have. And often, it almost feels like a factory, you bring the next patient in and you round and you start a new patient. Yeah, sometimes, there are certain things that you can kind of get the sense that others don't think that are as important as what's going on in the clinic. And I have talked to another colleague of mine that feels the same way. She was on the phone with a family once and someone came to get her and said 'come on, the clinic is busy!' and it is busy, but here's also other things that need to be done.

Other nurses reported that their colleagues supported and accommodated them in fulfilling this role. Unit culture was never described as a "hindrance", however certain units were portrayed as more supportive than others as described by nurse two of the in-patient department:

Well, often times, these people don't come with appointments, they just pop up on the unit and they need someone now. So if the day is slow, or if it's my break in a little while then I'll make arrangements with another nurse and I ask them to cover them. But if that means that I have to ask another nurse to give the chemo... you know, it really depends on the caseload.

Two issues cited in relation to the lack of time for bereavement support provision were “being short staffed” and “dealing with competing patient demands”. All nurses acknowledged their primary priority was their current patient load, whether they worked on the in-patient unit, in the oncology clinic, or had an administrative role. Nurses spoke of feeling torn at times between their current patients’ needs and the needs of bereaved family members. Nurse seven, an IPO explained:

I was very happy to be able to do this follow up in this role. It’s somehow not supported as much as I would like, hmmm, you know the patients that are here always take priority (...) and when you’re busy with all those things, it’s hard to make that phone call for somebody who’s not physically there... but you always want to and you wished that you had some reserved time where you could do it.

The above situation was further complicated by the lack of bereavement support documentation. As a result, bereavement support became an “invisible” aspect of the nurses’ practice; it was not acknowledged or recognized by management. This invisibility was further increased as some nurses made bereavement support calls or held meetings with bereaved family members during their breaks or after work hours. Nurse seven, an IPO, explained:

Another challenge actually is that often, and I know I should, I often don’t document. I used to and I don’t know what changed, and I often don’t write it down. And it’s a pity because then it’s lost, as if it never happened, if you don’t

write about it, nobody sees it. Also the charts of patients who've died have been removed so they are more difficult to get.

For the nurses who were able to take some time out of their schedule to provide bereavement support, a new challenge sometimes arose: dealing with an often emotionally difficult conversation and having to promptly return to work. Nurses described their feelings of sadness and explained how at times, they had to debrief with a colleague or recompose themselves before returning to their assignment. Nurse five, of the outpatient department gave an example:

I find it really hard, for other people... and it's a shock 'cause we didn't know that she had died. Her mother just showed up on the unit and apparently she had died just the day before, so, we knew it was coming, but still, it came as a shock. And you're like 'ok, next!', I can't just turn things off. So for me it was a bit hard, I don't know, you try and take a deep breath and focus on the next person that I'm having an interaction with.

Nurse eight, of the outpatient department described why she chose to abstain from continuing to provide bereavement support:

It's one of those things I find the most difficult. Because people are hurt, they are going through this loss and I have the impression that with some people, just by seeing us, we make them relive this whole process of illness, treatment, side effects, other issues. We are associated with this part of their life where they were sick, and I sometimes have the impression that I awake difficult moments...

because treatments aren't always easy. So yeah, I have this feeling that I'm making them relive this part of their life, this part that was already pretty difficult. And that makes me hesitant.

4.6.3 Competency Issues

Some nurses perceived themselves as inadequately prepared to face the challenge of providing bereavement support due to a lack of training in this field. These nurses reported feelings of insecurity and were concerned they were, to some extent, harming the bereaved. The perceived lack of training led the nurses to see themselves as “salt in the wound” of the bereaved. Certain nurses even felt they were re-opening their own wounds regarding their sentiments on the patient's death. They expressed the difficulty involved with re-contacting the family members and reported feeling as though they were reminding the bereaved, and themselves, of the patient's death. Nurse four, of the outpatient department, described her concerns:

Well, it's literally pouring salt in their fresh wounds. These patients who have cancer, we know them for extended periods, they almost become our friends and then when they die, the first thing we want to do is to forget them, like everyone I guess. And then you have to call the family and ask them ‘So how's it going?’

Information on grief, bereavement, bereavement support, and community resources were identified by the nurses as key factors for practice improvement. In-services were the preferred method, but some nurses were agreeable to reading packages and performing their own literature reviews.

When asked what kind of support they required to carry out this aspect of their nursing role, the nurses—particularly the ones with less experience and those who felt most insecure about the intervention—answered: “training”. These nurses went on to explain that they were never trained to fill this role and were providing bereavement support based on intuition developed from caring for previous patients and families, personal experience, and knowledge they had acquired while working in oncology as described by nurse two of the in-patient department: “And we never got any training in services... the experience that I have is because I did some palliative care as a student and my own life experience whereby I lost a lot of people I was close to...”

One nurse acknowledged that the communication techniques she learned in her basic training were of great importance to her. However, in order to improve her skills, she researched bereavement support interventions in her own time. Some of the nurses explained that experiencing loss on a personal level also helped them to feel more competent in supporting bereaved individuals. This is reflected by this quote from nurse two of the in-patient department: “... my own life experience whereby I lost a lot of people I was close to and ‘I know what it’s like to lose someone’, so it’s really personal...”

One of the interviewed nurses drew from her experience with the death of her father to help guide her interventions. She recalled how she and her mother were provided with support immediately after the death, but were left alone to deal with the loss soon after. In the following quote, nurse one, an IPO, stressed the importance of explaining to the bereaved what levels of support they can expect following the patient’s

death: “I think it’s important to prepare people [the bereaved], because this comes from my own personal experience that I’ve seen with my mother and that I may not have seen with other patients”.

Nurses who had both life and work experience in such situations explained that they seldom felt insecure about their ability to provide bereavement support. They felt confident in their knowledge base and were not intimidated by the bereaved’s sometimes-emotional reactions. Nurse one, an experienced IPO, described tears, silence, and sadness as an appropriate reaction from the bereaved; one she considered to be normal:

But sometimes it’s just an emotional moment they let it out... and sometimes, it’s just in our approach; they see an opening and they just start to cry. And often times when I meet with people, I mean, it’s in the approach, in the questions that I ask, people begin to cry. So I started to tell them ‘I have a tendency to make people cry’ (laughs). So that kind of allows them to do this, and it normalizes things. And people begin to cry and to open up and cry.

In comparison, the nurses who felt less secure in providing bereavement support would feel responsible for the bereaved’s strong emotional reaction. The nurses who had less work and life experience described reactions such as crying, sadness, and long periods of silence as a negative experience for them and the bereaved. Nurse eight of the outpatient department explained:

I’d have to say that in my work, it’s one of those things I find the most difficult. Because people are hurt, they are going through this loss and I have the

impression that with some people, just by seeing us, we make them relive this whole process of illness... I sometimes have the impression that I awake difficult moments. (...) I find that it's as difficult each time.

All nurses, regardless of experience or comfort level, acknowledged they were not bereavement counselors and their main priority was their current patients. Consequently, they could not invest themselves to the extent that may be required by the bereaved. In such cases, the nurses referred the bereaved to a different professional or a resource in the community. One nurse shared that despite her best intentions and desire to be therapeutic, she worried that her skill set was not sufficient for a thorough and comprehensive assessment of the bereaved individual. Nurse five of the outpatient department was afraid to overlook something that a professional with more experience would have noticed and attended to: "I want to be able to do a thorough assessment which I think I do. But I think I need to gain a little bit more experience", she went on to say: "So I don't know, I mean, I might think she's coping ok, but what if she's really not?"

Some nurses felt they represented the "illness", the "hospitalization", and the "battle", thus making it difficult for them to act as a therapeutic agent for a bereaved family member. One nurse explained that for a certain family, despite her strong bond with them, she would always represent a difficult period for them. Several nurses described the bereaved's emotional state as a fresh wound that was being re-opened every time they made a follow-up contact. Nurse four of the outpatient department, described her views on bereavement support and why she was so reluctant to do it:

“The person who doesn’t want to hear from you. Well she probably had 5 or 10 minutes in her whole day where she wasn’t thinking of the person who died and you happened to call at that time!!! That’s terrible! Of the 5 minutes she’s not thinking of it, you’re going to be there to remind her of it. I don’t even know how to express this. It’s sure that in her surroundings, no one would do that, no one would call to ask ‘so tell me, how have you been living through your husband’s death?’ that’s a pretty awful question to ask someone! I mean, it’s not fun. There’s nothing fun about this!

During their second interview (member checks), some of the nurses who did not consider themselves “salt in the wound” for the bereaved, were introduced to this concept. One nurse recounted how several of her phone calls included a period of crying for the family member whereby she would state, “It really is still difficult for you. I can see that. Maybe my voice reminds of you of situations here.” The nurse clarified that she did not view such an experience as challenging, but understood how less experienced nurses might feel uncomfortable and shy away from the process. Nurse one, an IPO, responded to this information by proposing her own solutions:

Debriefing is a must. You have to do it in order to gain perspective. More experienced nurses can reassure the nurse to help her progress. We need to encourage the nurse, maybe even do a role-play to help her prepare.

Nurses further explained that despite workload issues, being short staffed, and dealing with competing demands—such as current patients and their treatments—they are able to make adjustments and ask their colleagues to cover for them when necessary.

