Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

by

Jamie L. Penner

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfillment of the requirements for the degree of

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Abstract

Background: Dysphagia is a common symptom experienced by people with advanced head and neck cancer, who often require tube-feedings to help meet their nutritional needs. Family caregivers involved in the care of these patients report feeling ill-prepared to manage tube-feeding related aspects of care. The ability of the health care team to support these family caregivers is contingent upon a clear understanding of their experiences in caring for tube-feeding dependent patients, and the information and support needs they identify as being helpful to them in the provision of this care. To date these experiences have not been systematically examined and described, hence the need for, and purpose of this study.

Method: Consistent with the study's aim, and in response to the paucity of research examining family caregiving experiences, a qualitative study using a descriptive phenomenological approach was conducted with family caregivers of tube-feeding dependent advanced head and neck cancer patients (n=6). Initial audio-taped face-to-face and follow-up interviews were conducted with family caregivers to obtain a rich description of their experiences. Interviews were transcribed verbatim and data analysis was carried out using Spiegelberg's three step process of inductive data analysis. Rigor as it is understood in qualitative research and described by Lincoln and Guba (1985) were applied in this study.

Results: The experience of caring for a dysphagic family member with advanced head and neck cancer who is either totally or partially reliant on tube feeding means "negotiating a new normal". Five major themes emerged from the data that captured family caregivers' experiences. They included: i) decision making challenges; ii)

matters of negotiation; iii) facilitators of negotiation; iv) levels of negotiation; and iv) triggers for renegotiation.

Conclusions: The specific and considerable needs of patients with advanced head and neck cancer receiving tube-feeding place significant caregiving demands on family members. The findings from this study underscore the importance of: i) clinicians taking the time to assess and respond to the information needs that family caregivers have, and supporting them in their caregiving role as they learn to "negotiate a new normal" and; ii) the need for future research geared toward developing and testing psycho-educational interventions aimed at supporting family caregivers in the important and difficult caregiving work they do. Such research will enhance the ability of those in clinical practice, education, and research to provide meaningful support to family members caring for tube-feeding dependent loved ones.

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Dedication

To my precious Grandma, an extraordinary woman and wonderful friend. Your quiet strength spoke volumes and your laughter brought me so much joy. Thank you for believing in me. My life has been blessed because of you. I miss you dearly.

&

To the memory of a special patient whose brief acquaintance had a significant impact on my life. Thank you for inspiring me through your remarkable spirit. I will be forever grateful that our paths crossed.

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CHAPTER 1: STATEMENT OF THE PROBLEM

Cancer of the head and neck is a phrase used to describe various neoplasms that arise from the mucosa of the upper aerodigestive tract. More than 4,300 Canadians will develop cancer of the head and neck in 2008 (Canadian Society of Otolaryngology, 2008). Despite the fact that head and neck cancers only account for an estimated 3% of all cancers (Jemal, Siegel, & Ward, 2006), the specific needs of this patient population are considerable. Head and neck cancers are frequently diagnosed at an advanced stage, characterized by invasive tumors and involvement of cervical lymph nodes (Souhami, Tannock, Hohenberger, & Hariot, 2002). The five year survival rate for advanced head and neck cancer is poor (<50%), and despite significant research into treatment regimens for head and neck cancer, patient survival rates have remained relatively unchanged over the past few decades (Jemal et al., 2006).

Individuals with advanced head and neck cancer experience a multitude of challenges as they respond to their illness, including difficulty with speech, breathing, and the ability to eat and drink. Dysphagia, defined as difficulty swallowing (Zorowitz & Robinson, 1999), is present in over 50% of head and neck cancer patients prior to treatment, particularly in those individuals with advanced stage disease (Pauloski et al., 2000). Treatment of advanced head and neck cancer has evolved to include organ preservation protocols in the form of concurrent chemoradiation therapy. The assumption is that combined chemoradiation therapy will preserve the function of the treated organ and decrease morbidity associated with surgery and postoperative radiation. Despite high rates of locoregional disease control, however, organ preserving treatments are associated with severe side effects related to treatment, with the most

common long-term complication being dysphagia (Hanna et al., 2004). Persistent dysphagia poses significant challenges in the areas of nutrition and hydration, and increases the risk of aspiration. Of equal importance is the consideration that difficulty with oral intake also negatively affects the patient's social interactions and emotional well being; consequently, the quality of life in this patient population is gravely affected (Nguyen et al., 2005).

Patients with advanced head and neck cancer, who experience dysphagia, often require the initiation of tube-feeding to maintain their nutritional needs (Newman et al., 1998). In a prospective study (Newman et al., 1998) examining the weight and eating status of patients with advanced head and neck cancer (N=47) treated with concurrent chemoradiation before and up to 18 months after treatment, it was determined that patients lost approximately 10% of their pretherapy body weight during treatment, necessitating tube feeding. Newman and colleagues (1998) also reported that while only 9% of patients required a feeding tube at the start of treatment, 26% had feeding tubes immediately following the completion of treatment, and 13% of patients still required a feeding tube to maintain their nutritional status 18 months after treatment.

Cancer is a disease that affects the entire family and not just the individual who has been diagnosed with the illness. Thus families of individuals with advanced head and neck cancer are also deeply affected by the illness and side effects such as dysphagia. Families play an essential role in the care of patients with cancer (Northouse, 2005) and frequently undertake caregiving responsibilities for their loved ones, including the care of dysphagic patients with head and neck cancer discharged from the hospital. Silver and Wellman (2002) report that family members provide care

for more than 75% of older adults who are dependent on home care technologies such as home enteral nutrition, including those individuals with neoplasms of the head and neck. Though family caregiving can be rewarding, it is not without stress and anxiety (Payne, Smith, & Dean, 1999). In the case of family members caring for a loved one with enteral tube feeding, stress and anxiety may be caused in part by the new skills and unique knowledge they must acquire related to enteral tube feeding procedures and tube management. These caregiving responsibilities must be carried out whilst simultaneously monitoring the family member's fluid and nutrient balance, managing illness related symptoms, responding to emergency care needs, making care-decisions, and providing emotional care and support. Unsurprisingly, the literature consistently states that family members frequently report feeling ill-prepared to assume care responsibilities for patients with advanced disease (Ross, MacLean, Cain, Sellick & Fisher, 2001).

More than 235,000 Canadians die from all causes each year (Statistics Canada, 2008). An increasing number of these individuals, including those with advanced head and neck cancer, are dying at home. Population surveys have established that the majority of people would prefer to be cared for and die at home (Higginson & Sen-Gupta, 2000). Furthermore, the public health care system emphasizes home-based care in an effort to contain costs (Dunbrack, 2005). Home care is viewed as being fundamental to the overall sustainability of the health care system and governments are developing strategies to enhance home care services (Health Canada, 2004). However, models of home care are based on the premise that informal caregivers are key players in the provision of the very services which allow the seriously ill and those at the end-

of-life to remain in the community (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Moreover, the assumption on the part of governments and policy makers that informal caregivers are both willing and able to assume caregiving responsibilities is flawed, in that taking care of a loved one cannot be equated with the complex skill set necessary to care for a dying cancer patient. As such, understanding the role of the informal caregiver and identifying the specific needs of the families and friends who provide care to the ill person is imperative if health care providers are to learn how to best support these individuals in their caregiving role.

The ability of the health care team to support family members caring for head and neck cancer patients receiving tube-feeding is contingent upon a clear understanding of the experiences of family caregivers. To date, this issue has not been empirically examined. A descriptive phenomenological study will be conducted to redress this gap in the scientific literature.

Purpose of the Study

The overarching research question driving this study is: "What is the nature of the experience of caring for a dysphagic family member with advanced head and neck cancer who is either partially or totally reliant on tube-feeding?" Research sub-questions include the following:

1. How does caring for a family member, who has advanced head and neck cancer and who receives enteral tube feeding, affect the family caregiver?
2. Do family caregivers of this particular patient population have specific needs related to their caregiving responsibilities?

3. What are the specific needs of the family caregivers as identified by the caregivers themselves?

Assumptions Underlying the Study

The following assumptions underlie this study:

1. The experience of caring for a family member with head and neck cancer who is dependent on tube-feeding can be challenging.

2. Family caregivers are affected by their caregiving role.

3. Family caregivers have needs in relation to their caregiving role.

4. Family caregivers are able to express their caregiving needs.

Definition of Terms

The following terms are defined as they were used in this study:

Advanced Head and Neck Cancer: stage III or IV (TNM classification of staging) neoplasm of the upper aerodigestive tract (Greene, American Joint Committee on Cancer, & American Cancer Society, 2002).

Enteral Tube Feeding: feeding of the appropriate formula to a patient through a tube passed into the stomach or duodenum from the nasal passage (nasogastric or nasoduodenal tube), or by a gastrostomy or jejunostomy tube (Thomas, 1997).

Family Caregiver: also referred to as informal caregiver; those individuals identified by patients who provide patients with unpaid help in relation to their physical care or coping with disease. These individuals are not restricted to include only biological kin, but reflect a more inclusive definition of "family member" as perceived by the patient.

Significance of the Study

In order to provide family caregivers with the information and support they need to carry out their caregiving role, clinicians must first understand the nature of the caregiving experience from the family member's perspective. The findings from this study will provide relevant, empirically based guidance to clinicians that will enable them to better meet family caregiver needs regarding the care of the tube-fed patient, by addressing the needs that family members have identified as being salient. Developing a thorough understanding of the experiences of family caregivers of patients with advanced head and neck cancer who are receiving enteral tube feeding will also provide the foundation for future psychosocial/educational intervention studies aimed at supporting these caregivers in the important work that they do.

Summary

This chapter presented the statement of the problem and described the purpose of this study. The assumptions underlying this study were outlined and key terms that are relevant to this study were defined. As well, the significance of the study was discussed. The following chapter will provide the reader with a review of the empirical literature relevant to this study.

CHAPTER TWO: LITERATURE REVIEW

This chapter will provide an overview of the literature related to this study. Because the purpose and scope of a literature review when conducting research using a descriptive phenomenological approach is different than when conducting a quantitative study, a brief discussion of the use of literature in descriptive phenomenology prefaces the actual literature review.

The Use of Literature in Descriptive Phenomenology

Researchers utilizing a phenomenological approach to inquiry do not generally conduct a full review of the literature prior to the start of the study. Unlike quantitative methods that require an exhaustive search of the literature prior to the commencement of an investigation, in phenomenology, data collection is ideally complete prior to an extensive search of the literature being conducted (Speziale & Carpenter, 2007). The reason for not conducting an exhaustive literature review at the outset of the study is to reduce the likelihood that the researcher will develop preconceived ideas and biases about the topic under investigation. By being naïve to the literature, the researcher is protected from unduly leading study participants during the interview process in the direction of the researcher's beliefs and insights as a result of being immersed in the literature. This naiveté to the literature is necessary to help achieve a pure description of the phenomenon under investigation. Once data analysis is complete, researchers review the literature to situate their findings within the context of what is already known about the phenomena (Speziale & Carpenter, 2007).

A cursory review of the literature may be done to determine the necessity of the study (Speziale & Carpenter, 2007). In fact, proposal requirements for thesis and ethics

committees substantiate the need for a cursory review of the literature. As such, the aim of this literature review was to establish the need for this study by locating, critically reviewing, and summarizing bodies of literature related to: i) dysphagia in patients with advanced head and neck cancer; ii) family caregivers of patients with advanced cancer; iii) family caregivers of patients with advanced head and neck cancer; iv) family caregivers of patients receiving enteral tube feeding; and v) family caregivers of patients with advanced head and neck cancer who are receiving enteral tube feeding.

Dysphagia in Patients with Advanced Head and Neck Cancer

Individuals diagnosed with advanced head and neck cancer experience a number of challenges in relation to their disease. One of the main challenges is that of dysphagia, or difficulty swallowing (Zorowitz & Robinson, 1999). Dysphagia has a profound and multidimensional impact on the lives of patients and their families (Penner, McClement, & Sawatzky, 2007). It is therefore concerning that more than half of those individuals diagnosed with cancer of the head and neck experience dysphagia prior to undergoing treatment, particularly those with advanced stage disease (Pauloski et al., 2000). Furthermore, treatments for advanced head and neck cancer often exacerbate swallowing difficulties that are in turn persistent and enduring long after treatments are complete.

Standard treatment modalities for advanced head and neck cancer include surgical resection, followed by post-operative radiation therapy, or combined chemoradiation therapy (Souhami et al., 2002). Surgical resection and reconstructive procedures alter the normal anatomy required for effective deglutition (Zorowitz & Robinson, 1999). During radiation therapy, critical structures necessary for normal

swallowing commonly fall within the irradiated field and are thus subject to responsive tissue changes such as mucositis and erythema, which cause pain and burning on swallowing (Arcuri & Schneider, 1992). Radiotherapy treatments are also associated with taste disturbances, hyposalivation, dental problems, and tissue fibrosis exacerbating patients' swallowing difficulties and placing them at an increased risk for aspiration (Czreninski & Kaplan, 2005).

Recently, the treatment of advanced head and neck cancer has evolved to include organ preservation protocols in the form of combined chemoradiation therapies (Souhami et al., 2002). The assumption underlying these new treatment modalities is that preserving anatomical structures through combined chemoradiation therapy will in turn maintain the function of the treated organ and decrease the morbidity associated with surgery and radiation therapy. However, despite high rates of locoregional disease control, combined chemoradiation treatment modalities are still associated with severe adverse effects, the most common long term complication being that of dysphagia (Hanna et al., 2004).

Patients with advanced head and neck cancer who have difficulty with oral intake experience altered social interactions, feelings of embarrassment, and feelings of social isolation (Larsson, Hedelin, Johansson, & Athlin, 2003). As a result of these negative experiences, dysphagic head and neck cancer patients report a decreased quality of life (QOL) (El-Deiry et al., 2006; Nguyen et al., 2005). Individuals with moderate-to-severe dysphagia have a significantly lower QOL compared to patients with no or mild dysphagia (Nguyen et al., 2005). Moreover, despite assumptions that treatments involving organ preservation will result in a higher QOL for patients

receiving these particular treatment protocols, individuals with advanced head and neck cancer experience similar side effects from treatments, persistent swallowing difficulties, and social disruption regardless of the treatment modality they receive (El-Deiry et al., 2006).