Nurses report that their colleagues play an essential role in bereavement support provision by mentoring, teaching, and debriefing. Nurse two of the in-patient department explains: “I know that I have my colleagues to encourage me and to back me up if this intervention was difficult”. Whereas nurse one, an IPO added:

I think it's important that nurses get together and talk about it (...) I don't let it accumulate. Let's say I have just done a bereavement follow up and it's been emotional... I would speak to someone about it (...) talk about it amongst ourselves and support each other and every now and then, allow ourselves to cry... sometimes it feels good to cry (...) That's something that I do, sometimes I'll see nurses that are upset and I take them and say 'speak to me, do you want to talk about it?' (...) As a nurse you can't let it accumulate, 'cause as time goes by, we are on the receiving end of other people's emotional overloads... and we see it on a daily basis. So you really have to develop the tools to deal with it. When we talk about it amongst ourselves, it's helpful.

Nurses who were more experienced and had a positive attitude regarding the bereavement support intervention provided examples of how they have helped and mentored their colleagues. Nurse one, an IPO, described how she teaches younger nurses to troubleshoot when they are at a loss for words during a bereavement phone call:

There are little tricks to give to the nurses, let's say they get 'blocked' and they don't know what to say, they can always tell the person on the phone that there's someone at the door and put them on hold for a few minutes while you figure out what to say next... like you're full of emotions and you're not sure where to go

from there. Lots of little tricks like that work for nurses, for those nurses who are afraid of calling and are not at ease... you know, little tricks like that.

Even the nurses who viewed this intervention as “difficult” admitted that having colleagues to speak with and learn from was an important tool in helping them provide support to the bereaved. Nurse four, of the outpatient department explained:

I would ask the opinion of the experienced girls, or the Social Worker, the supportive care nurse. I would have asked her. In fact, before calling the lady at home, I had asked the lung cancer IPO and she told me “yes, do what you need to do whenever you need to do it, and if you think that the person needs this, and you feel comfortable doing it, then just do it.

4.7 Theme 3: NAVIGATING THE UNKNOWN

The “unknown” was a concept that often recurred in the interviews. Several nurses described how despite knowing the bereaved personally, they could not always predict the manner in which the intervention would unfold. The theme of “Navigating the Unknown” has been divided into two categories: *Not knowing what to expect* and *Bereavement support as a creative process*.

4.7.1 Not Knowing What to Expect

The unpredictable nature of the bereavement support intervention makes it difficult to plan for in advance. Nurses described how certain phone calls and meetings could last only a few moments, while others went on for much longer. Family members

also sometimes visited the in-patient unit or oncology clinic unannounced. As described in the previous theme, these occurrences affected the remainder of the nurses' work day, forcing them to spend time catching up on things they were unable to do while with the bereaved. The bereaved's unexpected visits occasionally affected the actual interventions, as nurses reported they sometimes felt rushed and could not provide the bereaved with the adequate level of therapeutic support. Nurse five of the outpatient department said:

It might not just be a five-minute phone call you know. You might want to speak to them in depth and they might also want to talk, and you don't want to feel like you have to cut them off.

The "unknown" also relates to the uncertainty of the bereaved's—and the nurse's—emotional reaction to the bereavement intervention. Due to the sad nature of the interaction, the nurses sometimes had to deal with the bereaved's intense emotions, in addition to their own. Nurse one, an IPO, recalls an especially angry widower. Although the intervention caught her off guard, she remained therapeutic:

There was a lot of anger. And having to listen to the anger... having to listen to their perception of how the whole thing happened (...) You don't expect it during a bereavement phone call... it was so destabilizing. But yet again, you have to consciously reflect on what emotions these people were going through.

Each bereavement intervention experience was different and thus the outcome was often unpredictable. Despite having pre-existing relationships with the bereaved, the nurses spoke of the moment before the call when they were unsure of the reaction that would greet them. Would it be someone who is too distraught to talk, someone who is angry, or someone who is glad to hear from them?

Nurses also worried about how they would themselves react during and after the intervention; would they be at a loss for words, would they begin to cry, or would they know how to deal with the family member's questions or concerns? Nurse eight of the outpatient department was especially worried:

It's difficult to tell before speaking to the person. (...) Well, not knowing what to say to people, not knowing what interventions are most likely to comfort them... that's it really, not knowing how to exactly... not know how to better help them. (...) Because after all, you can know how things are done but when you apply it, there are always little surprises and adjustments that are made.

4.7.2 Bereavement Support as a Creative Process

Another aspect of the unknown is related to the lack of a clearly defined bereavement support protocol. Despite the absence of such a protocol, the nurses saw the bereavement support intervention as an opportunity to use their own creativity and therapeutic use of self. Each nurse entered into the zone of the unknown differently, based on previous work and life experience. The unknown was not necessarily negative or positive; it was merely an aspect of the reality of bereavement support work, and each nurse dealt with it differently.

The nurses who reported using their creativity and therapeutic use of self to navigate the unknown were the ones who seemed to most enjoy this aspect of their role. It allowed them to deviate slightly from their routine nursing practice. They also perceived their intervention as beneficial to the bereaved. These nurses further

acknowledged how being a “primary nurse” and “knowing the patient and the family” assisted them in navigating through the unknown.

In the following quote, nurse one, an IPO, explained how she tailored her intervention based on her knowledge of the patient/family and her professional and life experience:

I didn't really have a list of questions. I called to simply offer my condolences and ask them “how have you been doing?” and from there, I just ask them more questions. I really geared it to their experiences and it was really beneficial I think.(...) My own way of using my creativity. Like creativity in my practice... that's how I would explain it. Intuition. Yeah, I go with it. Well, when I speak of ‘creativity’ I mean I don't go in there with guidelines. I just got at it with experience. I support them... with my years of experience.

On the other hand, nurses who viewed the unknown as an additional challenge expressed the most reluctance and discomfort with bereavement support. They perceived the intervention as being potentially detrimental to the bereaved.

4.8 Summary of the Findings

The collective experiences of oncology nurses who provided bereavement support represented a wide continuum. The experiences of the nurses were directly affected by their personal life and professional experiences. Their workplace, the nature of their professional roles, the extent of their intervention, and the frequency and manner in which they intervened further influenced their experiences.

Despite the challenges encountered in this aspect of their practice, oncology nurses reported a feeling of personal and professional satisfaction resulting from the provision of bereavement support follow ups. The nurses felt they were doing their job to its fullest extent by ascertaining that family members were coping with the death and that they had the appropriate resources available to them. Furthermore, the nurses were able to obtain closure with this intervention, as some were not always present at the time of the patient's death. The intervention allowed the nurses to formally say their goodbyes to the family members, a few days to a few weeks after the death of the patient.

Nurses described the importance of having a previously established rapport with the patient and the family when doing this intervention. Their knowledge of the patient, the family, and the disease trajectory was described as a facilitating factor. It allowed the nurses to answer specific questions and to recall with the bereaved some memorable events. Developing a close and therapeutic relationship with the patient and family unit enabled the nurses to connect with the bereaved on both a personal and professional level during the bereavement follow up.

Some nurses described their experience of this intervention as somewhat negative. These nurses reported a perceived lack of appropriate bereavement support training. This caused them to feel unprepared to meet all the needs of bereaved individuals, despite having a previously established rapport with them. They feared that contacting the bereaved would evoke strong and negative emotions and would likely cause the bereaved to cry or to become even more upset during this difficult period. In contrast, nurses who enjoyed providing bereavement support acknowledged that strong emotions and even

tears on the part of the bereaved were expected and normal, and thus did not make them feel untrained as professionals.

The findings suggest that nurses were able to formally detach from patients and families by means of providing bereavement support. Once they determined that the bereaved were coping in a healthy manner, they ended the relationship, but left the door open for further communication if the bereaved decided it was necessary—for example the nurses told the bereaved family members they could come back if they had questions, or if they simply needed to talk.

Time, staffing shortages, feelings of insufficient skills and/or knowledge to take on this role, and the lack of managerial support were considered factors that rendered the provision of bereavement support challenging. Several nurses also expressed concern regarding their perceived knowledge gaps, which they feared contributed to a poorly conducted bereavement follow up. This resulted in inconsistencies in practice and, for some, a reluctance to engage in bereavement support. Debriefing sessions were reported by several of the nurses as helpful in dealing with the often emotional nature of the intervention.

Chapter 5 - Discussion and Implications for Practice, Education and Research

5.1 Introduction

This chapter discusses the main findings of the study, factors that influenced the bereavement provision experience of the oncology nurses, and the support and resources they require to function more effectively in their role as providers of bereavement support. The final section in this chapter includes recommendations for nursing practice, education and research, as well as the implications of the study's findings for the role of the advanced practice nurse (APN) in bereavement support.

5.2 Main Findings

In addition to confirming that education and closure are important subjects and major areas of concern for nurses who provide bereavement support, this study contributed to the body of nursing knowledge by providing new information about how oncology nurses in various settings experience the provision of bereavement support, and how they operationalize their role, despite challenges encountered in practice. The main findings can be summarized in five points: (1) the experiences of oncology nurses who provided bereavement support ranged from negative to positive. The varying reactions can be attributed in part to the primary nursing model that allows nurses to develop meaningful relationships with the patients and their families. These pre-existing relationships made the nurses ideal for the provision of bereavement support, yet also occasionally resulted in nurses experiencing feelings of loss when patients died—these

feelings often resurfaced while providing bereavement support. (2) These nurses understood that their role in providing bereavement support was different and less comprehensive than that of a grief counselor, but still felt unprepared. Many nurses in this study voiced concerns regarding the lack of appropriate training to fill this role. (3) Nurses often turned to peer-mentorship to work through their insecurities regarding bereavement support and/or to seek advice about the practice. Nurses engaged in peer debriefing as a way to mitigate the difficult nature of this role. (4) Despite the role strain they experienced, and the constraints they encountered in their workplace, nurses felt it was important for them—as professionals and as individuals—to provide bereavement support as it allowed them to obtain closure. (5) The culture of a unit and the degree of managerial support affected the overall experience of bereavement support provision. The following section elaborates on what was learned from this study.

5.2.1 The Primary Nursing Model: Facilitating the Development of Meaningful Relationships

All of these oncology nurses practiced within the primary nursing model. They unanimously recognized how it allowed for continuity of care and provided them with professional satisfaction. Their continued and prolonged involvement with the patient and the family was viewed as facilitating their provision of bereavement support; they were able to draw on previous interactions with the bereaved, and recall specific details about the patient that were beneficial in initiating and maintaining the bereavement follow-up with the families.

Although previous research did not point to the importance of using a primary nursing model, several earlier studies conducted with nurses who provided bereavement

support revealed similar findings regarding the value of continuity of care. In a study conducted with hospice nurses, prior knowledge of the bereaved was identified by Marquis (1996) as a significant facilitating factor for the provision of bereavement support. Kaunonen and colleagues (2000) studied oncology nurses who followed up with the bereaved by means of a telephone call. These nurses reported that when they were unfamiliar with the patient and family they had a more difficulty relating to the bereaved and were uncomfortable with the interaction. McClain and Mandell (1994) studied community nurses who followed up with bereaved parents who lost a child to sudden infant death syndrome (SIDS); these nurses also described having difficulty when they were unable to discuss the specifics of the case with these families. Penson and colleagues (2002) described similar issues experienced by health care providers (physicians, nurses, social workers) who associated their inability to incorporate bereavement care in the oncology setting with financial and human resources constraints.

Nurses need to practice within a framework that allows for continuity of care and the opportunity to develop meaningful relationships with patients and families. Ultimately, for the participants in this study, practicing within the model of primary nursing care allowed for therapeutic relationships to be established between themselves, the patients, and the families, thus facilitating the nurses' provision of bereavement support.

5.2.2 Are Nurses Adequately Prepared to Provide Bereavement Support?

Although the nurses from this study acknowledged that providing bereavement support should be an integral component and a continuation of their role as oncology nurses, many of them felt they were inadequately prepared. They expressed concern that

they might be inadvertently causing the bereaved more harm than good if they relied solely on their clinical experience and current knowledge of bereavement support provision to guide their interventions. Integrating additional empirical knowledge of bereavement support into their practice was a primary concern. In this study nurses attributed their discomfort with bereavement support in part to their lack of formal training specific to this intervention. Findings from studies of hospice and oncology nurses and bereavement support conducted by Marquis (1996) and Perry (2008) also indicated that although these nurses felt that the knowledge they had acquired from life and work experience facilitated aspects of their nursing practice, they still felt that additional education and training on grief and bereavement support was required. Chan and colleagues' studies of obstetrical nurses who provide bereavement support also found that additional training was required for nurses to feel more comfortable with bereavement support (Chan, Chan, & Day, 2004; Chan, Day, & Chan, 2005; Chan, et al., 2008; Chan, Wu, Day, & Chan, 2005). Earlier studies by Jackson (1992) and Burke and Gerraughty (1994) of intensive care and oncology nurses revealed that lack of training was viewed by the nurses as a deterrent to engaging in this aspect of their role.

In support of the importance of providing nurses with additional educational opportunities, studies which provided descriptions of staff training prior to commencing their role of bereavement support providers have demonstrated that this additional training resulted in nurses feeling more confident in this aspect of their role (deJong-Berg & deVlaming, 2005; McClain & Mandell, 1994). For example, McClain and Mandell (1994) described a training program to help prepare nurses for their role as bereavement support providers to families whose baby had died of SIDS. This training involved

providing the nurses with extensive information on SIDS (pathology, prevalence, and causes), grief among adults and siblings (children), family dynamics and available community resources. The nurses interviewed in this study acknowledged that their work was emotionally challenging, but they did not cite inadequate training as a barrier (McClain & Mandell 1994). None verbalized the specific fear of harming the bereaved, which may indicate that they felt that their training program adequately prepared them to meet the challenges associated with this role.

However, other studies that explored the role of nurses and bereavement support in oncology, hospice, and intensive care settings revealed that these nurses did not suggest the need for additional training. In findings that support the results of this study, they identified workload and time constraints, role overload, discomfort with the work (i.e. the strong emotional nature of bereavement support), being upset by the prospect of interacting with bereaved individuals, and a desire to separate their work and personal life as reasons why they abstained from, or limited their bereavement support interventions (Jackson, 1996; Marquis, 1996; Rickerson, et al., 2005). The nurses' lack of attention to the possible need for additional education and training may be due to the fact that in these studies bereavement support was not their primary role, or because the bereavement support program was not a formal part of the care being provided. It is also possible that there was an assumption by management or the nurses themselves that nurses involved in caring for actively dying patients and dealing with situations of anticipatory grief already possess the education and skills required to support families in situations of non-complicated grief.

5.2.3 Building upon What Nurses Already Know

Undergraduate nursing programs include theoretical and clinical learning opportunities that should prepare nurses to evaluate elements associated with bereavement. Elements such as: assessing for somatic distress, the bereaved's current emotional state, level of cognitive function and daily activities, as well as risk factors for complicated grief are part of the nurse's scope and abilities (Douglas, Pemberton, & Hewitt, 2002; Greenstreet, 2005). Nurses also need to be available to listen to and support individuals through their grief, as well as provide the bereaved with information about the grief process and identify available community resources (Larese, 2008; Roach & Nieto, 1997). These interventions are within the scope of nurses' practice and are skills nurses use in their daily work. During the interviews, many of the nurses in this study described the process in which they supported bereaved individuals as involving the abovementioned tasks and skills, thus demonstrating that although they did not have formal training, they were able to support the bereaved.

Given that graduate nurses have already acquired the skills required for the provision of basic bereavement support, educational programs developed to target nurses' perceived learning needs can provide them with opportunities to build upon their clinical experience and current knowledge of bereavement support (Matzo, et al., 2003). Providing nurses with additional education and training on identified topics in bereavement support may serve to enhance their sense of proficiency and reduce their concerns of inflicting harm on the bereaved.

5.2.4 Integrating clinical experience, intuition and reflection into bereavement support practice

In addition to their basic knowledge of bereavement support, nurses in this study described how their clinical experience, personal experience, use of intuition, and reflection on their practice influenced the interventions they provided to bereaved family members. In their seminal work, Benner and Tanner (1987) defined the use of intuition in nursing practice as “understanding without rationale” and described this phenomenon as occurring most often among “expert” experienced nurses. This definition of intuition reflects what several of the nurses in this study described as being an important component in their process of providing bereavement support. They felt that the experience they had acquired throughout their careers often allowed them to develop an intuitive understanding of the needs of the bereaved.

Other nurse scholars maintain that intuition plays a central role in the process of reflection in nursing practice (Benner & Tanner, 1987; Schon, 1991; Winch, Creedy, & Chaboyer, 2002). Reflection in nursing practice has been defined as “a process of reviewing an experience of practice in order to describe, analyze, evaluate and so inform learning about practice” (Reid, 1993, p.3). The importance of self- reflection in nursing has been widely documented in the nursing literature within the context of education (i.e. teaching nursing students to reflect on their practice) and clinical practice (Gillings, 2000; Richardson & Maltby, 1995). The College of Nurses of Ontario (CNO) also views reflection as an important aspect of practice and has incorporated it into its quality assurance program. The CNO states that: “Reflective practice formalizes the act of critiquing practice by taking nurses through five steps: self-assessment, peer feedback,

developing a learning plan, implementing the plan and evaluating the success of the learning” (College of Nurses of Ontario, 2009, p.13). CNO emphasizes that this process of reflective practice acts as “a tool for the critical exploration and articulation of experiences, as well as a foundation for building knowledge on health care teams” (CNO, 2009, p.13).

Nurses in this study described occurrences in their practice where they felt uncomfortable or uneasy with their role as providers of bereavement support, and how these feelings forced them to reflect further on their practice. A similar practice was reported by the nurses who provided bereavement support to parents who lost their infant to SIDS (McClain & Mandell, 1994), where the nurses reflected on each family they had cared for. Although reflection and debriefing were regular occurrences, these nurses never reported a concern regarding their motives for providing this service.

Although the nurses in this study did not refer to their process of reviewing their cases and discussing their feelings with colleagues as “reflection”, they did describe situations where they reflected upon their practice and used their understanding of previous experiences to improve their care.

5.3 The Value of Debriefing

Nurses in this study noted that having the opportunity to debrief with their nursing colleagues was also very helpful to them, as it was sometimes difficult for them to return to their regular daily work after an especially challenging bereavement support intervention. The debriefing that occurred informally with colleagues whom they considered more knowledgeable and experienced allowed them to receive advice, and to have their feelings validated. Kaunonen and colleagues (2000) studied the experience of

Finnish oncology nurses who provided bereavement support and did not have the opportunity to debrief with their colleagues, and reported that after the intervention nurses felt sad and unfocused, and as a result found it difficult to immediately return to their patients. Barnard, Street and Love (2006) hypothesized that adequate levels of peer support would contribute to mitigating burnout levels among oncology nurses. Despite the lack of definitive findings, the authors reported that the informational and emotional support provided by nursing colleagues, similar to the process of debriefing described by the nurses in this study, decreased stress levels in these oncology nurses.