Little research has been done related to interventions that optimize swallowing function and QOL in patients with advanced head and neck cancer. However, studies examining the effects of swallowing maneuvers (Lazarus, 1993; Lazarus, Logemann, Song, Rademaker, & Kahrilas, 2002), tongue function (Lazarus et al., 2000), and pretreatment swallowing exercises on swallowing-specific QOL (Kulbersh et al., 2006) suggest that swallowing function and QOL can be improved for patients with advanced head and neck cancer who experience dysphagia. In addition to further studies examining swallowing interventions, research related to the lived experience of dysphagia in patients with advanced head and neck cancer would lead to a better understanding of the meaning that these individuals and their families attach to their experience and provide useful insights towards supportive interventions.

Inherent to swallowing function and QOL is the challenge that individuals who experience dysphagia are confronted with as regards maintaining their nutritional status. Patients with advanced head and neck cancer, who experience dysphagia, often require the initiation of tube-feeding to maintain their nutritional needs (Newman et al., 1998). In a prospective study (Newman et al., 1998) examining the weight and eating status of patients with advanced head and neck cancer (N=47) treated with concurrent chemoradiation before and up to 18 months after treatment, it was determined that patients lost approximately 10% of their pretherapy body weight during treatment,

necessitating tube feeding. Newman and colleagues (1998) also reported that while only 9% of patients required a feeding tube at the start of treatment, 26% had feeding tubes immediately following the completion of treatment, and 13% of patients still required a feeding tube to maintain their nutritional status 18 months after treatment.

Families play an essential role in the care of patients with cancer (Northouse, 2005), and frequently undertake caregiving responsibilities for patients, including dysphagic head and neck cancer patients discharged from hospital to home (Keating et al., 1999). Indeed, Silver and Wellman (2002) report that family caregivers provide care for more than 75% of older adults who are dependent on home care technologies such as home enteral nutrition, including those with neoplasms of the head and neck. As such, it is imperative that family caregivers are recognized and supported in their caregiving role.

Family Caregivers of Patients with Advanced Cancer

Families of patients diagnosed with advanced cancer are deeply affected by the challenges of the illness. Aside from dealing with their own emotional response to the illness, family members often assume the role of a caregiver laden with caregiving responsibilities. Advanced illness provokes considerable practical changes in the lives of patients and their families (Winterling, Wasteson, Glimelius, Sjödén, & Nordin, 2004) and may have significant and enduring effects on the physical, mental, and financial well-being of family caregivers (Kristjanson & Aoun, 2004; Winterling et al., 2004). As family caregivers become partners in the health care team they should be embraced by health care providers who have an awareness and understanding of the effects that caregiving may have on family members (Given, Given, & Kozachik,

2001). Moreover, it should be recognized that family members are in a unique position of both giving and needing support (Harding & Higginson, 2003).

Family caregiving during terminal illness is recognized as a process that occurs over time (Brown & Stetz, 1999). In the course of caregiving, family members progress from becoming a caregiver at diagnosis or when their loved one becomes symptomatic or incapacitated from treatment, to filling the vital role as a caregiver during the final phase of life (Brown & Stetz, 1999). The evolutionary process of becoming a caregiver is a significantly emotional time in which the caregiver adjusts to new roles, learns new skills, and gives up aspects of their former lives (Brown & Stetz, 1999). During this time, family caregivers view themselves as the persons primarily bearing responsibility and providing care for their loved ones which can be demanding and highly stressful (Wennman-Larsen & Tishelman, 2002). It is in becoming a caregiver that family caregivers grow to be aware of the source of their commitment to care, whether it be a sense of duty, affection, or the mere absence of other alternatives (Brown & Stetz, 1999; Burridge, Winch, & Clavarino, 2007). While some family caregivers may feel highly committed to providing care for their loved one, often caregivers may not be interested in caregiving, but prevailing social norms pressure them to accept the role, and reluctance may be hidden to avoid criticism (Burridge et al., 2007). As a result, carer-patient relationships may be compromised and quality of care reduced.

Thomas, Morris, and Harman (2002) describe the caregiving experience as being comprised of care work and emotion work. Care work is reflected in the range of new caring activities that family caregivers find themselves engaged in as the nature and distribution of care work tasks within the family changes. Care work demands vary

with the stage of the disease and social circumstances influence the capacity of the family caregiver to take on greater quantities of care work (Thomas et al., 2002). Emotion work is a crucial aspect of the cancer caregiving experience and involves the emotional effort made by family caregivers to manage their own feelings and those of the patient (Thomas et al., 2002). While it is convenient to view the caregiving experience in such an orderly and compartmentalized fashion, in reality the complexity of caring for a cancer patient reflects the variability associated with tumor type, treatment modalities and stage of disease (Thomas et al., 2002).

The Burden of Caregiving

Several studies have documented the burden that caring for a terminally ill person places on the family caregivers (Goldstein et al., 2004; Grunfeld et al., 2004; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Caregiver burden is "the distress that caregivers feel as a result of providing care" (Given et al., 2001, p.221).

Throughout the process of engaging in the caregiving experience, family caregivers often perceive their own needs as less important than the patients' (Kristjanson, 1986). In fact, research demonstrates that provision of quality care to the patient by the staff is an important component of family satisfaction with palliative care (Kristjanson, 1986). Clearly, family caregivers feel a responsibility to meet the needs of the patient; however they frequently report feeling ill-prepared to assume care responsibilities for patients with advanced disease (Ross et al., 2001). As a result, caregivers' unmet needs in relation to the patients' unmet needs are consistently associated with negative aspects of the caregiving experience (Sharpe et al., 2005).

Integral to meeting the care needs of the patient are disruptions in the caregivers' routine (Sharpe et al., 2005) and restrictions in caregivers' ability to participate in valued activities because of caregiving responsibilities (Cameron, Franche, Cheung, & Stewart, 2002; Goldstein et al., 2004; Payne et al., 1999). Such constraints contribute significantly to the burden of caregiving. Model caregivers reported in the literature, that is younger caregivers, females, and those who are a child of the patient often find disruptions to their own schedules especially burdensome (Payne et al., 1999). This perceived burden may be due to the stress of competing demands with respect to work and family life. Indeed, a longitudinal study conducted by Kim, Baker, Spillers, and Wellisch (2006) demonstrated that the multiple roles that are simultaneously carried out by caregivers are likely to compete with each other with respect to the caregiver's limited psychological resources, resulting in the caregiver feeling strained by the new caregiver role. Interestingly, however, family caregivers may benefit from being employed during the time they are providing care, in that employment may operate as a respite, providing caregivers with opportunities to restore their psychological resources. The beneficial impact of performing multiple roles does not hold true for employed caregivers who also have a parental role, however (Kim et al., 2006). According to Kim and colleagues (2006) the most advantageous combination and number of roles to facilitate optimal adjustment in family caregivers of patients with cancer remains unclear.

Psychological effects. The burden of caring for a seriously ill family member is associated with a number of negative sequelae. Of notable importance is the psychological and emotional distress that family caregivers experience as they

undertake new and demanding responsibilities associated with the caregiving role (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Cameron et al., 2002; Dumont et al., 2006; Kim et al., 2006; Payne et al., 1999). Caregiving responsibilities evoke a considerable amount of anxiety in family caregivers (Braun et al., 2007; Grunfeld et al., 2004). Stress and anxiety may be caused in part by the new skills and broad knowledge they must acquire in a short period of time, whilst simultaneously monitoring the family member's illness, managing illness related symptoms, responding to emergency care needs, making care-decisions, and providing emotional care and support. In addition, those caregivers with fewer social networks and low levels of available support are particularly burdened by the stressors associated with the caregiving experience and are especially vulnerable to psychological morbidity (Dumont, et al., 2006; Goldstein et al., 2004; Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001; Payne et al., 1999). The anxiety imparted by overwhelming caregiver responsibilities often manifest in largely fluctuant sleep quality and depressive symptoms (Carter, 2002, 2003; Carter & Acton, 2006; Hearson, 2007). Moreover, as the patient's disease progresses and caregiving demands change, psychological distress in family caregivers is heightened (Dumont et al., 2006). Considering the amount of pressure and anxiety that the caregiving experience brings to family caregivers, it is not surprising that caregivers' psychological morbidity is often equal to or greater than that of patients themselves (Grunfeld et al., 2004).

Inherent within caregiving responsibilities is the demand on family caregivers to effectively manage distressing symptoms that the patient may be experiencing, and, family caregivers have identified symptom management and patient comfort as their

primary concern in caring for patients with cancer at home (Kristjanson, 1986, 1989). In order for family caregivers to successfully care for patients it is essential that they develop the necessary skills to accurately assess and deal with the patients' distressing symptoms. Research indicates that caregivers have a natural tendency to imagine the patient's viewpoint when responding to patient symptom experiences (Lobchuk, McClement, Daeninck, & Elands, 2007). In fact, accurate perceptions about patients' illness and symptom experiences are enhanced when caregivers are prompted to imagine how patients perceive the situation (Lobchuk & Vorauer, 2003; Lobchuk, 2006; Lobchuk, Degner, Chateau, & Hewitt, 2006; Lobchuk, McClement, Daeninck, Shay, & Elands, 2007). Fortunately, family caregivers' perceptions of advanced cancer patients' symptoms are largely accurate and ratings of symptom distress between family caregivers and patients are often highly correlated (Kristjanson et al., 1998; McPherson, Wilson, Lobchuk, & Brajtman, 2008). That said, developing assessment and caregiving skills may be taxing for family caregivers, and lack of mastery in relation to these skills contributes to the psychological and emotional distress of the caregiving experience (Nijboer et al., 2001).

The burden of family caregiving may well extend beyond the actual period of direct care provision into the bereavement period. A longitudinal study conducted by Ferrario, Cardillo, Vicario, Balzarini, and Zotti (2004) revealed that one year after the death of patients with advanced cancer, family caregivers show a perceived increase in emotional and social problems regardless of their gender or the duration of their patient's disease. Elderly caregivers were found to be at a greater risk of developing problems over time (Ferrario et al., 2004). Moreover, poor family functioning and

negative changes in mental health status and cognitive performance experienced by caregivers in the palliative care phase of the patient's illness as a result of decreased family satisfaction with care received by hospital staff continue into the early bereavement period (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). These findings reflect the significant and enduring impact that the caregiving experience has on family caregivers of patients with advanced cancer, and underscore the need for research to understand and support family members in their caregiving role.

Although most research has focused on the assessment of the negative psychological ramifications associated with caregiving, the psychological rewards and satisfaction of caregiving have also recently been recognized (Hudson, 2004). Home-based palliative caregiving results in life-enriching experiences for many caregivers, including opportunities for reciprocity, finding meaning in the situation, and spending time with the patient (Stajduhar, 2003). Similarly, Koop and Strang (2003) found that in home-based family caregiver situations, positive bereavement outcomes predominated over negative reactions because the caregivers had an overall sense of having accomplished something difficult and extremely valuable.

Physical effects. While much of the literature reports on the effects of caregiving on the mental health of family caregivers, there is evidence that the physical health of caregivers is also affected. A prospective population-based cohort study conducted by Schulz and Beach (1999) found that the strain of caregiving for a patient with cancer increased the *caregiver's* risk of mortality by 63% within five years. Family caregivers are at risk for negative health effects that surface as the demands for care increase and as caregiving responsibilities extend through time (Burton, Newsom,

Schulz, Hirsch, & German, 1997; Morse & Fife, 1998). In particular, during the palliative care phase and bereavement period, the health status of family caregivers is poorer compared with the "normal healthy" population (Kristjanson et al., 1996).

Financial effects. The impact of family caregiving is also reflected in the economic burden that caregiving places on the caregivers. Many caregivers of terminally ill patients in the United States report spending 10% of their household income on health care costs, requiring a loan or second job to cover costs (Emanual, Fairclough, Slutsman, & Emanual, 2000). Family caregivers in Canada also bear the financial costs associated with caring for a patient in a home care setting (Morris & Thomas, 2001). Many caregivers quit their job, decline advancement, lose work hours, or use special leave or holiday time in order to fulfill caregiving responsibilities (Grunfeld et al., 2004). Furthermore, lack of support services in many geographic areas exacerbates the economic impact of caring for an ill family member (McCorkle & Pasacreta, 2001).

Quality of Life

Providing care over an extended amount of time in a home setting can impose significant demands and cause considerable stress that dramatically affects family caregivers' quality of life (QOL). QOL has been conceptualized as a multidimensional construct in which physical (physiological), psychological (emotional), and social/financial domains are the most frequently included (Chen, Chu, & Chen, 2004). Functional and spiritual aspects may also be considered, depending on the scale used to measure QOL (Chen et al., 2004). A number of influences are associated with the QOL of family caregivers of patients with cancer. Not surprisingly, lesser performance of

healthy behaviours and the presence of emotional strain contribute significantly to a decreased QOL in family caregivers (Matthews, Baker, & Spillers, 2004). Considering the physical and psychological effects of the caregiving experience on family caregivers, attention to their QOL warrants consideration. Decreased caregiver QOL is also associated with a low income, living only with the patient, diminished marital satisfaction, a high level of patient dependency, and a higher intensity of caregiving tasks (Chen et al., 2004; Meyers & Gray, 2001; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). In addition, the longer the dying process is requiring a longer time in the caregiver role the more likely caregivers will experience a decreased QOL (Meyers & Gray, 2001). Interestingly, a cross-sectional study by Chen and colleagues (2004) that examined the impact of cancer patients' QOL on that of their caregivers' QOL found that caregivers' QOL did not correlate with that of patients' when caregiving duration was between seven and twelve months but was significantly correlated beyond twelve months. The authors suggested that these findings may reflect the caregivers' adjustment to the caregiving role and stability of the patients' disease during this time period. However, when caregivers are required to fulfill the caregiving role beyond twelve months (Chen et al., 2004) or when dying takes longer than anticipated (Meyers & Gray, 2001), the burden on caregivers is amplified.

Although many aspects of family caregiving may lead to negative effects on the caregivers and a decreased QOL, there are facets of providing care to a loved one that contribute to sustaining a positive QOL. Caregivers' positive expectations, self-efficacy, and feelings of meaningfulness are positively related to caregivers' QOL (Chen et al., 2004; Matthews et al., 2004; Nijboer et al., 1999). Moreover, those

caregivers who derive self-esteem from caregiving are better able to maintain a positive QOL (Chen et al., 2004; Nijboer et al., 1999).

Research findings examining the impact of cancer patients' quality of life on that of their family caregivers are equivocal. Clark and colleagues (2006) examined the QOL of caregivers of patients with advanced-stage cancer in relation to the patients' QOL. Although the patients' QOL improved after a structured, multidisciplinary intervention, there was no evidence that improving the patients' QOL had an impact on the caregivers' QOL (Clark et al., 2006). Similarly, Chen and colleagues (2004) found that the physical and emotional aspects of the patients' QOL do not play a significant role in determining the QOL of their family caregivers. Interestingly, however, these authors asserted that the social and functional aspects of the patients' QOL are associated with their caregivers' QOL (Chen et al., 2004). Clearly family caregivers' QOL is a complex phenomenon requiring careful consideration.

Needs Identified by Caregivers

Parallel to the effects of the family caregiving experience are the caregivers' identified needs. Family caregivers have unmet needs particularly with respect to information, support, and communication (Kristjanson & Aoun, 2004; Osse, Vernooij-Dassen, Schadé, & Grol, 2006). An assessment of family caregivers of patients with advanced cancer (Wong et al., 2002) revealed that the greatest need for information identified by caregivers is in relation to pain and symptom management and home palliative care resources. To support family caregivers and improve their psychological coping, assistance is required to diagnose and manage symptoms effectively and information is seen as a mechanism to meet this need and enhance decision making for

family caregivers in palliative care. Conversely, insufficient information exacerbates stress, frustration and feelings of uncertainty (Kirk, Kirk, & Kristjanson, 2004).

Navigating the health care system can be challenging and poses additional challenges for family caregivers. As such, caregivers desire that health care providers pay attention to and address issues concerning quality of care. Specifically, caregivers identified the need for better coordination of care, access to care provision, and the opportunity to consult another health care provider (Osse et al., 2006).

Caregivers' Perspectives

As evidenced throughout this discussion, the literature reflecting the impact of advanced cancer on family caregivers frequently involves the psychometric measurement of psychological distress, physical health effects, financial burden, and quality of life. While these findings are useful, they fail to provide an understanding of the lived experience of caring for a loved one with advanced cancer from the family caregivers' perspective.

Qualitative research seeking to describe the lived experience of family caregivers is starting to be conducted, and emergent studies are revealing findings that support the quantitative findings. Through qualitative research studies, caregivers have described the perceived changes in their lives in terms of the challenges associated with the caregiving role as well as the positive aspects of care (Hudson, 2004; Sherwood, Given, Doorenbos, & Given, 2004; Winterling et al., 2004). In so doing, caregivers have identified many of the negative reactions to caregiving reported elsewhere in the literature such as fatigue, depression, financial stresses, and lack of time (Jo, Brazil, Lohfeld, & Willison, 2007; Sherwood et al., 2004). In addition, the benefits of

improved communication and a better relationship with the care recipient have been brought to a more detailed understanding (Sherwood et al., 2004).

Examining the lived experience of family caregivers of patients with advanced cancer by means of a qualitative research approach allows for caregivers to provide a rich description of the caregiving experience from their perspective. As such, existing quantitative indicators of the caregiving experience can be complemented with an experiential description and a more comprehensive understanding of family caregiving for this patient population can ensue. While there is promise in the existence of some qualitative literature related to family caregivers of patients with advanced cancer, its presence is scarce, begging the need for further qualitative work to be done in this area.

Family Caregivers of Patients with Advanced Head and Neck Cancer

There is a dearth of empirical evidence related to family caregivers of patients with advanced head and neck cancer. However, existing literature suggests that this particular cohort of family caregivers is significantly impacted by their caregiving role. In a comparative study by Vickery, Latchford, Hewison, Bellew, and Feber (2003), partners of patients with head and neck cancer were found to have significantly higher levels of anxiety than the patients themselves ($p = .001$) and showed levels of anxiety that exceeded the general population. In the case of family members caring for a loved one with advanced head and neck cancer stress and anxiety may be caused in part by the physical and emotional care required as a result of the patients' functional disability and disfigurement associated with cancer treatments.

A correlational study by Verdonck-de Leeuw and colleagues (2007) revealed that 20% of spouses of patients who receive treatment for head and neck cancer

demonstrate clinically significant levels of emotional distress measured by the Hospital Anxiety and Depression Scale (HADS). Emotional distress in spouses was related to the presence of a feeding tube in patients; a passive coping style characterized by being pessimistic or worried, turning inward on oneself, not being capable of taking action to improve difficult situations; and a disruption in their daily schedule as a result of caregiving (Verdonck-de Leeuw et al., 2007). Evidence suggests that informal caregivers of patients with advanced head and neck cancer require psychological support from health care providers in order to cope with multiple ongoing stressors that accompany the demands of caregiving responsibilities (Baghi et al., 2007). In addition to receiving psychological support, many caring relatives desire to have contact with self-help groups and a large percentage of these individuals desire to be given more information about the cancer disease and different therapeutic modalities (Baghi et al., 2007).

Again, while these quantitative findings are informative they do not provide an emic or insider's understanding of the nature or essence of the caregiving experience. Given that the ability of the health care team to support family members caring for advanced head and neck cancer patients is contingent upon a clear understanding of the experiences of family caregivers, this gap in our knowledge is problematic, and calls for further study.

Family Caregivers of Patients Receiving Enteral Tube Feeding

Few studies have explored the impact of enteral tube feeding from the family caregivers' perspectives, yet often it is the caregiver who has primary responsibility for organizing and administering the tube feeds. In addition to the demands of managing

the underlying disease, the responsibility of administering enteral tube feeds may place added pressure on caregivers during the caregiving experience. The management of home enteral nutrition requires an inordinate amount of time for family caregivers, and is often unidirectional and dependent in nature, lending to a stressful experience for the caregivers (Silver & Wellman, 2002). Indeed, family caregivers report a wide range of feelings towards managing enteral tube feeds including loss, depression, regret, confusion, anxiety, and strain (Rickman, 1998).

In their descriptive, correlational study, Silver, Wellman, Galindo-Ciocon, and Johnson (2004) sought to identify family caregiving variables that are most important to the experience of managing older adults' home enteral nutrition. These authors reported that family caregivers are often not trained in the technical and nutrition-related tasks that are necessary to maintain the feeding tube and equipment and prevent side effects associated with enteral nutrition support. Moreover, Silver and colleagues (2004) asserted that a high percentage of unmet training needs leaves caregivers unprepared for mastering these skills and as a result unprepared for caregiving overall.

Interestingly, qualitative studies examining the impact of enteral tube feeding on daily life from the perspective of patients and caregivers revealed that caregivers adapt fairly quickly and experience very few problems with the delivery of tube feeds, but rather express issues around mealtimes and social occasions as being salient (Brotherton, Abbott, & Aggett, 2006; Liley & Manthorpe, 2003). Caregivers often feel guilty about eating meals in front of patients who are unable to eat. In addition, being unable to attend important social events due to others' reactions or the patients' inability to eat summons negative psychological effects in both the patient and the family

caregivers (Brotherton et al., 2006; Liley & Manthorpe, 2003). Anis and colleagues (2006) suggested that the impact of enteral tube feeding on the daily lives and emotional well being of caregivers is poorly understood. The paucity of literature in this regard, along with the conflicting evidence supports this claim and points to the need for further research to understand family caregivers' experience while caring for a loved one receiving enteral tube feeding.

Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

No English language literature was located that empirically examined family caregivers experiences caring for patients with advanced head and neck cancer receiving enteral tube feeding. This is not surprising considering the limited research that exists concerning either family caregivers of patients with advanced head and neck cancer, or family caregivers of patients receiving tube feeding. This gap in knowledge precludes clinicians from being able to effectively support these particular family caregivers. It is thus evident that undertaking an examination of family caregivers of patients with advanced head and neck cancer who are receiving enteral tube feeding is necessary.

Summary

This chapter provided an overview of the empirical literature related to this study. A discussion regarding the use of literature in phenomenological research prefaced the literature review. A critical review and synthesis of bodies of literature relevant to the study, conducted in accordance with the aims and goals of phenomenological research was presented, and included: the issue of dysphagia in

patients with advanced head and neck cancer; family caregivers issues in caring for patients with advanced cancer generally and patients with advanced head and neck cancer specifically. Finally, literature related to both family caregivers of patients receiving enteral tube feeding and family caregivers of patients with advanced head and neck cancer who are receiving enteral tube feeding was reviewed. The following chapter will present the study methods and procedures.

CHAPTER THREE: METHODS AND PROCEDURES

This chapter describes the methods and procedures used to conduct this study, and includes a discussion of the: i) methodology; ii) sensitizing conceptual framework; iii) study setting; iv) sampling approach and recruitment procedures; and v) data collection and analysis steps. Strategies used to ensure study rigor as this is understood in qualitative research, and ethical considerations relevant to the study are also presented.

Methodology

A descriptive phenomenological study was conducted to explore and describe the experiences of family caregivers of patients with advanced head and neck cancer who are receiving enteral tube feeding. Qualitative research methods are employed when little is known about a topic, and the aim of the study is to better explicate and understand the phenomenon of interest from the perspective of those directly involved in it (Speziale & Carpenter, 2007). Phenomenology, which examines subjective human experience, has evolved as a philosophical context for nursing science inquiry and as a research method. However, phenomenology is associated with the writings of a number of phenomenologists from various philosophical perspectives; therefore, research findings generated will depend on which philosophical approach is used. The two main phenomenological approaches evident in the nursing literature include descriptive (eidetic) phenomenology and interpretive (hermeneutic) phenomenology (Lopez & Willis, 2004). Each of these approaches also includes a number of methodological interpretations that have been developed. Examining the philosophical underpinnings of a method prior to its implementation, and identifying the procedural interpretation being

used, will result in research that is clear in its purpose, structure, and findings (Lopez & Willis, 2004).

The movement of phenomenology was inaugurated by German philosopher Edmond Husserl (Dowling, 2007). In a broad sense, phenomenology puts emphasis on the endeavor of getting to the truth of matters to describe phenomena as whatever appears in the manner in which it appears (Moran, 2000). In other words, phenomenology attempts to describe phenomena as it manifests itself to consciousness, to the person experiencing it. Husserl's philosophy argues that the aim of phenomenology is the rigorous and unbiased study of things *as they appear* in order to arrive at an essential understanding of human consciousness and experience (Dowling, 2007). As such, Husserl's philosophical ideas about how science should be conducted gave rise to the *descriptive* phenomenological approach to inquiry.

An important element of phenomenology that Husserl borrowed from his mentor Franz Brentano was intentionality; the notion that the main characteristic of consciousness is that it is always intentional (Moran, 2000). Husserl maintained that consciousness is the circumstance of all experience. Intentionality is the principle that every conscious act is related to some object, and implies that all perceptions have meaning (Dowling, 2007).

Husserl (1970) argued that lived experience involves the immediate consciousness of life, prior to reflection and without interpretation. Furthermore, Husserl believed that in order to recognize the domain of pure consciousness, and thus grasp the essential lived experiences of those being studied, researchers need to put aside all prior expert knowledge and personal biases (Lopez & Willis, 2004). In an

attempt to explain how to overcome preconceptions placed on the experience, Husserl devised phenomenological reduction. Phenomenological reduction is a fundamental strategy of phenomenology and involves 'reducing' the world as it is in the natural attitude, that is, where knowledge is held with judgment, to a world of pure phenomena (Dowling, 2007). Through phenomenological reduction, the goal of the researcher is to achieve transcendental subjectivity, meaning that "the impact of the researcher on the inquiry is constantly assessed and biases and preconceptions neutralized, so that they do not influence the object of study" (Lopez & Willis, 2004, p.728). Epoche, or learning to look at things in a way such that researchers see only what stands before their eyes, and only what they can describe and define, facilitates the suspension of researchers' beliefs and minimizes interpretation. Thus, the essence of the phenomena is allowed to emerge (Moustakas, 1994). In order to set aside one's preconceptions and presuppositions, one must firstly make them overt, and render them as clear as possible. Bracketing is a specific technique that has been proposed by descriptive phenomenologists to achieve this (Speziale & Carpenter, 2007). Bracketing involves the researcher setting aside preconceptions and personal knowledge when listening to and reflecting on the lived experiences of those being studied. In order to distinguish phenomenological inquiry as a research endeavor versus a philosophical pursuit in nursing, the views of the study participants are included in the research process and respondents are not asked to bracket. More so, bracketing usually relates to the researcher addressing their biases in phenomenological nursing studies (Dowling, 2007).

Another important tenet in Husserl's phenomenological approach is that any lived experience has features that are common to all individuals who have the

experience. Husserl (1970) referred to these as universal essences. These essences represent the commonalities in the experience of the participants, and thus the true nature of the phenomenon being explored, allowing a generalized description to be made. Moreover, Husserl believed that essences can be abstracted from lived experience without consideration of the context, reflecting the values of descriptive phenomenology versus those imbedded in an interpretive approach (Lopez & Willis, 2004).

Herbert Spiegelberg was an American philosopher, whose work was largely influenced by that of Husserl (Moran, 2000). Spiegelberg played a prominent role in the advancement of the phenomenological movement in North America and offered one of many methodological interpretations of descriptive phenomenology. Specifically, Spiegelberg (1975) identified three steps for carrying out descriptive phenomenology: i) intuiting; ii) analyzing; and iii) describing. This methodological interpretation will be described in greater detail in the section of this chapter discussing data analysis.