In further support of the value of debriefing, the results of studies that explored the experiences of intensive care nurses who provided bereavement support (Jackson, 1996) and nurses who provided bereavement support to parents who lost an infant to SIDS (McClain & Mandell, 1994) revealed that for these nurses debriefing with their colleagues was helpful on two levels; it allowed them to validate each others' feelings and to provide each other with feedback and advice on current and prospective bereavement support interventions. McClain and Mandell (1994) described how debriefing was a mandatory aspect of the nurses' role and was recognized as an important factor in keeping them nurses emotionally well, in spite of the difficult nature of their job. Although in this study there was no formal debriefing procedures, or expectations from management that debriefing become part of the provision of bereavement support, the nurses consistently sought debriefing support from their colleagues.

5.4 Nurses Mentoring Nurses

In addition to valuing the opportunity to debrief with their colleagues, nurses in this study also described the influence of mentorship on their bereavement support

practice. The nursing literature acknowledges the importance of the role of mentorship in contributing to the proficiency of nurses. Mentorship begins during basic nursing education with clinical supervision and continues post graduation with the use of expert nurses (Butterworth, Faugier, & Burnard, 2002). Many organizations have a mentorship program for nurses and consider this approach to be important in recruiting and retaining nurses (Greene & Puetzer, 2002). The implementation of formal mentorship programs recognizes the need to develop and maintain relationships between new and experienced nurses; it also promotes team building, guides novice nurses into the culture and environment of their new role, and serves to recognize and utilize expert staff (Greene & Puetzer, 2002). Butterworth and colleagues (2002) list the goals of mentorship as expanding the person's knowledge base, assisting in the development of clinical proficiency, autonomy, and self-esteem as a professional. Although this pertains to the supervision and mentoring of nursing students, the same principles can be applied to the novice nurse or to the nurse who does not yet possess the knowledge, skill, and confidence required to provide bereavement support.

In this study, the nurses who have had more work and life experience described the process by which they mentored more novice nurses, or nurses who were less comfortable with the provision of bereavement support. Nurses who were mentored by their colleagues explained that they received helpful guidance on how to implement and manage the difficult aspects of the bereavement intervention. Despite the apparent importance of mentorship, and its widespread use in many areas of nursing (Burke & Gerraughty, 1994; Kaunonen, et al., 2000; Marquis, 1996), only McClain and Mandell's 1994 study on nurses and bereaved parents suggested a mentorship component as a

strategy to support nurses in this role. Providing nurses with formal opportunities for peer-mentorship and debriefing within their work environment is a management strategy that can have an important role in supporting nurses on an emotional level, and for preparing them to meet the challenges of bereavement support provision.

5.5 Bringing it All Together: A Comprehensive Approach to the Provision of Bereavement Support

The nurses' interactions and interventions with the bereaved reflected components of nursing knowledge similar to those described by Carper (1978) in her seminal work on "the fundamental patterns of knowing in nursing". Carper explains that knowledge in nursing is formed and acquired through a multitude of ways including: "Empirics: The Science of Nursing", "Esthetics: The Art of Nursing", "The Component of Personal Knowledge", and "Ethics: The Moral Component". These four "ways of knowing" guide nurses in their practice and their understanding of their nursing role. In essence, nurses in this study integrated all four patterns of knowing into their bereavement support practices, allowing for a holistic approach to bereavement support. Although these nurses did not necessarily use Carper's terms, they drew on all these components of nursing knowledge in their bereavement support interventions. The nurses acknowledged the importance of understanding the grief process and recognizing differences between normal and complicated grief (empirical knowledge), but stressed that this alone was not enough to meet the needs of the bereaved. Knowing the family member and having an established rapport facilitated the therapeutic use of self (component of knowledge of self), used by the nurse to support the bereaved. The provision of bereavement support was also very much a creative process, and was considered by these nurses to be part of

the overall care they provided (esthetic knowledge). Finally, the act of providing bereavement support was carried out in an ethically sound manner despite the limitations and constraints encountered in the nurses' practice environment (component of moral knowing).

Carper states that: "Each pattern may be conceived as necessary for achieving mastery in the discipline, but none of them alone should be considered sufficient. Neither are they mutually exclusive" (Carper, 1978, p.21-22). The experience of the nurses in this study revealed that they integrated all four ways of knowing in their provision of bereavement support, allowing them to better understand the needs of the bereaved and support them during this difficult time. However, findings of this study highlighted the significance of the nurses' previously established relationship with the family as an essential factor in their ability to integrate the various components of their nursing knowledge in their provision of bereavement support.

5.5.1 Fostering a Culture that Values Bereavement Support

In this study, there was a clear distinction between the experiences of the nurses who worked in units where management encouraged the provision of bereavement support and the ones that did not. Managers who valued this aspect of the nurses' role not only encouraged its practice but also attempted to make adjustments to the nurses' workload in order to accommodate this role. In contrast, other nurses lacked the time and framework to follow-up with bereaved family members, and felt torn between caring for their current patients and the bereaved individuals who would sometimes drop by unannounced.

A similar concern was reported by Jackson (1996) in a study of intensive care

nurses who had contact with bereaved family members, but felt that they were inconsistent in their provision of bereavement support; it was provided only if they had time or if the family had specifically requested this type of support. Gordon's (1994) study of midwives and their provision of bereavement support revealed that bereavement follow-up can become a very time consuming endeavor that may require changes to the provider's main clinical role. These authors maintain that the provision of bereavement support is a complex role, and suggest that it be practiced continuously, and not only when time and resources allow for it. deJong-Berg and deVlaming (2005) examined bereavement support in the pediatric setting and found that nurses, social workers, and physicians of a palliative care team were better positioned to provide bereavement support, and recommended that a designated bereavement support team be developed for this purpose. This recommendation may be unrealistic for many settings, due to issues in the current health care system that challenge administrators and clinicians to provide professional and compassionate care in spite of dwindling human and financial resources (Tam, 2009). Notwithstanding that elements such as financial and human resource constraints may be difficult to change, designated time for the provision of bereavement support as part of the nurse's workload is a management strategy that can potentially be integrated into the unit's practice.

5.5.2 Despite the Challenges: Reaching for Closure

Nurses interviewed in this study felt that an important part of their oncology nursing role involved offering bereavement follow-up to the family after the death of the patient; despite the fact that neither their employers nor the bereaved individuals expected it from them. Their main reason for doing so was the desire to ensure that family

members were coping well with their loss and, if necessary, to provide them with specific resources. It was also extremely important for these nurses to say a formal goodbye to the bereaved. Similar findings were reported in studies where nurses expressed the need for closure when they practiced in settings such as intensive care units, oncology units, and hospices where prolonged contact with patients and families, and subsequently bereavement support, was commonplace (Lloyd-Richards & Rees, 1996; Marquis, 1996; Ruden, 1996).

Results of this study revealed that practice settings, time constraints, and shortages of staff could negatively impact a nurse's ability to provide bereavement support. Despite these challenges the nurses continued to perform this role, perceiving it an essential aspect of the overall care they provided, highlighting the importance of closure for nurses who practice in settings where prolonged relationships with patients and their families are common.

In addition to supporting many of the findings of previous studies on nurses and bereavement support that describe the importance of this role, this study brought forward new knowledge regarding the significance of using a primary nursing model when providing bereavement support, the perception that bereavement support is an essential part of oncology nursing practice, the importance of peer mentorship and debriefing and the influence of unit culture and managerial support. Based on these findings, the following recommendations can be made for nursing practice, education, and research.

5.6 Recommendations for Practice

The specific demands of each nurse's role, the presence or absence of time available within their regular workload for bereavement support, and varying levels of

managerial support all impacted the manner and consistency of the support provided by these nurses. These findings are reinforced by studies that highlighted similar influences on the nurses' bereavement support practices (Chan, Wu, et al., 2005; Stein, et al., 2006). Based on the findings of this study, it is suggested that the nursing provision of bereavement support could be enhanced through strategies such as: allocating time within the workday for the provision of bereavement support, changing the unit culture to one that recognizes bereavement support provision as an important component of the role of oncology nurses, providing nurses with opportunities to receive additional education and training on the provision of bereavement support, and developing mechanisms within the work environment that support primary nursing care, peer debriefing, and mentorship.

5.7 Recommendations for Education

This section will provide recommendations for education prior to and post graduation. In recent years, undergraduate nursing programs have been adding palliative care education into their curriculums (Matzo, et al., 2003). Although bereavement support provision may not be part of the palliative care education currently available for students, educators should emphasize that the skills required to provide bereavement support are similar to those learned when learning about therapeutic communication (Larese, 2008). Although it was acknowledged by participants in this and similar studies (Marquis, 1996; Perry, 2008) that the knowledge acquired from life and work experience facilitates aspects of nursing practice—including the provision of bereavement support—participants also recognized that additional education and training on grief and bereavement support was required.