Procedures

A descriptive phenomenological approach was used to conduct this study because it is consistent with the aims and goals of the study. Descriptive phenomenology involves the direct exploration and analysis of a particular phenomenon in order to arrive at a description of the lived, or subjective, experiences of the participant (Speziale & Carpenter, 2007). This process is undergone as free as possible from preconceptions and personal biases in order to understand the phenomenon in its essential form, independent of context (Lopez & Willis, 2004). A descriptive phenomenological approach is used when little is known about an issue, and the aim of

the study is to make clear and understand the phenomenon of interest from the perspective of those directly involved in it (Speziale & Carpenter, 2007). Based on these understandings, the use of a descriptive phenomenological approach was consistent with this study's purpose of examining the experiences of family caregivers of patients with advanced head and neck cancer who are receiving enteral tube feeding. Moreover, this approach was especially appropriate considering the paucity of research examining this particular cohort of caregivers and the need for a fundamental understanding of their lived experience.

Conceptual Framework

The Transactional Model of Cancer Family Caregiving Skill proposed by Schumacher, Beidler, Beeber, and Gambino (2006) provided a sensitizing conceptual framework for this study. While the purpose of the study was not theory testing, the concepts within this framework provided direction regarding facets of the caregiving experience that may be explored, and a context within which to situate the study findings. This model focuses on family caregiving as a process that occurs in response to an illness. According to Schumacher and colleagues (2006) various cognitive, behavioral, and interpersonal caregiving processes are used to respond to the demands of the illness situation, in relation to the dyadic patterns of care exhibited by caregiver/patient. Family caregiving skill is apparent in the transactions between a caregiver's use of the various caregiving processes and the context of care. In addition, caregivers and patients are seen as both individuals and as dyads and each of their personal qualities that are brought to the cancer situation are considered to influence their respective responses. This transactional model promotes the reciprocal

relationship between the major concepts in cancer family caregiving (eg. demands of the illness situation, caregiving processes, pattern of care) , and provides a theoretical perspective from which to consider caregiving skill in family caregivers of patients with advanced head and neck cancer receiving enteral tube feeding. Thus, the researcher was not looking for data to fit the framework but was mindful that some of the items in the framework may have relevance for exploring family members' experiences.

To ensure that the framework did not unduly bias the data collection process, assumptions and thoughts about the salience of the model were bracketed out at the outset of interviewing.

Study Setting

This study was conducted through the Head and Neck out-patient clinic at CancerCare Manitoba and the Manitoba Home Nutrition Program of the Winnipeg Regional Health Authority. CancerCare Manitoba is an out-patient health care facility responsible for cancer prevention, detection, care, research and education for the people of Manitoba. CCMB is also dedicated to enhancing the quality of life for those living with cancer and blood disorders, and to improving control of cancer for all Manitobans. The CCMB out-patient clinics provide consultation, assessment and diagnostic surgical procedures for certain health problems such as occur in individuals with head and neck cancers, and thus was an appropriate venue from which to recruit potential research participants (CancerCare Manitoba, 2008).

The Manitoba Home Nutrition Program (MHNP) falls under the jurisdiction of the Winnipeg Regional Health Authority and provides nutritional support to those individuals who require hydration therapy, parenteral nutrition, or enteral tube-feeding

in their home. The role of the MHNP is to establish individualized nutrition goals, train the patient and/or care provider to administer and manage the nutrition support, and monitor nutritional status and progress. Clients who are eligible for the MHNP have a documented inability to meet their nutritional needs via the regular enteral or oral route such as is often experienced by individuals with head and neck cancers.

The head and neck out-patient clinics at CCMB take place each week on Monday (full day), Wednesday (afternoon) Thursday (full day), and Friday (morning). During their clinic visits, patients are seen by various members of the multidisciplinary team involved in their care. The number of dysphagic head and neck cancer out-patients receiving enteral tube feeding at any given point in time ranges from 80-100 patients, thus theoretically, sufficient numbers of potential patients and family participants could be accessed through CCMB and the MHNP to allow for the desired sample size to be achieved.

Sampling, Inclusion Criteria, and Recruitment Procedures

The following discussion will outline the sampling approach used for the study, the inclusion criteria, and the recruitment procedures used to obtain the sample.

Sampling Approach

The study participants, that are family members of advanced head and neck cancer patients receiving tube feeding, were selected through a purposive sampling technique. This method of sampling selects individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge (Polit & Beck, 2004). Purposive sampling was thus an appropriate method to use in selecting the participants for this study since the aim of a descriptive phenomenological

approach is to understand and describe the lived experience from the perspective of those who have experienced it (Speziale & Carpenter, 2007).

In this study, family caregivers were broadly defined to include those individuals identified by patients who provide patients with unpaid help in relation to their physical care or coping with disease. These individuals were not restricted to include only biological kin, but reflected a more inclusive definition of "family member" as perceived by the patient. While blood relatives are frequently the main caregivers for patients with advanced disease who remain in the community (Emanuel et al., 1999), individuals other than biological kin often provide daily care or emotional support to persons who are receiving care at home. As such, it is important to look beyond the borders of the nuclear family and define "family member" as those individuals that the patient identifies as important to them (McClement & Woodgate, 1998).

Compared to quantitative research, sample sizes in qualitative studies are small, and 10-15 participants are often adequate, provided participants are able to provide rich description of the phenomena (Speziale & Carpenter, 2007). Unlike as occurs in quantitative studies, sample sizes in qualitative work are not calculated a priori based on power analysis. The focus in qualitative research is not on the generalizability of the findings, but rather, on thick rich description about the phenomenon of interest. Sample sizes are thus deliberately kept small in phenomenological research to allow the researcher to conduct an in-depth examination and analysis about the topic of inquiry (Speziale & Carpenter, 2007). A total of six family caregivers were recruited for this

study. The researcher continued to interview family members until saturation was reached; that is, when no new information was forthcoming in the data.

Inclusion Criteria

For inclusion in the study, family caregivers were required to be 18 years of age or older, able to speak and read English, involved in the care of the patient who was receiving tube-feeding at home; and to provide written consent to participate in the project. In order to capture a range of caregiving experiences, attempts were made to recruit both male and female family caregivers.

Recruitment Procedures

After receiving approval from the University of Manitoba Education/Nursing Research Ethics Board (ENREB), the Research Resource Impact Committee of CancerCare Manitoba, and the Winnipeg Regional Health Authority Research Review Committee, the investigator conducted an information session about the study and reviewed the recruitment procedure with those members of the health care team at CancerCare Manitoba who were going to be inviting patients and family caregivers to the study including the clinic nurses in the Head and Neck clinic, Nurse Practitioner and clinic nurse in the Radiation Oncology department, speech language pathologist, dietitian, and social workers. Individual meetings were arranged for the investigator to meet with those members of the health care team who were unable to attend the information session. In addition, the investigator obtained permission from the supervisor of the Manitoba Home Nutrition Program (MHNP) to attend one of their staff meetings. At the meeting, the investigator provided information to the MHNP nurses and dietitians about the research project and the recruitment procedure.

Members of the health care team at CCMB and the MHNP who were inviting patients and family caregivers to the study approached patients who met the inclusion criteria and provided them with a package of information sheets about the study. Those patients who agreed to participate in the study were asked to identify the individual that they considered to be their family caregiver and give them the family caregiver information sheet enclosed in the information package. Then, if both the patient and their family caregiver agreed to participate in the study they were asked to fill in their names/contact information on each of their respective forms and return them to the researcher in the self-addressed, stamped envelope provided. The researcher then contacted the patient and family caregiver to provide more information about the study and answer any questions about participation in it. The researcher obtained written consent from all patient and family caregiver participants prior to the onset of data collection and the voluntary nature of participation was explained.

The investigator also promoted the recruitment of participants by attending the Head and Neck Cancer Support Group: A Head Above. This support group is run by CancerCare Manitoba as a service to individuals with head and neck cancer and their families. The group is facilitated by an oncology social worker and speech language pathologist and is intended to meet the unique needs of individuals who have or have had some form of head and neck cancer. The support group is open to patients and family/support persons and meets in the evening on the third Monday of every month.

The researcher obtained permission from the facilitators of the support group to attend a scheduled meeting. At the beginning of the meeting the researcher presented information about the study to the attendees and invited them to voluntarily participate

in the study; after which the researcher left the premises. Those individuals who were interested in participating in the study were asked to obtain a package of information sheets about the study from the facilitator of the support group. The recruitment procedure then proceeded as outlined above. That is, those patients who agreed to participate in the study were asked to identify the individual that they considered to be their family caregiver and give them the family caregiver information sheet enclosed in the information package. Then, if both the patient and their family caregiver agreed to participate in the study they were asked to fill in their names/contact information on each of their respective forms and return them to the researcher in the self-addressed, stamped envelope provided. The researcher then contacted the patient and family caregiver by telephone to provide more information about the study and answered any questions about participation in it. The researcher obtained written consent from all patient and family caregiver participants prior to the onset of data collection and the voluntary nature of participation was explained.

Data Collection

Multiple approaches to data collection were used in this study. The use of more than one data collection strategy, known as triangulation, provides breadth and depth to a study by ensuring complete and thorough findings (Speziale & Carpenter, 2007). As such, the researcher gains a more accurate picture of the phenomenon. Written informed consent was obtained from all participants prior to the onset of data collection, and the voluntary nature of participation was explained (See Appendices A and B).

Consistent with phenomenological research, data was collected through face-to-face interviews. Exploration of the phenomena in this study was initiated with a broad,

open-ended question aimed at generating responses that described the experience the participants were having caring for a family member who was receiving tube feeding (See Appendix C). Probes were used as needed to clarify the meaning of responses and encourage in-depth descriptions (Speziale & Carpenter, 2007). This approach to the interview maintained the focus around a specific topic area, but still allowed for flexibility of scope and depth of exploration (Speziale & Carpenter, 2007). In addition, face-to-face interviews allowed the researcher to seek immediate clarification or expansion of the participants' expressed thoughts and attend to non-verbal cues such as gestures and facial expressions. Ultimately, the interviews elicited information that was central to developing a clear understanding of the participants' lived experience. Interviews were conducted at a mutually convenient date, time and location for the family caregiver and the investigator. The majority of interviews occurred in the participants' homes. Of the twelve interviews that were conducted, eight occurred in the participants' home, one occurred in the board room at the Palliative Care Research Unit at CancerCare Manitoba, and three were conducted via long distance telephone calls with the participants' situated in their home. Conducting the interviews in a place that was comfortable and convenient for the research participants facilitated sharing by family caregivers.

Two interviews per participant were conducted. Multiple interviews are commonly used in phenomenological research to enable participants to adequately reflect and describe their experiences and allow the researcher to clarify points raised in earlier conversations (Speziale & Carpenter, 2007). Initial interviews lasted on average 1 ½ hours and ranged from 1 hour to 2 hours in length. The second interview lasted

approximately 30-45 minutes, and its purpose was to further explore and verify content shared during the initial interview.

Field notes were recorded after the interview to describe the context in which the interview occurred, and to capture any elements that may have impacted on the data collection process. Brief notes detailing a description of the environment, observations regarding the participant and their reactions to the investigator, and the dynamics of the interview were written during the interview and were expanded upon as soon after the interview as possible. Demographic data was also collected to describe the characteristics of the sample (See Appendices D and E).

Data Analysis

The process of data analysis will be described in the following section. Interviews were tape-recorded and transcribed verbatim by a transcriptionist to preserve their authenticity. As a method to ensure rigor, prior to the onset of data analysis, the researcher listened to the audio-tape and compared it to the transcript to check for any errors in transcription, making corrections in the margins as needed.

Data analysis was an ongoing, iterative process that began after the transcription of the first interview and occurred simultaneously with the data collection phase of the study. Multiple readings of individual transcripts and comparisons between transcripts were made. Data was analyzed using Spiegelberg's (1975) three step process of: i) intuiting; ii) phenomenological analyzing; and iii) phenomenological describing. Characteristics of the sample were analyzed using descriptive statistics.

The first step in Spiegelberg's (1975) process for descriptive phenomenology is that of *intuiting*. Intuiting requires the researcher to practice complete immersion in the

data while suspending criticism and evaluation by way of bracketing (Speziale & Carpenter, 2007). Through the interview process, the researcher listens to the participants' descriptions, and then repeatedly reviews and studies the data as they were transcribed. In so doing, the researcher begins to know about the phenomenon as described by the participants.

Identifying the essence or invariant structure of the phenomenon being studied, through a process called *phenomenological analyzing,* is the second step in Spiegelberg's (1975) process. Here the researcher identifies qualities of the phenomenon that make it what it is, and without which it could not be what it is (Dowling, 2007). By 'dwelling with the data', the researcher begins to recognize the emergence of universal essences, or eidetic structures, in relation to the phenomenon under study (Lopez & Willis, 2004). Different aspects of the experience are intentionally altered in the imagination of the researcher by either taking from or adding to the proposed alteration through a process called imaginative variation. In so doing, the researcher uses their imagination to stretch the proposed transformation until it no longer resembles the naïve description of the phenomenon (Dowling, 2007). This process verifies whether a particular essence essentially belongs to the phenomenon and lends to a representation of the true nature of the phenomenon being studied. For example, when contemplating those structures that were essential to the experience of caring for a dysphagic family member with advanced head and neck cancer who is reliant on tube feeding, the initial emerging data revealed a large number of different matters that caregivers negotiate to arrive at a new normal. The researcher intentionally altered via her imagination different aspects of these matters of negotiation all the while

asking whether the family caregiving phenomenon would still be the same if certain matters of negotiation were imaginatively changed or deleted from the experience. Through this process, ultimately it was determined that changing roles, an altered lifestyle, the meaning of the feeding tube, and ways of coping were essential matters of negotiation that made the caregiving experience what it was and without which it would not be what it was. Relationships of the essences with contiguous phenomena are then explored. During the process of phenomenological analyzing, it is essential that the researcher dwell with the data for as long as necessary to ensure a true description (Speziale & Carpenter, 2007).