The expectations of nurses in the role of bereavement support providers differ from those of other professionals; therefore the training program does not need to be extensive. It should, however, hold a didactic and practical component that focuses on the basics of the grief and bereavement process, the approaches to best support bereaved individuals, and the knowledge of community resources (Matzo, et al., 2003). Estabrooks and colleagues (2005) demonstrated that nurses seldom use formal sources of knowledge when acquiring new skills, and therefore the most current evidence based knowledge may not be reaching the target population if bedside nurses do not habitually use this source of knowledge in their practice. Consequently, it would be important to incorporate information from best practice guidelines relevant to the provision of bereavement support into training programs to ascertain that nurses have access to the most current knowledge on the topic. For example, the best practice guidelines (BPG) for the nursing care of bereaved individuals is currently being developed by the Registered Nurses Association of Ontario (RNAO), and should be integrated into future educational initiatives (RNAO website).

Providing nurses with additional training on identified topics in bereavement support may serve to enhance their sense of proficiency and reduce their concerns of inflicting harm on the bereaved.

5.8 Recommendations for Research

In order to evaluate the effect of educational programs it would be important to examine the influence of additional training on nurses' levels of perceived efficacy, comfort with the bereavement support intervention, and job satisfaction. Additional research is also required to determine how different pedagogical strategies, such as

didactic and practical components, influence nurses' implementation of bereavement support interventions. Longitudinal studies conducted with oncology nurses who provide bereavement support could indicate if providing this service influences professional satisfaction, and consequently the retention of nurses who have integrated this aspect of family care into their clinical practice.

It would also be essential to understand how families evaluate these services and to determine which aspects they find particularly beneficial. Exploring how different disciplines impact the care of bereaved individuals, and how collaborative interprofessional practice influences the experience of those who provide this service could contribute to further understanding the specific role of oncology nurses who provide bereavement support.

5.9 The role of the Advanced Practice Nurse

The role of the advanced practice nurse (APN) has existed in nursing in various and evolving forms for decades (Hamric, Spross, & Hanson, 2005). Advanced practice nursing focuses on clinical services rendered at the nurse-client interface, uses a nursing orientation, has a defined but dynamic and evolving scope, and is based on competencies that are acquired through graduate nursing education (Brown, 1998). The Ottawa Hospital's APN model, based on the model described by De Grasse and Nicklin (2001), reflects five core roles that define the practice of the APN: 1) clinical practice, 2) leadership/administration, 3) consultation, 4) research, and 5) education (De Grasse & Nicklin, 2001; TOH website, 2009).

The components of practice of advanced practice nurses enable them to be at the forefront of nursing care by leading and participating in research projects; educating staff

and patients; providing direct care; acting as a leaders and mentors to colleagues on local, provincial, national and international levels; and by holding administrative roles within the workplace. Oncology APNs are integral members of the interprofessional team and are responsible for providing clinical care at one or many points across the cancer continuum; cancer prevention, screening, palliation, and end-of-life care (Cancer Care Ontario, 2009). Using the five core roles of the APN as a framework, the following section will discuss the role of the oncology APN and the provision of bereavement support within the context of the implications of the findings of this study.

5.9.1 Expert Clinician

The APN is considered to be a clinical expert with experience in caring for the oncology, palliative, and bereaved population (Hamric, 2005). This aspect of practice requires that the APN has direct contact with patients and their families throughout their illness and during the bereavement period. As an integral member of the interprofessional team, the APN can use advanced nursing knowledge and skills in the assessment of the needs of bereaved family members and in the development of comprehensive care plans. The APN is instrumental within the health care team. He or she can meet regularly with nursing staff and other disciplines to discuss families and their bereavement needs, or assist nurses with their bereavement support interventions by working with them to integrate current evidence on bereavement support provision into their practice (i.e. RNAO best practice guidelines). In addition, the APN is ideally situated to mentor staff nurses who are new to this aspect of nursing practice. For example, he or she can observe and review nurses' bereavement phone calls and follow up with constructive feedback, or provide nurses with opportunities for practice sessions

using role-play scenarios that reflect realistic bereavement support situations. These strategies would help meet the competency and educational concerns expressed by the nurses in this study.

5.9.2 Leader

Bereavement has been associated with increased levels of morbidity, a decline in overall health, and the misuse of health care resources (Parkes, 1996; Quigley & Schatz, 1999). These significant outcomes have been recognized by organizations such as the World Health Organization (WHO), Health Canada, and the Canadian Hospice Palliative Care Association (CHPCA), who strongly recommend that bereavement care be integrated into the overall care of the patient receiving palliative care.

APNs can take a leadership role in working with clinicians and administrators to examine and support the changes required to initiate, enhance, and/or sustain bereavement support programs within their context of care through involvement on interprofessional committees dedicated to the development of policies, procedures, standards, education and research related to bereavement care. As a leader in bereavement care, the APN can anticipate future changes and issues regarding bereavement support; responding to them with specific short-term interventions and providing assistance in the development of a long-term strategic plan. The APN is also well positioned to take a leading role in establishing links and collaborating with local and regional stakeholders, helping to develop initiatives that improve the distribution of the human and financial resources required for the implementation and sustainability of bereavement support programs.

Nurses in this study identified unit culture and managerial support as factors that influenced their experience of providing bereavement support. As APNs often hold management positions (Hamric, 2005), the APN can develop strategies that foster a work culture where bereavement support is considered to be part of the overall care provided to patients and their families. Adopting a primary nurse model, making time for debriefing sessions, and holding monthly bereavement rounds where patient/family needs are discussed are examples of interventions that can contribute to the development of a more positive unit culture surrounding the provision of bereavement care.

5.9.3 Consultant

The APN acts as a consultant in the clinical setting by sharing expertise with other colleagues, thereby enhancing their professional development and practice and enabling them to manage future similar situations more effectively. If a problem is common in the clinical setting, the APN may develop educational sessions and written guidelines (Hamric, 2005). The APN working in the field of oncology or palliative care can act as a consultant to nursing staff, managers, physicians, and other members of the health care team regarding clinical practice issues pertaining to bereavement and bereavement support. The APN can also be a consultant to other health care organizations, and providers of care within the community setting, regarding the care and follow-up of bereaved individuals. With his/her expertise in bereavement care, the APN can collaborate with the interprofessional team to coordinate the follow-up of family members with risk. The need for additional education in bereavement support was clearly identified by the nurses in this study. By monitoring, evaluating, and documenting outcomes of bereavement support interventions (i.e. emotional support, answering

questions, and referral to community resources), important feedback could be provided by the APN to the oncology nurses, contributing to meeting their educational needs. Documentation of this service also increases its visibility and can support the process of advocating for additional resources.

5.9.4 Researcher

Results of this study highlight the issues that influence oncology nurses' provision of bereavement support. With a graduate nursing education, advanced practice nurses are academically prepared to collaborate with their nursing and interprofessional colleagues in the development of research studies that explore the challenges encountered in the provision of bereavement support (Hamric, 2005). For example, the APN can examine the facilitators and barriers at the clinical and administrative levels that are associated with the implementation of best practice guidelines (BPG) guidelines on bereavement support. An understanding of these issues can contribute to the development of specific educational and/or administrative interventions aimed to enhance the provision of bereavement support and assist in managing several of the challenges identified by the nurses in this study. Additional research activities of the APN can involve participation on internal research committees, the critical appraisal of literature applicable to the care and delivery of care of bereaved individuals, and the dissemination of research findings through scholarly activities such as publications in peer-reviewed journals and presentations at academic conferences.

5.9.5 Educator

Findings of several studies have indicated that nurses desire further education and training in the provision of bereavement support (Burke & Gerraughty, 1994; Kaunonen, et al., 2000), findings supported by the results of this study. As an educator, the APN is ideally positioned to develop educational sessions for nurses who wish to undertake bereavement support, based on an assessment of their perceived learning needs in this area. Educational needs assessments are an important initial step to identify preferred content and format of educational interventions, and to guide the development of programs targeted to the participants' identified learning needs, preferences and work environment (Grant, 2002). Possible educational interventions could include a didactic component, a self-directed learning module along with case studies, and examples of how to conduct bereavement support intervention. As demonstrated by Estabrooks and colleagues (2005), nurses seldom use formal sources of knowledge when acquiring new skills; consequently it would be important to incorporate information from evidence based guidelines into bereavement training programs to ensure that nurses have access to the most current knowledge.

As the APN is an expert in bereavement care, he/she acts as a role model and clinical expert for this clinical specialty and as such, can also provide guidance to nursing staff to improve their bereavement support provision expertise in the clinical setting. In addition, the APN can contribute to the development of nursing, interprofessional, institutional, and community educational programs for health professionals and health care recipients, focusing on bereavement support.

5.10 Limitations of the study

There are several limitations that should be considered when interpreting the results of this study. The study was conducted in a large teaching hospital in Montreal, which has a large and culturally diverse population, and therefore results cannot necessarily be extrapolated to other Canadian settings. In addition, the study was conducted in a hospital where a primary nursing model was utilized and a previous relationship usually existed between the bereaved and the nurses involved, which may have influenced how the nurses perceived the effect of their interventions on the bereaved. However, the sampling procedure employed in this study included nurses holding a variety of positions and years of experience, enhancing the applicability of the findings. Also, five of the nine interviews were conducted in French but were directly translated into English during transcription by the fluently bilingual researcher. Some words employed to translate from French to English may have failed to capture the actual meaning as described by the participant. Despite the use of two languages, the researcher and the committee agreed that the content of the interviews was rich in description and was appropriate for the purpose of this study.