Spiegelberg (1975) identified *phenomenological describing* as the final phase in his three-step process for descriptive phenomenology. In this step, the researcher brings to written description the distinct, critical elements of the phenomenon (Speziale & Carpenter, 2007). Description involves organizing and describing the critical elements of a phenomenon individually and then within the context of their relationship to one another. As such, a comprehensive description of the experiences of family caregivers of patients with advanced head and neck cancer receiving enteral tube feeding emerged.

Ensuring Rigor in Qualitative Research

Ensuring rigor in qualitative research involves an evaluation of the researcher's attention to and confirmation of the data generated from the study (Speziale & Carpenter, 2007). Hence, the goal of rigor in qualitative research is to accurately represent the experiences of study participants. Strategies for ensuring rigor in qualitative research as described by Lincoln and Guba (1985) were applied in this study. They included: i) credibility; ii) dependability; iii) confirmability; and

iv) transferability. Each of these strategies will be described and the steps taken by the investigator to enhance the rigor of this study will be discussed.

Credibility

The principle of credibility refers to the actions taken by the researcher to increase the probability that credible findings have been produced (Speziale & Carpenter, 2007). Lincoln and Guba (1985) referred to this as the study's "truth value" (p. 294). An effective way to establish credibility is through sustained engagement with participants (Speziale & Carpenter, 2007). In this study, the investigator conducted two interviews with each of the participants over a seven month period and spent seven months analyzing the data in an effort to ensure credibility.

An additional means of establishing credibility is to have participants review the results of the study to see whether the findings are recognized to be true to their experience (Speziale & Carpenter, 2007). This process of returning back to the informants to verify if they recognize the findings is known as 'member checking' (Lincoln & Guba, 1985). Credibility was addressed through the provisional verification of emerging findings with participants at the time of the second interview. Provisional verification was carried out with all six participants in the study. Each of the participants readily confirmed the emerging findings and none of them had any suggestions for revision.

Dependability

While issues of reliability and important within quantitative studies, and relate to issue of stability, consistency, and predictability, reliability is neither understood nor evaluated in the same way in qualitative research (Lincoln & Guba, 1985). Within

quantitative studies, reliability is demonstrated by replication of study findings. However, Lincoln and Guba (1985) asserted that replication does not make sense in qualitative research where the necessary framework to serve as a benchmark for replication is ever changing due to the nature of naturalistic inquiry. As a result, Lincoln and Guba (1985) introduced the concept of dependability, that is, the question of how dependable the results are, as a criterion to be met once researchers have established the credibility of the findings.

One strategy to contribute to the dependability of research findings is the triangulation of methods (Speziale & Carpenter, 2007). Triangulation involves the use of more than one tactic for data collection in order to ensure complete and thorough findings (Speziale & Carpenter, 2007). Data triangulation, investigator triangulation, method triangulation, and theoretical triangulation comprise the four different types of triangulation strategies. This study employed the triangulation of data sources in the form of interview data, field notes, a reflexive journal and relevant literature examining family caregiving experiences. This allowed for a more detailed and balanced examination of the phenomenon and thus enhanced the dependability of the study. The description of the experiences of family caregivers of patients with advanced head and neck cancer receiving enteral tube feeding was arrived at through the data analysis procedures described previously (See Appendix F). This description was checked against the original data by the investigator's thesis advisor and appropriate revisions were made. This process of investigator triangulation further enhanced the dependability of the study findings.

Confirmability

The criterion of confirmability refers to the extent that the study findings accurately reflect the study participants' experiences and are kept free from preconceptions and biases (Lincoln & Guba, 1985). A strategy that is often used to accomplish value-free stance is bracketing. Bracketing is "the cognitive process of putting aside one's own beliefs, not making judgments about what one has observed or heard, and remaining open to data as they are revealed" (Speziale & Carpenter, 2007, p.27). The researcher's preconceptions were documented prior to the onset of the study and later compared to what was observed and heard in the study. In addition, the investigator was cognizant of using the participants' own words throughout the process of data analysis and phenomenological description.

The audit trail is another means of establishing confirmability of the data (Speziale & Carpenter, 2007). This process refers to the way in which the activities of a study were documented so as to be traced and followed. An audit trail allows the reader to follow the thought processes of the researcher that lead to the conclusions. Any decisions made in relation to data analysis were documented on the working copies of the transcribed interviews. The investigator also made notes after analytical discussions with the advisory committee.

Transferability

The final criterion identified by Lincoln and Guba (1985) to ensure rigor in qualitative research is that of transferability. Transferability refers to how meaningful the study findings are to different participants in similar situations (Speziale & Carpenter, 2007). Notably, the 'fit' of the study findings with other participants rests

with the potential users of the findings and not with the investigator (Lincoln & Guba, 1985). In this study, transferability was addressed through the provisional verification of emerging findings with participants at the time of the second interview. In addition, transferability was demonstrated through the provisional verification of emerging findings with clinicians and researchers who attended the presentation of these findings in the fall of 2008 at the Hospice Palliative Care Manitoba provincial conference, the Canadian Association of Nurses in Oncology (CANO) conference, the International Congress on Palliative Care, and the Canadian Hospice Palliative Care Association (CHPCA) national conference. The informal feedback received from these conference attendees suggested that the findings from this study are reflective of reality in the clinical setting and ring true for clinicians dealing with family caregivers of patients who are dependent on tube feeding.

Ethical Considerations

Prior to the onset of the project, ethical approval was obtained from the University of Manitoba Education/Nursing Research Ethics Board (ENREB) and access approval secured from the Research Resource Impact Committee of CancerCare Manitoba and the Winnipeg Regional Health Authority Research Review Committee. Written consent from the participants was also obtained prior to the start of data collection, and the voluntary nature of their participation was reinforced.

Procedures were implemented to ensure that the information that participants provided in this study was kept private. Anonymity refers to the steps taken to protect the participants in a study in such a way that even the researcher cannot link individuals with the information provided (Polit & Beck, 2004). As is common in qualitative

research, data collection in this study was done through the use of face-to-face interviews making anonymity impossible. However, short of being able to ensure anonymity, confidentiality promises that the information that participants provide will not be linked to their individual identities or be publicly divulged (Polit & Beck, 2004). Strict adherence to procedures ensuring confidentiality was maintained.

As regards confidentiality, all participants were assigned a unique code number. Consent forms were stored separately from the data. No names or other identifying information appeared in any of the data generated from the study. Any such information arising in the interviews were replaced with pseudonyms when audio-tapes were transcribed. Findings from the study were presented in aggregate form and not linked to a specific participant. In the spirit of reciprocity, participants were given the opportunity to receive a summary of the study once it was completed if they so desired. At the end of the consent form, the option to receive a summary report of the findings was presented and participants were able to tick a "yes" box and provide a mailing address if they desired a summary to be sent to them.

Audio-tapes used during the interviews were stored in their original case identified only by the code number assigned to it and the date of the interview. Following completion of the study, audio-tapes were erased. Transcribed interviews were stored on the computer hard drive, with a back-up copy being kept on a memory stick. In addition, two hard copies of the transcribed interviews representing both a clean copy and a working copy for coding were printed. Field notes and demographic data were also stored on the computer hard drive with backup on a memory stick. Access to all computer files was protected by encryption and limited to the researcher.

All data was stored in a locked filing cabinet at the office of the researcher's advisor. The data will be stored for a period of seven years and will then be destroyed and treated as confidential waste.

During four of the initial interviews with family caregivers the patient was present. In order to address the issue of confidentiality, prior to starting the interview the researcher confirmed with the caregiver that the presence of the patient was acceptable to them. At the time of the second interview, each of the participants was alone with the researcher allowing the caregiver to speak freely about their caregiving experience and say those things which they may not have said during the initial interview.

Speaking about the experiences of being a family caregiver to a relative with advanced head and neck cancer who is receiving tube-feeding had the potential to evoke feelings and emotions in participants, and past experience suggested that family caregivers may become teary, or even cry openly during the course of recounting their experiences. During two of the interviews in this study participants became teary and one participant cried openly in the course of recounting her experience. However, as identified in the literature, family members are also frequently appreciative of having the opportunity to share their stories with someone who is genuinely interested in what they have to say (Donalek, 2005). In the event that a family member became upset during the interview, the investigator stopped the interview and provided emotional support to the person. The family member was given the option of stopping the interview, and rescheduling for another time. The voluntary nature of participation in the study was also reviewed with the person, and they were given the opportunity to

withdraw their participation if they so desired. If, in the opinion of the investigator, the person required some psychosocial follow-up, she obtained the family members' permission and contacted the Department of Psychosocial Oncology at CancerCare Manitoba to arrange an appointment. These services are available to all family members of patients being seen at CCMB and thus did not constitute an additional burden to staff who provide such services. None of the participants in this study were referred to the Department of Psychosocial Oncology.

Summary

This chapter outlined the methods and procedures used in conducting this study. A description of the methodology, sampling approach, and recruitment procedures was presented. As well, the methods of data collection and data analysis were discussed. The strategies for ensuring the rigor of the study, as they are understood within a non-positivist paradigm, were examined, along with a discussion of the ethical considerations required for the study. The following chapter presents the study findings.

CHAPTER FOUR: FINDINGS

This chapter presents the findings from the study. The characteristics of the sample, and the essence of family members' experience caring for patients with advanced head and neck cancer receiving enteral tube feeding with its attendant themes and sub-themes are described.

Characteristics of the Sample

A purposive sample of six patients and their family caregivers was recruited through the Head and Neck out-patient clinics at CancerCare Manitoba (CCMB) and the Manitoba Home Nutrition Program (MHNP). Of 28 patients approached by the recruitment team, 6 agreed to being contacted by the researcher, while 22 patients declined; resulting in a response rate of 21%. The reasons for patients deciding to decline to participate were not recorded by those who were recruiting. Given that no demographic information was collected on those declining to take part in the study, it is not known if the sample of participants differed from non-participants in terms of any demographic characteristics.

Patients

Patient participants ranged in age from 47-74 years. Three of the six patients were male, and three were female. Five of the patient participants were diagnosed with stage IV, and one was diagnosed with stage III cancer of the head and neck; two had oropharyngeal cancer, three had cancer of the oral cavity, and one had cancer of the neck with an unknown primary tumor. Of the types of treatment received, two patients had combined chemoradiation, one had a surgical resection followed by chemoradiation, one had a resection with reconstructive surgery, and two had resections

with reconstructive surgery followed by chemoradiation. Four of the patient participants had feeding tubes inserted prior to the start of their chemoradiation treatment, one during the course of chemoradiation, and one had a feeding tube inserted after surgical resection and reconstruction. Patient characteristics are summarized in Table 1.1.

Table 1.1 Patient Demographic Data

Patient Demographic Data	
Age	47-74 years
Gender	3 - female 3 - male
Stage of Tumor	5 - Stage IV 1 - Stage III
Location of Tumor	2 - Oropharyngeal 3 - Oral cavity 1 - Neck with unknown primary
Type of Treatment	2 - Combined chemoradiation 1 - Surgical resection + chemoradiation 1 - Surgical resection + reconstruction 2 - Surgical resection + reconstruction + chemoradiation
Insertion of Feeding Tube	4 - Prior to chemoradiation 1 - During chemoradiation 1 - Post-operatively

Family Caregivers

Family caregiver participants ranged in age from 49-64 years. Four of the six family caregivers were female. Four of the family caregivers were spouses and two were siblings of the patient. Four of the six family caregivers lived in the same household as the patient. Five of the family caregiver participants reported sharing care activities with the patient, and one reported having more of a stand-by role. One of the participants had previous caregiving experience with tube feeding, but none of the

family caregivers had professional caregiver training. Family caregiver characteristics are summarized in Table 1.2.

Table 1.2 Family Caregiver Demographic Data

Family Caregiver Demographic Data	
Age	49-64 years
Gender	4 - female 2 - male
Relationship to Patient	4 - spouses 2 - siblings
Proximity to Patient	4 - lived in same household
Pattern of Care	5 - shared care activities 1 - stand-by role
Experience with Tube-Feeding	1 - previous experience 0 - professional caregiver training

The final description of the experiences of these family caregivers is discussed here and is also captured in a schematic in Appendix G.

Negotiating a New Normal: Overview

The essence of the experience of caring for a dysphagic family member with advanced head and neck cancer who is either totally or partially reliant on tube feeding is captured by the process of "negotiating a new normal":

> When somebody in your family has cancer, your whole family has cancer. And, it's true. Like, it's ...you don't physically have it, obviously, but...like I said to him the other day, I don't even remember what normal is anymore. Like, we...in...our whole life...this is our whole life...and then you just kind of sit there one day and you go, you know what, this is our new reality. This is what we've got to deal with, so we got to do it.

The decision of whether or not the patient would have a feeding tube inserted was the precursor to the family caregiving experience. Once the decision had been made to insert the feeding tube, life as these patients and caregivers knew it was significantly disrupted. In response to this disruption, family caregivers moved through a complex

process of "negotiating a new normal". By definition, to negotiate is "to move through, around, or over in a satisfactory manner" (Soanes, Hawker, & Elliott, 2005). Central to their caregiving experience was the caregivers' need to negotiate changing roles. In relation to changing roles, caregivers also negotiated an altered lifestyle, the meaning of the feeding tube, and ways of coping. Information, communication, and support were seen as facilitators of the negotiation process. Furthermore, negotiation happened at the level of the individual caregiver, the caregiver-patient dyad, their social network, and the greater health care system. If caregivers were able to move through the process of negotiation successfully, they arrived at a new normal. However, any marked changes in the patient's status caused a disruption in this new normal and the process of negotiation began anew. Decision making challenges, matters of negotiation, facilitators of negotiation, levels of negotiation, and triggers for renegotiation represent the major themes emerging from the data and are discussed here.

Decision Making Challenges

Decision-making challenges related to the insertion of a feeding tube emerged from the data as a precursor to the caregiving experience and the process of negotiating a new normal. Some patients and their caregivers were not given a choice by health care professionals about whether or not they would receive a feeding tube as part of their care:

> I guess when we saw the CancerCare doctors and they described what the, uh, treatment was going to be. And they … with her type of throat cancer, they said you're not going to be able to eat so the only way you're going to get nutrition is through the peg tube. So, there is no alternative. And that's basically the way we approached it. It was, uh, you know, this … there … there was no alternative.

Those patients and family caregivers who were given a choice about the insertion of a feeding tube, while appreciative of the control that they were being given over this aspect of their care, nonetheless felt overwhelmed with the sheer number of decisions that had to be made in relation to the patient's treatment above and beyond that of the feeding tube:

> And then you have all these decisions to make and, of course, one of the decisions is do you want to put a tube in. And, uh, you know, they can't pressure you one way or the other. You have to make the decision yourself and you're trying to make this horrible decision amongst a whole bunch of other things that are coming at you.

Family caregivers expressed that the decision about whether or not to have a feeding tube inserted was particularly difficult if the patient was not feeling sick:

> ...and, I mean, there was all these things we had to deal with and ... and you're not ready. Like, you're ... you're told, okay, here's what's ... here's what your diagnosis is. You've got this cancer and here's all the things we have to do. And you're just ... your head's spinning and then you have to go through this surgery and I don't know what the, uhm, percentage of people who choose not to get the stomach tube. I know that most people we run into ... or ran into at the treatments that were either before or after, seem to not have it. But, uhm, I can understand why because you're inundated with all these decisions and all these things that you have to think about and do at a time where you're ... you're thinking that, you know, this must be a nightmare and somebody's going to wake me up. And then this is a decision you have to make fairly quickly and, uhm ... I mean at a time when you're not feeling sick and you're not feeling ... like you're able to eat perfectly well, so why would I need this thing? And you can't even begin to envision ... like I still can't envision how painful you ... how much pain you'd have to be in to not be able to swallow. I ... I don't understand that. And I hope I never do have to understand that.

Family caregivers reported that even when they were given the option of deciding, they looked to health care providers for information and guidance regarding whether or not to have a feeding tube inserted prior to treatment:

> It was the nutritionist and the chemo doctor who mainly sort of suggested it fairly strongly. So, uhm, you know, we kind of take a belief or philosophy with

> anything that we do that that's what experts are there for. So, that's what we decided to do.

However, caregivers reported receiving information related to the insertion of a feeding tube from various members of the health care team, such as physicians, nurses, and dieticians. Moreover, caregivers reported receiving mixed messages from health care providers about whether or not a feeding tube was really needed. These gaps in communication caused confusion and further complicated the decision making process:

> ...the feeding tube is the one thing you can choose to do or choose not to do. So, at the time that you have to make this choice, all you ... I mean I know, for me, all I could think of was, oh, my goodness. Like, that's surgery...So, you know ... our initial response was no. And, in fact, the radiologist says, oh, you'll be fine. You know, you're strong and ... and whatever. You'll be fine. Okay, well then we won't do it. But, uhm, I think it's important that, uhm, people talk to ... that ... that the different ... like the different people, specialists that you meet ...at that point, that as many of them as possible trying to encourage you and let you know, uh, what the downside can be. Like, I think the person that really convinced us was the nutritionist. And, uh ... because I mean at that point we met with the chemo doctor and she had very casually said, you know, you may want to rethink that decision because she ... she had already seen a note saying, you know, patient has decided not to go with the feeding tube. And she kind of came in and said, you may want to rethink that decision and we kind of thought, oh, I wonder why she's saying that. But it was really the nutritionist who said, uhm, you know, I really would encourage you to consider the feeding tube because ... and she ... you know, she didn't ... she didn't gloss over...And, so she kind of pointed out a few other side effects besides the pain. And I would have to say that that kind of information was, uhm, enough information to make us completely go the other way and say, well, I think we have to do this.

In addition, family caregivers reported that they were not fully informed of any possible complications that could occur with the feeding tube prior to making the decision about whether or not to have it inserted:

> I was never under the impression that there was any possible problem. It was just in the stomach and that was it. I never, uh, I guess I never asked and I never assumed there'd be any other sort of complication to it. And no one suggested that there maybe.

As such, caregivers whose loved ones did experience complications with the feeding tube were not prepared to deal with these problems and expressed that they were second-guessing their decision to have the tube inserted:

> And, I understand the doctor because there was a real concern that it might be worse because it was her third bout of radiation that it would be worse. But then the machine was different this time. The technology had changed and so, you know, we … we didn't know how much it would affect her and it didn't affect her eating as much. And if we would have known it affected her the way it ended up affecting her, we wouldn't have had the tube…. Yeah. I … looking back at it, too, I … we sort of debated whether or not we should wait for the surgery and then have it. Just to see, I think … We sort of thought that. Looking back at it now … I think about now from what we've experienced, we would have waited and seen and once … if … if it got really bad then we would have gone to get it in… Because it's …I don't know … we found it just quite difficult to go through.

Aside from consistent and comprehensive communication from health care providers, family caregivers felt that being enlightened by the experience of others who had experienced a feeding tube would have helped them to make a better informed decision:

> It was really scary having to make the decision. And … and there's all these other things going on. Because I'm sure everybody … or most people, must go through the same emotional roller coaster, you know, in … in … you know, during the process. Uhm, you know, so, I mean if you're able to read something from somebody who's just gone through it and said, you know, we were… our heads were spinning with all this information and everything was scary and there was all these things we were told we'd have to do to deal with this but the one thing we had an option of doing was the feeding tube and the idea of something that was going to be surgically in … you know, put in and whatever, it was the one thing you're able to control making a decision on. And it would have been easy to have said no. But, you know, testimonials like that. Where you can kind of … somebody who's done it, can relate to people who may have to …do it in the future.

Matters of Negotiation

To reiterate, once the decision had been made to insert the feeding tube, life as these family caregivers knew it was significantly disrupted. In response to this disruption, family caregivers moved through a complex process of "negotiating a new normal". Four major themes emerged regarding those matters that were negotiated as family caregivers moved through the process of negotiating a new normal. These included the: I) need to negotiate changing roles; II) need to negotiate an altered lifestyle; III) meaning of the feeding tube; and IV) ways of coping with their caregiving situation.

I) Changing Roles

Family caregivers negotiated a number of changing roles as they moved towards a new normal. These included: a) becoming a caregiver; b) assuming caregiving responsibilities; c) dealing with the effects of the caregiving role; and d) achieving caregiver self-efficacy.

a) Becoming a caregiver. During the course of becoming a family caregiver, those individuals who were assuming the caregiving role indicated that their role in relation to their loved one changed from the existing role as they knew it. For example, caregivers indicated that their roles as spouses, or siblings, were redefined to that of "caregiver and patient":

> You go from being a husband and wife where you're doing things together and you're going to work and he's going to work, and whatever, and all of a sudden you're in a position where you're the caregiver and he's the sick person. And, uhm, it alters the relationship just because, I mean, I can't really hug him. I can't, you know, because he's got this tube, you know....and whatever, and I mean, you just...you...your roles change.

This change in roles inevitably affected the relationship between the family caregiver and their loved one. Said this family member:

> Uhm, you know, like through this whole thing there's been, you know, different ebbs and flows with the relationship. Like, initially when we started thinking there might be a problem when the lump came up in his neck and then when we got the diagnosis, and waiting up to the, uh, treatments, he was very clingy and we were very clingy with each other. And we both wanted to just be home together and … and we didn't want to be going out with our friends … you know, it was like we couldn't have been closer than we were for that period of time. Uhm, and then there was a second period of time where he was starting, you know, the pain from his treatments were starting to increase and … and whatever, where legitimately when you're not feeling well, it's like you don't want anybody touching you. You don't want anybody hovering around you. You just want to be alone to deal with the pain. So, but then, you know, he's kind of come over that hill and … and then the last few weeks he's been … he's always been a very, like affectionate and … and, uh … we've always been a couple that are always saying to each other, you know, I love you and … and whatever. And, you know, kind of in the middle of all of this, that was the furthest thing from his mind was to tell me or be affectionate or whatever. And I certainly didn't take it personally because that's just what was going on at the time was the pain and … and whatever. So, we're kind of getting back to that and, you know, he's starting to feel a little bit more … you know … I don't know … just a little bit more … like he's thanking me all the time for taking such good care of him and … and, you know, helping him through this and … and that sort of thing.

Some of the family caregivers interviewed considered their new caregiver and patient roles as positively strengthening communication between them and their loved one and fostering appreciation for each other. This family member observed:

> …we really did, I think, uhm, communicate a lot better than we had for a long time because I wanted her to communicate with me. I wanted her to tell me if she was in pain or whether she was hungry or … you know, different … just to let me know.

Another family member stated:

> And I would say our relationship is stronger dealing with … because you … when your life … we take life for granted until it's threatened and then all of a sudden … I mean, all I've been able to … all I could think of, you know, when this all happened was the fear of being alone. Uh, and … and not just being alone but more importantly having a life without (him). And, uhm, you know,

> you don't ... you always know in the back of your head that that can happen to a person at any time but when it's a legitimate life-threatening illness, it's, uhm ... you don't have a choice but ... but to think about it, so I think we appreciate each other more. But, you know, we were saying ... in fact we were sitting in bed last night because with the feeding tube he needs help – I mean, I guess he could manage on his own, but it would be very difficult I would think to try and manage the feeding tube by yourself – and we were sitting in bed last night and I said to (him), I said, could you imagine going through this alone. Like there's people out there that do. And, uh, I can't imagine ...what it must be like to be all alone and not have ... you know, I'm helping him with his morphine. I'm helping him with, uh, uh, getting food into the tube, you know, encouraging him to go to work. And, you know, oh, I'll come and pick you up or, you know, all this stuff that I'm doing for him that I know he would do for me if the tables were turned. Uhm, it must be awful to go through it alone.

However, many of the caregivers viewed their new roles as negatively affecting the relationship between themselves and their loved one. In particular, the feeding tube was perceived as a physical barrier between the patient and caregiver:

> I mean I certainly have felt it and, I mean, obviously ... and I mean I would assume it's pretty normal, but I mean, obviously there's no way you can have much of a really intimate life when somebody's got cancer and is going through treatments. I mean, it's just ... it's the furthest thing from your mind. But what I have missed the most through this, is (he) and I have always been very affectionate with each other. Like holding hands and cuddling in bed all night and ... and cuddling on the couch when we watch TV and whatever. And that's one thing that the stomach ... or the feeding tube has. It kind of come between us. Like it's a physical thing between us, but it's also ... because if I go to give him a hug you have to kind of ... I kind of have to lean over because, uhm, because if you press on the feeding tube it hurts. And uh, you know, he's not keen on cuddling too close at night because he's afraid of – and I'm afraid of – accidentally hitting it or knocking it or ...or whatever. So, I miss that a lot. But, you know ... but I know he does too.

Becoming a caregiver meant that family caregivers had to negotiate a pattern of care with the patient. One family caregiver assumed a standby role to support their loved one who was largely independent with their care activities. In contrast, the remaining caregivers interviewed reported sharing care activities with the patient. Said the wife of this patient:

> what happened is he got used to it and he got so it kind of was his job and after...after that what I start doing is I would just, you know, clean...do all the cleaning of the bags and...or, you know, get the water measured and ...the little bowl of water that he needs to do the tube...like, all the auxiliary stuff...the actual flushing of the tube he would do himself...and the actual connecting of the gravity line feed...he would just hook it up

Many of the family caregivers indicated that they were carrying out multiple roles simultaneously. One of the caregivers had the added responsibility of a parental role. Caring for young children while at the same time filling family caregiving responsibilities was difficult and time-consuming:

> You had to schedule your day because ...because you had to wake up and ... and give me my first feed (*patient*)... like that and get the kids to school. And then, it's like almost the same time that you're making supper for everyone else so you almost had to have a separate time so it's another, I don't know, sit down and ... *(inaudible)*...Yeah, and then put medication in and then rinse it and then you ... it's almost like times when you needed another hand. So it ... it just seemed ... like maybe I never got the rhythm that ... but ...Having three young kids, too ...made it a little bit busier.

A number of the other caregivers were employed out side the home and found themselves juggling responsibilities between work and home in an effort to fulfill their roles as both caregiver and employee:

> Well, up till then, because I'm working all day, so I would help with the feed tubes in the morning and then during the day he was getting various people at work to help him with either his morphine because he ... the morphine goes through the tube and the food goes through the tube, uhm, he has tried doing it himself but it's really awkward because if you don't pinch the tube, you know, it's just a real mess. So he was getting people to help him. It has become a little more awkward this past week because he's at home all day so I've had to figure out, okay, how do we do this? Like, we just moved the morphine to every 5 hours. But that's going through the tube because he can't ... he finds drinking it is just too hard on the throat. Well, that's every 5 ... but last ... all last week up till Friday – or up to Sunday – it was every 3 hours. Well, I'm at work and I'm trying to figure out, well, how to do this. So last week we kind of had to juggle things a little bit and I'm running back and forth from work and then we had different friends that were stopping by, and it was a little bit ... this is the part I'm finding a little bit ...It's working out fine and it's ... we know it's

> just temporary for a week or two. And then this week I just made sure that I had no client appointments so....So I'm just running back and forth during the day.