Self-selection of participants was also a limitation as only those interested in the research topic volunteered to participate in the study. Notwithstanding these limitations, the information received from the nurses in this study reflected the experiences of nurses in different oncology nursing roles and practice settings, ultimately providing an overview of a range of nursing experiences in the provision of bereavement support.

5.11 Conclusion

"When we honestly ask ourselves which person in our lives means the most to us, we often find that it is those who, instead of giving much advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief or bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is a friend who cares" (Nouwen 2004).

Oncology nurses have a pivotal role to play throughout the cancer trajectory; they provide care, education, and support during diagnosis, treatment, and the end-of-life stage. Oncology nurses who provide bereavement support can build upon the pre-existing rapport they developed with family members during the patient's illness, and continue to support the bereaved in coping with this challenging period. They are ideally positioned to assess the bereaved for complicated grief, answer their questions, provide them with emotional support, and refer them to appropriate community resources as necessary.

A critical step in being able to support families during this difficult time is by enhancing our understanding of the experiences of the nurses who provide the bereavement service, as well as the support and resources they require in this role. Knowledge gained from this study can be used by administrators, educators, and clinicians to inform and guide the enhancement and/or implementation of nurse-led bereavement support programs, and contribute to assisting nurses to meet their

educational and supportive needs in this area. The painful reality of the loss of a loved one cannot be changed, however nurses who are better prepared to provide bereavement support can enhance the provision of end-of-life care by identifying and meeting the needs of family members during their often difficult grief and bereavement process.

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APPENDIX B: Poster French



HÔPITAL GÉNÉRAL JUIF
SIR MORTIMER B. DAVIS
HÔPITAL D'ENSEIGNEMENT DE L'UNIVERSITÉ MCGILL



L'EXPÉRIENCE DES INFIRMIÈRES EN ONCOLOGIE OFFRANT DU SOUTIEN AUX PERSONNES ENDEUILLÉES



Êtes-vous une infirmière ou un infirmier qui travaille en oncologie et qui a déjà fait le suivi de personnes endeuillées?

Si oui, je suis intéressée à vous rencontrer et mieux connaître votre expérience. Cette étude est menée par une infirmière, étudiante à la maîtrise en sciences infirmières à l'Université d'Ottawa.

Votre participation consistera en une ou deux entrevues individuelles qui dureront approximativement 60 minutes.

Cette étude a été approuvée par le comité d'éthique de l'Université d'Ottawa et par celui du Sir Mortimer B. Davis Hôpital Général Juif.

Pour organiser une rencontre ou obtenir plus d'information sur l'étude, prière de contacter :

Vicki Meyouhas RN, BScN

N.B. Chaque participant recevra 20 dollars par entrevue.



APPENDIX A: Poster English



SIR MORTIMER B. DAVIS
JEWISH GENERAL HOSPITAL
 A MCGILL UNIVERSITY TEACHING HOSPITAL



The Experience of Oncology Nurses who Provide Bereavement Support



Are you a nurse working in oncology who has also provided bereavement support?

If so, we are interested in learning more about your experiences. This research study is being conducted by a Master's of Science in Nursing student at the University of Ottawa

Participation consists of one or two individual confidential interviews lasting approximately 60 minutes.

This study has been approved by the University of Ottawa's Research Ethics Board and by the Jewish General Hospital's Research Ethics Committee

For more information about the study and/or to arrange for an interview at your convenience please contact.

Vicki Meyouhas RN BScN

Each participant will receive 20 dollars per interview



APPENDIX C: English Information Letter

Study Information Letter for Participants

Title of the study:
**The Experience of Oncology Nurses who Provide
Bereavement Support**

Researchers:

Vicki Meyouhas RN BScN
Masters of Science in Nursing student
University of Ottawa
Faculty of Health Sciences
School of Nursing

Susan Brajtman RN PhD
Assistant Professor
University of Ottawa
School of Nursing
Faculty of Health Sciences

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'5

Sylvie Lauzon RN PhD
Associate Professor
Associate Vice-President, Academic
University of Ottawa

Gail Macartney, RN MScN, ACNP
Hematology Department
The Ottawa Hospital

Purpose of the study: Your participation is being requested for a research project conducted by Vicki Meyouhas, Masters of Science in Nursing student of the University of Ottawa School of Nursing. The purpose of this study is to describe the experiences of nurses who provide bereavement support to family members of patients who were under their care during the course of their illness. The knowledge gained from this study will assist in improving bereavement care to family members.

Procedure: Your participation will consist of meeting with the primary investigator, Vicki Meyouhas, for an individual audio recorded face to face interview of approximately 60 minutes to talk about your experience in providing bereavement support. You will be asked a number of open-ended questions about your experiences. The session will be scheduled and located at your convenience. You will also be asked to participate in a second individual audio recorded interview of approximately one hour to review the findings of the study. If you agree to participate in the second interview it will be scheduled at a time and place that are convenient to you.

Duration of Participation: It is expected that each of your two interviews will last approximately 60 minutes. The first and second interview session will be separated by several weeks.

Confidentiality: The data collected for this study will remain confidential. Your information will be coded. Only the researchers will see the information, which will be kept in a locked filing cabinet at the University of Ottawa and in the primary investigator's apartment. The data will be stored for five years after the study completion. The study results will be published. No personal identifying information will appear in any presentations or the published reports.

Anonymity: Anonymity will be protected in the following manner; during the transcription of the interview all personal identifying information will be removed and the tape and transcript will receive a code number.

Risk: It is anticipated that your participation in this study will involve minimal risks consisting of possible emotional upset when recalling experiences providing bereavement support.

Benefits: This study will give you the opportunity to discuss a component of your nursing practice. Your participation in this study will provide information that may contribute to the body of knowledge of the nursing discipline as little is currently known about how oncology nurses perceive their role as bereavement support providers. This information can be used by organizations to develop strategies to support nurses in their delivery of bereavement support interventions that assist family members experiencing the loss of a loved one.

Voluntary Participation: You are under no obligation to participate in this study and you may withdraw from this study at any time. You can refuse to participate or to answer individual questions without any impact to yourself or your status as a nurse employed in Jewish General Hospital.

Compensation: For each interview you will receive \$20.00 to cover parking fees or child care expenses.

Please keep this study information sheet for your records.

If you are interested in participating in this study and/or have any questions about the study, please contact:

Vicki Meyouhas RN BScN

If you have any questions regarding the ethical conduct of this study, you may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 159, Ottawa, ON K1N 6N5

Tel.: (6113) 562-5841

Email: ethics@uottawa.ca

OR

Jewish General Hospital Patient Representative,
Ms. Laurie Berlin

APPENDIX D: French Information Letter

Lettre d'information aux participants

Titre de l'étude :

**L'expérience des infirmières en oncologie offrant du soutien aux personnes
endeuillées**

Chercheurs :

Vicki Meyouhas IA BScN
Étudiante en Maîtrise, Sciences Infirmières
Université d'Ottawa
Faculté des Sciences de la Santé
École des Sciences Infirmières

Susan Brajtman IA PhD
Professeure assistante
Université D'Ottawa
Faculté des Sciences de la Santé
École des Sciences Infirmières

Sylvie Lauzon IA PhD
Vice rectrice associée aux études, professeure agrégée
Université d'Ottawa

Gail Macartney IA MScN, Infirmière Praticienne
Département d'hématologie
L'Hôpital D'Ottawa

But de l'étude : Votre participation est demandée pour un projet de recherche entrepris par Vicki Meyouhas, étudiante en maîtrise en Sciences Infirmières à l'Université d'Ottawa. Le but de l'étude est de décrire l'expérience des infirmières qui travaillent dans le milieu d'oncologie et qui font un suivi de deuil auprès des familles dont elles ont prises soins lors du cours de la maladie. Les connaissances dérivées par cette étude serviront à améliorer les soins destinés aux familles endeuillées.

Procédure : Votre participation consistera de rencontrer la chercheuse principale, Vicki Meyouhas, pour une entrevue individuelle qui se fera face à face et qui sera audio enregistrée. Lors de l'entrevue qui durera environ 60 minutes, la chercheuse vous demandera quelques questions à nature ouverte. La session se fera à un temps et lieu qui vous est convenaient. Vous serez demandée de participer à une deuxième entrevue qui se fera face à face et qui sera audio enregistrée. Le but de cette deuxième rencontre est de vérifier les résultats de l'étude. Si vous êtes en accord à participer à la deuxième entrevue, celle-ci se fera à un temps et lieu qui vous est convenaient.

Durée de la participation : Il est anticipé que votre participation aux deux entrevues durera environ 60 minutes pour chaque. La première et deuxième entrevue seront séparées par quelques semaines.

Confidentialité : Les données collectées pour cette étude demeureront confidentielles. Votre information sera codée. Seulement les chercheurs auront accès à l'information, qui sera gardée dans un cabinet verrouillé à l'Université d'Ottawa et à l'appartement de la chercheuse principale. Les données seront gardées durant cinq ans après la fin de l'étude. Les résultats seront publiés, cependant, aucune information qui a le potentiel d'identifier le participant n'apparaîtra dans des présentations ou dans des publications.

Anonymat : L'anonymat sera protégé de cette manière; durant la transcription des entrevues chaque donnée identifiante sera enlevée et chaque cassette et transcription recevront un code.

Risque : Il est anticipé que votre participation à cette étude consistera de risques mineurs tels que d'éprouver des émotions de tristesses lorsque vous parlez de vos expériences avec le suivi de deuil.

Bienfaits : Cette étude vous donnera la chance de discuter d'une partie de votre pratique infirmière. Votre participation dans cette étude procurera de l'information qui pourra contribuer aux connaissances de la discipline des Sciences Infirmières puisque très peu est connu à propos des perceptions des infirmières qui travaillent en oncologie et qui font le suivi de deuil. Ces informations pourront être utilisées par des organisations pour développer des stratégies qui supporteront les infirmières dans leur rôle de suivi de deuil.

Participation volontaire : Vous n'êtes sous aucune obligation pour participer à cette étude, vous pouvez retirer votre participation à n'importe quel moment. Vous pouvez refuser de répondre à certaines questions sans aucun méfaits à votre statut en tant qu'infirmière employée à l'Hôpital Generali Juif.

Compensation : Pour chaque entrevue vous allez recevoir 20\$ pour vos frais de stationnement ou service de garde.

S'il vous plait, gardez cette lettre d'information.

Si vous êtes intéressée à participer à cette étude et/ou vous avez des questions sur l'étude, s'il vous plait contactez :

Vicki Meyouhas IA BScN

Si vous avez des questions portant sur l'éthique de cette étude, vous pouvez contacter l'officier du protocole de l'éthique en recherche, Université d'Ottawa, Tabaret Hall, 550 rue Cumberland, chambre 159, Ottawa Ontario, K1N 6N5

Tel : 613-562-5841
ethics@uottawa.ca

OU

Hôpital Generali Juif, Représentative des patients
Mme Laurie Berlin

APPENDIX E: English Consent Form

SMBD - Jewish General Hospital
 University of Ottawa, School of Nursing
 Vicki Meyouhas RN BScN

Consent form

The Experiences of Oncology Nurses Who provide Bereavement Support.
 CIHR STP Palliative Care

Introduction:

I am invited to participate in the research study entitled “The Experience of Oncology Nurses who Provide Bereavement Support” conducted by Vicki Meyouhas (Primary Investigator and Master’s of Nursing student at the University of Ottawa), Dr. Susan Brajtman (Master’s of Nursing student’s thesis supervisor) and Dr. Sylvie Lauzon (member of the master’s student’s thesis committee). This research study is funded by the Canadian Institute of Health Research (CIHR)’s Strategic Training in Palliative Care initiative.

1. Purpose of study:

The purpose of the study is to better understand the experiences of nurses who provide bereavement support to family members’ of patients who were under their care during the course of their illness. The knowledge gained from this study will assist in improving bereavement care to family members.

Objectives of the study:

- 1) To explore how nurses perceive the benefits of providing bereavement support;
- 2) To explore how nurses perceive the challenges of providing bereavement support;
- 3) To understand the support nurses require to carry out their roles of bereavement support providers.

2. Procedures:

My participation will consist of meeting with Vicki Meyouhas for an individual audio recorded interview of approximately 60 minutes to talk about my experiences in providing bereavement support. I will be asked a number of open-ended questions. The session will be scheduled at a time and place that are convenient for me. I will also be asked to participate in a second individual audio recorded interview of approximately one hour to review the findings of the study. This second interview will be scheduled at a time and place that are convenient for me and will occur a few weeks after the 1st

interview. My participation is entirely voluntary, my manager/head nurse will not know of my participation in this study. My manager/head nurse has not been asked to recommend me for this study. During a presentation of study results no direct quotes from my interview will be used so as to keep my identity secret.

3. Risks and discomforts:

My participation in this study will involve the description of my experiences providing bereavement support. This may cause me to feel upset when I recall certain situations. I have received assurance from the researcher that every effort will be made to minimize these risks. I have been provided with the telephone number of the employee assistance program should I feel that I require additional support

4. Benefits:

This study will give me the opportunity to discuss a component of my nursing practice. My participation in this study will provide information that may contribute to the body of knowledge of the nursing discipline as little is currently known about how oncology nurses perceive their role as bereavement support providers. This information can be used by organizations to develop strategies to support nurses in their delivery of bereavement support interventions that assist family members experiencing the loss of a loved one.

5. Voluntary participation/withdrawal:

I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be destroyed. Audiotapes will be deleted; transcribed interviews will be deleted from the computer and paper copies will be shredded.

6. Confidentiality:

I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for the research thesis and for academic publications and presentations and that my confidentiality will be protected by the use of code number instead of my personal identifying information; for example "nurse #3". **Anonymity** will be protected in the following manner; during the transcription of the interview all personal identifying information will be removed and the tape and transcript will receive a code number.

Conservation of data: I have received assurance from the PI that the information I will share during this study will remain strictly confidential. I understand that the information I provide through the interview and any follow-up will be anonymous and that only codes will be used to identify my information. I have been instructed that only the researchers

listed above will see the information, which will be locked up in a filing cabinet at the home/office of the PI during the duration of the study and then transferred to a locked filing cabinet of Dr. Susan Brajtman, from the University of Ottawa, for a minimum of five years upon completion of the study. I have been made aware that the findings will be published but no personal identifying information will appear in any presentations, quotations, or published reports. During the study the tapes and hard copies of the transcripts will be kept in a locked cabinet in the primary investigator's home. The interview transcripts will also be located on the researcher's personal computer which is password protected. Only the researcher and members of the thesis committee will have access to the data. Upon study completion the tapes will be stored in a locked cabinet in the office of Dr. Susan Brajtman of the University of Ottawa for a period of five years, after which they will be destroyed.

7. Costs and compensation:

I will receive \$20.00 to cover my parking and/or childcare expenses.

8. Contact information or questions:

If I have any questions about the research now or later, I should call Vicki Meyouhas

If I have questions about my rights as a research participant, I may call the
Jewish General Hospital patient representative, Ms. Laurie Berlin

OR

If I have any questions regarding the ethical conduct of this study, I may contact
the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall,
550 Cumberland Street, Room 159, Ottawa, ON K1N 6N5

Tel.: (613) 562-5841

Email: ethics@uottawa.ca

STATEMENT OF CONSENT

The Experience of Oncology Nurses who Provide Bereavement Support

I have read the above information and my questions were answered to my satisfaction. A copy of this signed consent form will be given to me. My participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my medical care now or later. I do not give up any of my legal rights by signing this consent form. I agree to participate in this study.

I, _____, agree to participate in the **first** interview of the above research study conducted by Vicki Meyouhas of the Health Sciences, School of Nursing from the University of Ottawa, which research is under the supervision of Dr. Susan Brajtman.

AND

I, _____, agree to participate in the **second** interview of the above research study conducted by Vicki Meyouhas of the Health Sciences, School of Nursing from the University of Ottawa, which research is under the supervision of Dr. Susan Brajtman.

Signature: _____ Date: _____

Name of Participant: _____

Consent form administered and explained in person by:

Signature: _____ Date: _____

Name of Investigator (or its delegate) _____

APPENDIX F: French Consent Form

SMBD – Hôpital General Juif
Université d'Ottawa, École des Sciences Infirmières
Vicki Meyouhas IA BScN

Formulaire de consentement

L'expérience des infirmières en oncologie offrant du soutien aux personnes endeuillées

IRSC Plan Stratégique en Soins Palliatifs

Introduction : Je suis invité(e) à participer à la recherche intitulée «L'expérience des infirmières en oncologie offrant du soutien aux personnes endeillées » menée par Vicki Meyouhas (chercheuse principale, étudiante à la maîtrise en sciences infirmières) sous la supervision de la professeure Susan Brajtman, PhD et de la professeure Sylvie Lauzon PhD qui agit à titre de membre du comité de thèse. Ce projet de recherche est subventionné par les Instituts de recherche en santé du Canada (IRSC) dans le cadre du programme *Planification stratégique en soins palliatifs*

But de l'étude : Le but de l'étude est de décrire l'expérience des infirmières ou infirmiers qui offrent du soutien aux personnes endeillées à la suite du décès d'un proche qu'ils avaient soigné au cours de leur maladie. Les connaissances amassées par cette étude contribueront à améliorer le service de suivi offert aux personnes endeillées

Objectifs de l'étude :

- 1) Explorer la perception des infirmières et infirmiers quant aux bénéfices associés au soutien des personnes endeillées
- 2) Explorer la perception des infirmières et infirmiers quant aux difficultés associées au soutien des personnes endeillées
- 3) Cerner l'appui requis par les infirmières et infirmiers qui offrent le soutien aux personnes endeillées

Procédure : Ma participation consistera à rencontrer la chercheuse principale, Vicki Meyouhas, pour une entrevue individuelle qui se fera en personne et qui sera enregistrée sur bande audio. Lors de l'entrevue, d'une durée d'environ 60 minutes, la chercheuse me posera quelques questions ouvertes. La session se fera à un moment et dans un lieu qui me conviennent. On pourra me demander de participer à une deuxième entrevue, qui se fera aussi en personne et qui sera enregistrée sur bande audio. Le but de cette deuxième rencontre est de confirmer les résultats de l'étude. Si je suis d'accord pour participer à cette deuxième entrevue, celle-ci se fera à un moment et dans un lieu qui me conviennent.

Risque et inconforts : Puisque ma participation à cette recherche demande que je parle de mon expérience de soutien aux personnes endeuillées, il se peut que j'éprouve des sentiments de tristesse. La chercheuse m'a assurée qu'elle fera tout le nécessaire pour minimiser ces risques. Elle m'a aussi informée que je pourrais contacter le Service aux employés au si je nécessitais plus de soutien.