Many of the family caregivers in this study reported feeling like they had little choice in becoming a caregiver. Said this participant:

> Well, just ... they're not roles ... the roles we're in right now are not roles we would choose to be in. Well, I mean he wouldn't choose to be sick. And I wouldn't choose to be his caregiver. Like, again, if I wanted to be a caregiver by choice, then I would have gone down a different career path and that wasn't what I chose to do. And I'm doing it happily and I'm doing it, uhm ... I wouldn't have it any other way because I care about him and I love him and ... and I want him to get better and this is what we have to do as a team to ... to make that happen. But, uhm, we weren't given a choice about this. I remember when he was in getting his ... I think he was getting his mask or he was getting something, and I was talking to a guy who ... who's on his 30th treatment. He had 5 more to go and he said ... he said, oh, you know, are you here with someone? And I said my husband's just getting fitted and he goes, oh, somebody else who won ... won the wrong lottery. And that's how he put it and I thought interesting. An interesting way to put it. And, uhm, because it ... it's not our choice I tell you, but it's ... somebody said earlier on, it's your new reality. I said, you know what, it is our new reality so we deal with it.

b) Assuming caregiving responsibilities. Family caregivers of patients who were dependent on tube-feeds, of necessity, needed to acquire new skills and unique knowledge in relation to the feeding tube. Many caregivers found these new responsibilities to be intimidating and reported feeling ill-prepared to assume their caregiving role:

> ..there's all these different things, you know. Three months before you're going merrily along in life and then all of a sudden you've got all these things coming at you that are new and just a little intimidating...like, it's been very comforting knowing that he's been getting his nutrition through this feeding tube...but it was just scary when we had to start using it because we didn't know how to use it

Regardless of their readiness to assume their caregiving role, once they had become a caregiver, family members assumed certain caregiving responsibilities. Of primary importance to the family caregivers interviewed was ensuring that their loved

one was receiving adequate nutrition. Frustrations arose when the caregivers' ability to ensure adequate nutrition was thwarted:

> ...my role is to make sure that the food, you know, he was getting his nutrition and...and whatever. But then when it started getting more difficult for him to eat...then all of a sudden it went through a bit of frustration phase because I'm not...I can't envision how his throat must feel and it's like...to me it was just like swallow it. Like, just take this food and swallow it and he's going I can't swallow. So, all of a sudden you're in this frustration mode where my job is to try and get nutrition into him and he's not going along with it because it's hurting too much.

When challenges arose with respect to the caregivers' ability to ensure the patient's adequate nutrition, the feeding tube was considered to be an advantage because it reduced any such tension between caregivers and their loved ones and assisted the caregiver in providing their loved one with ample nutrition:

> It's the one thing we haven't had to worry about is how to get...how to get good nutrition inside of him...it's been extremely comforting to know that we don't have to worry about how he's going to get his nutrition

However, despite the feeding tube being advantageous, some caregivers reported the convenience of the feeding tube to be a "catch 22". This was particularly true for caregivers whose loved ones had reached a point in their illness where oral intake was being encouraged in an effort to maintain swallowing function and wean the patient off of the feeding tube:

> ...I would say there was probably a good two to three weeks where he wasn't taking anything orally. Well then when we met, uh, [health care provider] last Tuesday and she, uhm, indicated that he really needed to start with his oral intake and, you know, indicated that ... or explained why...she had indicated that, uh, with the radiation your throat muscles tighten and if you don't strengthen your throat muscles and your swallowing muscles enough, that the, uh, tightening will continue even after treatments. And if you don't challenge that enough, then you can get some permanent tightening that never goes away and you can have permanent damage ...and ... and find it hard to swallow for the rest of your life. So, of course, that panics me. *(chuckles)* And I'm thinking, okay, you got to start eating but I'm not the one with the pain. And I find out at

> the meeting that one of the reasons he was being a little bit stubborn and resisting my encouraging him to do that prior to seeing [health care provider] was because he was afraid he was going to do damage to the … you know, his throat…but [health care provider] said, no, you know, it's okay. You've got to start doing this…So, anyway, he's kind of now forcing himself to be drinking some Club Soda. He's drinking water. So he's probably up to maybe like two tins of pop-type drinks a day and … and a bottle of water, which, you know, I wasn't sure if that was progress or not… [health care provider] said that that is progress but that he needs to keep moving towards, uh, like clear … like maybe some clear soups, like something with calories in it. So that's going to be the next challenge but, you know, it's just going through my head the last week that maybe as much as the feeding tube has been a huge blessing and I wouldn't change that decision, it's almost like right now it may be hindering his recovery because he's reliant on it. And isn't having to force himself to take things orally.

In addition to ensuring adequate nutrition, family caregivers interviewed also felt responsible for managing any symptoms that the patient was experiencing related to complications of the feeding tube; symptoms arising in addition to those attributed to the patient's disease:

> she's had problems with her tube from the day she had it put in…she's had lots of infections and lots of stomach, uhm, problems with it and a lot of, uhm, irritation…and she's been taking a lot of medication for the pain and anti-inflammation and, uhm, muscle relaxants. So that's been a problem…I think the most difficult part was her being in pain all the time because then I can't do anything about it, you know

Family caregivers described the patients' symptoms as being a cascade of events. The challenge of responding to numerous symptoms simultaneously left caregivers feeling like they were "stamping out fires all the time":

> I said it's like juggling and you've got all these balls in the air at the same time because, you know, we go to see [health care provider] last week and she says, okay, uh, he's got to start increasing his oral intake and you've got to keep his pain under control. And I want him to get more active and all this kind of stuff. Okay, well, if we keep his pain under control and Tylenol's not working and we have to stick with the morphine. If we have to increase the amount of morphine that he's taking, we have to be careful that we don't increase it to the point where he becomes … he goes back to being lethargic and kind of zoned out… And then over here, we have to increase his oral intake but to do that we have to

> manage the pain. Like, it just keeps kind of going around. And then, of course, the morphine leads to this constipation issue…ahh, you just clear up one problem … you know, like, the hemorrhoids, you know, because of the constipation…So, it's like you're trying to get off the morphine so you can fix the constipation problem. But, it's just … it just keeps going around.

Another important caregiving responsibility identified by family caregivers was that of providing emotional support to their loved ones. Caregivers provided this psychosocial support whilst simultaneously dealing with their own emotions, which they reported to be extremely difficult:

> But it's like every so often you just get a day or a couple of days where you have this emotional breakdown, almost, where it's like you just literally … you know, like at the beginning, uhm, I couldn't stop crying. Like, you know, for about two or three weeks all somebody had to do was look at me the wrong way and I'd burst into tears or I'd be at work and I'd be working away and then all of a sudden I'd start to cry, you know, because something would come into my head…ah, I would have to say the walls that I hit are whenever (he's) been going through something hard. Like when he … like, I said, I felt really strong and really confident and really, uhm, you know, good about what we were doing when he was having the pain and we were able to deal with that with the morphine and I could kind of tuck him in bed and … and make sure he was okay and check up on him and be around and whatever. But then a couple of weeks ago when he went through more of a depression phase, I couldn't deal with that. Like, it really upset me because, you know, I love this person. He's a wonderful person…And when you see that person and they're in pain and they're depressed and … uh, he says, you know, he said, I look at myself in a mirror and all I see is a really sick person…. Those are the kind of things that have made me hit walls because, uhm, I just don't like seeing him upset. I don't like seeing him depressed and I don't like him feeling about … that way about himself…. And I have to say that we both hit walls at the same time because he hits a wall about something and then I just, you know, it's like I'm trying to be strong through this whole thing but I just can't stand seeing him upset or feeling down about himself or, you know, crying…for me to see him crying because he feels so crappy about himself, uhm, you know, I can be strong but I…you know, it's hard to be strong…at something like that.

c) Dealing with the effects of the caregiving role. The family caregivers interviewed reported experiencing negative physical and psychological effects as a

result of fulfilling their caregiving role. Many of the caregivers reported feelings of fear and anxiety in relation to fulfilling their caregiving responsibilities. Said this caregiver:

> … I mean even when she's sleeping, you'd think, oh gosh, I hope everything's okay, you know. And if she's fed, you know, I know she ate well and this and that. But it's just that you're the one there and, uh, you just … just want to be sure you're doing everything properly and …on time and all that. Just the responsibility.

Family caregivers also reported a change in their sleeping patterns in response to their new caregiving roles. Oftentimes, the caregivers interviewed indicated that their sleep was interrupted by the schedule of their caregiving responsibilities:

> Because I was going to say, too, the other thing – just going back a couple of questions, uh, with the feeding tube thing – because the other thing, especially with the morphine, he needs it every 3 hours and its going through the tube, so if … well, we started changing it now to 5 hours. But like all last week we had to have the clock set so that every 3 hours we were waking up to go … it was like having a baby … *(chuckling)* … you know. And it's like your sleep is completely disturbed and, uhm …you're just not rested like you should be because you've got the clock set to come on to wake you up every 3 hours so you can get up and put the morphine in. It was easier a few weeks ago before when he was still able to swallow because then he was on T3's and then if he needed them, he just kind of sat up in bed, popped them in and whatever.

Other caregivers reported trouble sleeping due to stress and anxiety that they were experiencing in the caregiving role:

> Well, I guess right now I'm very anxious. I'm not sleeping great at night. The last week or so I find I'm tense and … and whatever because I'm so afraid that … and I mean I … I know when I have time to kind of step back and think about it logically, I know that everything will be fine. But, uhm, most of the time though all I'm think … fretting about is, like, you know, what if he just keeps being … uh, like, what if he leaves it too long and … and he has … ends up having all these problems with his throat muscles? Like, what if he doesn't push himself enough and ends up with some permanent damage that … that's caused because he's not pushing himself enough to … to increase his oral intake? And I think it's probably also because I'm just tired and exhausted and, you know, kind of emotionally drained myself that I'm worrying about all of this.

Overall, caregivers experienced a psychological burden and reported feeling emotionally drained from the demands of their caregiving responsibilities:

> But it consumes your life. Like, all you talk about…I mean he can barely talk and when he can talk, it's to talk about, you know, this ache or this pain or this something, you know. But it's your whole life and it…it's not fun. But, uhm, I've hit a wall a couple of times. Like Saturday I found was a tough day. I don't know why. I just woke up and thought, you know what, I'm fed up with this. Like, this every 3 hours we've got to…you know, I'm running around and…and get food in him… And...and, uh, you know, I've had enough of this…I'm fed up and…and I was just kind of having a little…a little pity party for myself and then, uh, I got over it, you know, because it's like, this is all going to be fine...But it…it's very emotionally hard because you're watching somebody that you care about go through a really hard time. And you don't want them to go through that hard time, but you don't have a choice

d) Caregiver self-efficacy. Despite the negative effects that family caregivers experienced as a result of assuming their caregiving role, these individuals reported feeling a sense of pride in being able to fulfill their caregiving responsibilities:

> But I mean there was a certain amount of leakage and … and stuff, so … it was about ten days of discomfort and … and kind of getting used to it. And … and, like for me, there's a reason I'm not a nurse. Like, I have a very queasy stomach when it comes to anything medical or whatever, so I'm trying to envision like … I'm trying to help out with this thing coming out of his stomach and whatever. *(laughs)* But I'm very proud of myself because it didn't really bother me that much and, uhm, it didn't take that much to just get comfortable about doing the flushes a couple of times a day and whatever.

In particular, the caregivers in this study developed a sense of self-confidence through the mastery of those skills that were needed to manage the feeding tube and care for their loved one who was being tube-fed:

> practice makes perfect, I guess…because we…you know, we got to know how…how to set it up and we knew to watch the drip and the speed of the drip and we could adjust it and…gosh, we just got so good…We were quite proud of ourselves once we got on to this. You know, we thought we were the only ones who knew how to do it... (laughs)

II) Need to Negotiate an Altered Lifestyle

Family caregivers negotiated an altered lifestyle as they moved through the process of negotiating a new normal. An altered lifestyle included a) shifting routines; b) a diminished social life; and c) changes at work.

a) Shifting routines. The family caregivers interviewed indicated that the process of negotiating a new normal included a shift in their daily routines. These caregivers reported a marked decrease in the flexibility of daily routines and a pronounced lack of freedom in their schedules. Said one participant:

> Well, we … we're … we're two, uh, older people who have always had the freedom just to pick up and go wherever we wanted, when we wanted. And we really don't have that now. We have to consider that he has to feed in the morning and feed in the evening and we have to be somewhere where we can, uh, make sure that he has his supplies with him to be able to use. And, uh, so it's like, uh, timing where you're going to be. And we weren't used to … really used to that where … we're used to just, well, let's take off here or let's go there or …whenever.

Another participant said:

> …yeah, being a caregiver puts your life on hold. Whether you're doing it in the home or you're going and visiting somebody in the hospital just to oversee what's going on with their care in the hospital and what's going on with them…It totally puts your life on hold because you can't plan anything.

Many of the caregivers described life as happening "between feedings" in that the patient's tube feeds took priority and all other aspects of their day were scheduled around the feeding regimen:

> Well, I guess initially, uh … uhm, when we were doing the tube feeding and the radiation, we sort of set a schedule. We were up at 6:30 in the morning to start the first feeding. Uh, then scheduled a second one, get everything prepared. The Home Care nurse would always drop by and uhm, you just sort of had things scheduled at specific times throughout the day. And, uh, my outside activities were sort of … uhm, between the feedings. … I was sort of mostly retired but I was doing a little bit of contract work so I'd always get her feeding

> done, go out and do my little activity, but I would always be back in time to start the next feeding.

The tube feeds were reportedly also very time-consuming, which caregivers indicated left little time for other responsibilities or leisure activities:

> It takes a lot of time in your day to help with those things. Yeah, because it takes an hour of the feeding and then, you know, then you take, you know, a little while later it's medicines before and a little after, and then flushing it and then you're in pain, so you had a lot of stuff you that you were taking. So she had to end up taking quite a bit of stuff throughout the day. So it … it filled up the day, that's for sure.

In addition to scheduling and managing the tube feeding regimen, family caregivers reported assuming tasks and responsibilities that were normally outside of their role. These added responsibilities placed a large demand on caregivers' time and required them to keep a strict schedule:

FC: Well, uhm … it just meant that I had to take on more of the, uh, uh, sort of shopping. And, uh, basically I had to look after myself. You know, I had to cook my own meals. Plus I had to get her, uh … uh, feedings set up. Had to keep a pretty strict schedule. Uhm, you know, and then there was just normal routine housework and stuff like that, that you had to do.

I: Yeah. And how did you manage with that?

FC: Oh, I didn't have any problem. There was probably, uh … well, I shouldn't say probably. There were a lot of, uh, I guess tasks or, uh, things that didn't get done. Like, uh, I didn't get a … I didn't get the rooms painted that I planned on doing. You know, there were just some functions that, uh, never got done. Uhm, you know, the same with outdoor stuff. It was just sort of basic upkeep. Nothing … no home improvement …work, at all. And, uh … but we managed.