Bienfaits : Ma participation à cette recherche me donnera l'occasion de partager mon expérience relative au soutien que j'offre aux personnes endeuillées. Ceci pourra contribuer au développement de nouvelles connaissances dans le domaine des sciences infirmières ainsi que sur le rôle des infirmières et infirmiers quant au soutien aux personnes endeuillées. Les résultats obtenus pourront aussi guider les organisations de soins de santé dans le développement de stratégies pour appuyer les infirmières et les infirmiers qui offrent du soutien aux personnes endeuillées.

Participation volontaire : Je ne suis sous aucune obligation de participer à cette étude. Si je décide de participer, je peux retirer ma participation à n'importe quel moment ou refuser de répondre à certaines questions sans conséquences négatives. Si je décide de retirer ma participation, toute l'information acquise sera détruite; les cassettes et les transcriptions seront effacées de l'ordinateur et les copies papier seront détruites. Ma participation est entièrement volontaire, ma gestionnaire/infirmière chef ne sera pas avisée de ma participation à cette étude. Ma gestionnaire/infirmière chef n'a pas été demandée de me recommander pour cette étude. Lors d'une présentation des résultats de l'étude aucune information révélatrice à mon sujet ne sera présentée.

Confidentialité : J'ai l'assurance de la chercheuse que l'information que je partagerai avec elle restera strictement confidentielle. Je m'attends à ce que le contenu ne soit utilisé que pour la rédaction de la thèse, la présentation des résultats et la publication de travaux scientifiques. Ma confidentialité sera protégée en tout temps par l'utilisation de codes (i.e. « infirmière #3 ») à la place d'information qui m'identifierait. L'anonymat est garanti par l'omission de toute information personnelle lors de la transcription des entrevues et l'assignation d'un code à chaque transcription et cassette audio.

Conservations des données : On m'a assuré(e) que l'information que je vais partager demeurera strictement confidentielle. Je comprends que l'information que je donne durant l'entrevue ainsi que le suivi seront anonymes puisque des codes seront utilisés pour identifier mon information. J'ai été assuré(e) que seulement les chercheuses inscrites ci-haut auront accès à mon information. Cette information sera gardée sous clef dans à la résidence de la chercheuse principale durant la durée entière de l'étude et sera transférée par la suite au bureau de la superviseure de thèse, Dr. Susan Brajtman, pour être gardée pendant un minimum de cinq ans. J'ai été informé(e) que les résultats seront publiés mais qu'aucune information identifiante ne sera utilisée dans des présentations, des publications et des extraits de texte. Pendant l'étude, les cassettes et les copies papier seront gardées dans l'appartement de la chercheuse principale. Les transcriptions seront aussi sauvegardées sur l'ordinateur personnel de la chercheuse principale et seront

protégées par un mot de passe. Seule la chercheuse et les membres du comité de thèse auront accès aux données. Lorsque l'étude sera terminée, les cassettes seront gardées dans le bureau du Dr. Susan Brajtman de l'Université d'Ottawa pour une période de cinq ans. À la fin de cette période, les documents et les cassettes seront détruits.

Compensation : Pour chaque entrevue je recevrais 20\$ pour mes frais de stationnement ou de service de garde.

Information de contact : Si j'ai des questions sur l'étude, maintenant ou plus tard, je peux contacter Vicki Meyouhas au 613-594-3504. Si j'ai des questions portant sur mes droits en tant que participante, je peux contacter la représentante des patients du Sir Mortimer B. Davis Hôpital Général Juif, Mme Laurie Berlin

OU

Pour tout renseignement sur les aspects éthiques de cette recherche, je peux m'adresser au responsable de l'éthique en recherche, Université d'Ottawa, Pavillon Tabaret, 550, rue Cumberland, salle 159, Ottawa Ontario, K1N 6N5.

Téléphone : 613-562-5841

Courriel : ethics@uottawa.ca

CONSENTEMENT
L'expérience des infirmières en oncologie offrant du soutien aux personnes
endeuillées

J'ai lu l'information si haut et mes questions ont été répondues à ma satisfaction. Une copie de ce document signé m'appartient. Ma participation est volontaire et je peux me retirer de l'étude à n'importe quel moment sans donner de raisons, sans que cela affecte mon statut d'infirmière employée au Sir Mortimer B. Davis Hôpital Général Juif maintenant ou plus tard. Je n'ai pas perdu mes droits légaux en signant ce consentement. Je suis d'accord à participer à cette étude.

Je, _____, suis d'accord à participer à la **première** entrevue de l'étude de recherche nommée ci-haut, menée par Vicki Meyouhas de l'École des sciences infirmières, Faculté des sciences de la santé de l'Université d'Ottawa, sous la supervision de Dr. Susan Brajtman.

ET

Je, _____, suis d'accord à participer à la **deuxième** entrevue de l'étude de recherche nommée ci-haut, menée par Vicki Meyouhas de l'École des sciences infirmières, faculté des sciences de la santé de l'Université d'Ottawa, dont l'étude est sous la supervision de Dr. Susan Brajtman.

Signature : _____ Date : _____

Nom du participant(e) : _____

Formulaire de consentement administré et expliqué par :

Signature : _____ Date : _____

Nom de la chercheuse : _____

APPENDIX G: Interview Questions and Demographic Data- English

Interview Questions/ Demographic Data

Participants will be asked for general demographic data:

- 1) How many years of experience do you have in nursing?
- 2) How many years of experience do you have in oncology nursing?
- 3) What is your highest level of education?
- 4) Do you have a certification in oncology nursing?

Interview Questions

Participants will then be asked the general question:

“Please describe your experience of providing bereavement support”.

Prompting questions may be employed as necessary to generate more data. These questions may include:

- 1) What are some of the benefits involved in this role for you?
- 2) What are some of the challenges associated with this role for you?
- 3) Can you share some experiences that have been particularly significant for you?
- 4) What kind of support do you need to carry out this aspect of your nursing role?

APPENDIX H: Interview Questions and Demographic Data- French

Données sociodémographiques et questions pour l'entrevue

Des questions générales porteront sur les données socio-démographiques :

- 1) Combien d'année(s) d'expérience avez-vous en tant qu'infirmière?
- 2) Combien d'année(s) d'expérience avez-vous en tant qu'infirmière dans le milieu de l'oncologie?
- 3) Quel est votre plus haut niveau d'éducation?
- 4) Avez-vous une certification en oncologie?

Questions d'entrevue :

La question générale suivante sera posée :

« Pouvez-vous, je vous prie, me décrire votre expérience relative au suivi de personnes endeuillées ? »

D'autres questions seront employées afin de générer plus d'information. Ces questions sont les suivantes :

- 1) Quels sont, d'après vous, les bénéfices que vous retirez de ce rôle ?
- 2) À votre avis, quelles sont les difficultés associées à ce rôle?
- 3) Pouvez-vous me parler de certaines expériences qui vous ont spécialement marqué(e)?
- 4) De quelle sorte de soutien croyez-vous avoir besoin afin de mieux assumer ce rôle auprès des personnes endeuillées ?

APPENDIX I: Description of Nursing Roles

The IPOs

Infirmière pivot en oncologie (IPO) is a relatively new nursing role developed in the early 2000s as an initiative by the Quebec Ministry of Health. Nurses in this position hold a Bachelor's or a Master's degree in Nursing. These nurses work closely with oncology patients and their families, and follow them from diagnosis to the end-of-life, including bereavement. The IPOs may also maintain contact with patients and their families during remission. They are an integral part of the interdisciplinary team and interact with the patient and/or family on a regular basis. There are four main components within the role of an IPO: evaluating, teaching/informing, supporting, and coordinating. The IPO is also expected to take part in pertinent research at the regional, provincial, national and international levels (Quebec-Ministry-of-Health, 2009).

These nurses do not necessarily provide direct patient care, such as chemotherapy or dressing changes, but they remain quite involved in the patient's care as they coordinate necessary consults, arrange appropriate services, and are an important resource for both patients and their families. IPOs act as a consistent presence for cancer patients and their families, who tend to have contact with numerous professionals and resources during the disease course.

Patients with lymphoma or bowel, breast, and lung cancer, are followed by an IPO who specializes in cancers in these areas of the body. A large component of the IPO's work occurs over the telephone or involves follow-ups with patients for symptom management,

appointment scheduling, and other issues that may arise. IPOs place the family at the center of their interventions by teaching, providing information, and offering support to

Oncology Clinic Nurses

Nurses in the oncology clinic work in a fast-paced environment where patients come to receive chemotherapy and blood products before returning home the same day. Nurses who follow the primary nursing model have the opportunity to get to know their patients and their families very well as treatment may last weeks to months. The contact these nurses have with patients is periodically disrupted if the patient is hospitalized, or if remission is achieved. Nurses usually find out about the death of a patient through colleagues, families, or by reading obituaries in the newspapers.

In-patient Oncology Nurses

Nurses who work in the in-patient department provide complete care to patients, which involves conducting thorough assessments, providing basic care, and the administration of chemotherapy. The model of primary nursing is used on the in-patient department, however due to occasional issues with staffing and heavy patient assignments, it is possible that a primary nurse may not be assigned to her patient on certain days. The nurses' workloads have been described as "very heavy" and the work "very busy". They often spend hours per week with these patients and consequently know them and their families very well. As primary nursing is practiced on this particular unit, the bond developed between nurses and their patients/families can be very strong. Patients usually die in hospital and their primary nurse may or may not be on shift at that time.