Those family caregivers that were not living in the same household as the patient indicated that they were negotiating multiple shifting routines. Caregivers negotiated a new routine with their loved one and the provision of care, whilst simultaneously shifting their regular routine to maintain their own household:

> Yeah, well, when we'd come home, we'd of course catch up on the laundry and the housework and like groceries and all of that at our home base. But, uhm, you know, once that was done, uhm, we were ready to go back and just, you know, at (her place) that's what we were doing, too. Grocery shopping and laundry and cleaning …and meal preparation, for ourselves and (her), and … and that type of thing. It was certainly a different routine.

b) Diminished social life. Closely linked to shifting routines, family caregivers reported that their social life had diminished as a result of their caregiving situation. Most notably, family caregivers reported that they no longer dined out of their home. Regardless of their previous habits with respect to dining out, caregivers reported that the practice of going out for dinner had ceased due to the patient's inability to engage in oral intake:

> … we used to go out for dinner frequently…we don't do that anymore because …she's unable to, uh … uh, sort of partake in the, uh … uh, restaurant experience. So … but … you just, uh, learn to live with it.

Family caregivers indicated that the engagement in mealtimes at home had also changed. Many caregivers found themselves cooking for one and eating meals alone. Even if their loved one was present during the meal, the dining experience felt isolated:

> I mean our friends are, like, hovering around and … but I mean, we … obviously we don't go for dinner. I mean if I go out for dinners with my girlfriends but, uhm … and … and that's … it's probably a little thing, but every night I come home and we give him his tube feed and then I have to find something for myself for dinner. So it's like you're cooking for one and you're eating alone. And that's kind of a petty thing and it sounds silly but it's like, okay, I'm having this glass of wine by myself. I'm having my meal by myself. And it's not that (he's) not there – he's sitting there – but somehow it's different, you know. And it's not that I'm the best cook or … *(chuckles)* … or, uhm, you know, that I'm very good at … and I don't even enjoy cooking, to be honest with you, but it just … it's very subtle but you suddenly sit there and think, you know, here I am having a glass of wine by myself. Here I am eating dinner by myself. Here I am preparing another meal by myself. So it's funny little things like that, that all of a sudden are different. And, you know, we're obviously not going out for dinner because he can't eat out for dinner. Uhm, we're not going out to any of the social things that we would normally go to. We're not going out to a movie like we're … our whole life is here. I mean,

that's the jigsaw puzzle and … and, uhm, you know, but friends are there and if we need them, we call and somebody comes over and sits with us. But that's our whole life right now, you know.

Often family caregivers felt guilty for eating around their loved one who was being tube-fed. In response to these feelings of guilt, some caregivers would choose not to eat or would only eat when they were not around the patient:

FC …you feel guilty for eating…Like, uhm, I always had … I was kind of glad to be at the Health Sciences Centre. Because you could go there to, uh, downstairs and not have to … but it was hard when we came home. Then I would have to go other places to try to eat because I didn't want to put him through, uh, you know, the nausea. He was very nauseated and …

I: And why did that make you feel guilty?

FC: Well, mostly because, like, he wasn't eating at all. And I really felt bad, you know. That …that's just about it. Because he wasn't eating at all and I just … I hated eating.

In addition, caregivers often had to alter what they were cooking for themselves. In an effort to be conscious of their loved ones' feelings of nausea or inability to eat, caregivers chose not to cook or to cook and eat things that were bland with minimal aroma:

FC: When we were home. I wouldn't cook anything. So, I would end up starving half the time.

I: Can you tell me more about that?

FC: Because he … it would make him sick. So, like I wouldn't have coffee in the morning. You can't go outside because it's freezing out there. Or even go start up the car to go somewhere.

Closely tied to the inability to go out for dinner, many of the caregivers indicated that their attendance at social functions had vastly decreased:

FC: Oh, our social activities, uh, combined … combined social activities have come to a complete halt. Uhm, there were other social activities that I just, uh … uh, didn't go to because just didn't feel like it.

I: Okay. Can you tell me more about that?

FC: Well, these were sort of, uh, curling wind-ups, you know, banquets, uh, activities like that. And I just didn't feel comfortable going to these activities without [spouse]

Even when opportunities arose for caregivers to go out or attend a social function, many of them chose not to attend because they did not want to leave their loved one alone:

> But, I mean I could go out every night if I wanted to and have my friends and … and do all these different things, but I don't feel right about that, leaving (him) alone. And, you know …We have people that are coming over, like … you know, like last night I was out with some girlfriends and we had somebody who called because I don't feel comfortable with him – I mean he doesn't need to be babysat – but I just feel better if somebody's here.

Other caregivers felt that their interest in socializing had diminished, which they attributed to their caregiving situation. One participant said:

> … uhm, like even with friends or something. Because they'd say, oh, do you want to do such and such on Saturday night or something and you ask me that on a Monday and I'll think, I don't know. Friday is such a long way away…Like I don't know how I'm … whether I'm going to feel like it or not on Friday. Whereas in the past, or before, I would say, sure, yeah, let's do whatever. And we'd like things that are planned. And now, I kind of don't want to plan anything in advance because maybe Friday or Saturday comes along and I would just as soon stay home and do nothing…And I think … I don't know whether that's because I'm tired or because I'm, uhm, just withdrawn from …things that … from the here and now, I guess. I think maybe I think … I think a lot about L.'s progress and how he's doing, so I'm more concerned about that than I am about anything else.

Some family caregivers expressed discomfort with attending functions alone and having to explain to others why their loved one was absent:

> … the thought of, uh, going to social functions without her sort of made me feel guilty…like she was being left out. So, rather than going out by myself, and having to explain to everybody, you know, why I was there by myself. Uh, I just didn't go.

c) Changes at work. Those family caregivers who were active in the workforce needed to negotiate their responsibilities at work in relation to their caregiving responsibilities. Some of the caregivers needed to take time off from their paid employment in order to assume and enact their caregiving role. Other caregivers reported having to shift their routines and organize their work and caregiving responsibilities simultaneously:

> Well, I'm at work and I'm trying to figure out, well, how to do this. So last week we kind of had to juggle things a little bit and I'm running back and forth from work and then we had different friends that were stopping by, and it was a little bit … this is the part I'm finding a little bit …It's working out fine and it's … we know it's just temporary for a week or two. And then this week I just made sure that I had no client appointments so – and I just work across the bridge. So I'm just running back and forth during the day.

III) Meaning of Feeding Tube

In their quest towards negotiating a new normal, family caregivers negotiated the meaning of the feeding tube. One of the caregivers associated the feeding tube with the presence of cancer:

> … you know what, as long as she's got the feeding tube her, uh, her recent bout of cancer is still with us, sort of. So, like once that's gone, I think it will be the beginning of another phase of her healing, you know. I think getting rid of that thing is going to be …We're really looking forward to that.

Said another participant:

> …so having the feeding tube, it was just, you know … it's not a reminder, it's just part of this whole thing that she's gone through. And once you're finished with that, then we're sort of moving on to the next stage of getting better.

For many of the caregivers, the presence of a feeding tube had a paradoxical meaning. On the one hand, the feeding tube was associated with illness and suffering. Family caregivers felt that an increased reliance on tube feeds meant that their loved one was experiencing increased pain and difficulty swallowing:

FC: Yeah, sort of the same thing because, again, and it's probably, again, the association with what it means. Is that you know that okay, you know, uh, we very quickly got into how to flush it and we were both very comfortable with that but we weren't using it to give him nutrition. So, I mean there had been a bit of a fear thing about getting the surgery in the first place and then we get over that. And then you learn how to flush it and you master that but it's not being used for nutrition. But I think, again, that's what it is, is that okay, if he needs it, it's because he's in a lot of pain and he can't swallow properly. So, again, it's just more of an unknown … something … there's all these different things, you know. Three months before you're going merrily along in life and then all of a sudden you've got all these things coming at you that are new and just a little intimidating. And I think it's what they're associated with.

I: What are … what are they associated with?

FC: Pain and suffering. And, uh, the disease.

Yet, at the same time, caregivers associated the meaning of the feeding tube with sustaining life and offering hope:

> Mostly that I thought he was dying. Like, someone to go that long without eating and even limited water …worried me. So it was almost like a lifesaver. Because I could see him … like, he wasn't his self. And, uhm, like the … the guy I knew. He was very sick. So putting the tube in …It relieved a lot of that … like, it was a relief to me. Like, I figured from there on at least he'd have a chance …to fight his battle, you know.

IV) Ways of Coping

In relation to their changing roles, an altered lifestyle, and the meaning of the feeding tube, family caregivers also had to negotiate ways of coping as they moved towards a new normal. Three major themes that emerged from the data in relation to family caregivers' ways of coping included a) adopting a certain mindset; b) finding psychosocial support; and c) distractions.

a) Adopting a certain mindset. The family caregivers interviewed reported adopting a certain mindset in order to cope with their new caregiving role and negotiate a new normal. Regardless of how they felt about becoming a caregiver, all of the

caregivers expressed resignation to the fact that this was just something that had to be done. One participant said:

> it's something that had to be done ...and I was going to do it. That's ... that's basically the way it went. It had to be done.

Another participant said:

> I resigned myself to the fact that this had to be done ...and, uh, just went about doing it.

Family caregivers also chose to maintain a positive outlook in relation to their situation:

> And uh, you know, I know in our family I'm sort of ... like, between my brothers and my whole family, I'm kind of the pivotal person that organizes family dinners and ... and make sure people get their birthday cards and people get this and that and ... and whatever. And, you know, I'm just that type of personality. Uhm, so I mean, when this whole thing came up, it's like, okay, we've got to be strong, we've got to deal with this, we've got to do it. And initially you're kind of ... your head's spinning and ... and you're just a little bit in shock and ... and ... and whatever. But then we reached a point, uhm, you know, at the beginning where, okay, we can either choose to be completely depressed about this for a long, long time or we can choose to say, you know what, we've got a good shot here at beating this, so let's just assume we're going to beat it and not even consider that there's any other outcome and until somebody tells us that, you know, guess what, this is ... something else has come up and ... and things are not good. So unless we hear those words, we're not going to go down this road without just truly believing that we ... we're going to have anything but a positive outcome. And so that's kind of the road ... and ... and when we were able to get to a point where we could take that approach, uh, once we got to that point, then we were able to sleep okay again at night and ... uhm, it's like, you know, I remember sitting there one day thinking, God, it's amazing how you can adjust to ... to things in life no matter how bad they are, if you choose to. Like, if you convince yourself that it's okay to do that.

b) Psychosocial support. Family caregivers indicated that a major way of coping with their situation was to avail themselves of psychosocial support. Some of the caregivers found that talking about their experience with a health care provider was helpful. However, most often, caregivers found informal support through family and friends:

> As much support as you can have. I mean I … it's been amazing to me. It's been huge through the whole process of the treatments, the radiation, everything. Uhm, of having people around, friends come around to … yeah, we'll do that, you know, whatever you have to do. So, the support … the support system is huge.

c) Distraction. The family caregivers interviewed reported that while the caregiving role was busy with added responsibilities, being distracted by some of their usual responsibilities was a positive way of coping. In particular, work responsibilities helped some family caregivers to divert their attention from the stress of their caregiving responsibilities:

> For me, I'm coping, uhm … I mean I have a job that I love so going to work and dealing with my job gets my mind completely off of all of this, so that's helpful.

> And, I mean, yes, I'm going to work and I'm grateful that I have a job where I can go and kind of get my mind off things during the day. And when (he) was feeling up to it, that's why he was going to work, uhm, as long as did, because he absolutely adores what he does and, uh, he's dealing with kids on a regular basis that, uhm, have far worse problems than … than this, you know, in our minds. Uhm, it keeps your mind off it. But it consumes your life. Like, all you talk about … I mean he can barely talk and when he can talk, it's to talk about, you know, this ache or this pain or this something, you know. But it's your whole life and it … it's not fun.

Facilitators of Negotiation

Facilitators of negotiation refer to those things that enable caregivers to acquire skills and knowledge needed to enact their caregiving role and negotiate a new normal. Information, communication, and support were needed to facilitate the negotiation process. Conversely, inadequacy, or absence of these things hindered negotiation. The family caregivers interviewed reported receiving some information, communication, and support from both informal and formal sources. However, these caregivers indicated that within the categories of information, communication and support they still had needs that were not met.

Informal Information, Communication, and Support

Family caregivers reported receiving most of their support informally from family and friends. This informal support consisted of both emotional and task oriented help. Family and friends provided emotional support by allowing caregivers to talk about their situation:

> Well, thankfully I had a nice, uhm … uh, social group…. Uhm, I belong to a Newcomers' Club and there were a lot of … a lot of really nice women that became my … like my sister substitutes. And, uh, so when I was home I could pick up on those activities that I was doing with those ladies. And they were just … uhm, just so nice, you know. And they would get me talking about it, which was a good thing. They would always ask questions and I could tell them and they were just wanting to keep right up to date on what was happening. One of the girls is a nurse …so she was very concerned and asked specific questions and … yeah, so it was good.

Some family caregivers received physical help and support by friends and family who brought meals or assisted with household chores:

> … well, we had a lot of help with people, too, which is an amazing thing. A lot of people brought meals for us, which was … made my life easier.

Said this participant:

> Well, like I said, we had a lot of support. We had a lot of family help us out. Uh, that's all positive, and we didn't want to put them through all that, but …like his daughter having to come all the way from Toronto. His son stopped in with us everyday. Uhm, my daughter looked after my house and looked after the cat. His father looked after the house and we had a lot of help, a lot of support.

Often times, family caregivers reported receiving support from family members and friends who had a background in health care. When support came from a friend or family member with health care experience, the help received was largely in relation to managing the feeding tube which they found to be extremely useful:

> Uhm, a girlfriend of mine is a retired nurse – uh, like she just retired and she's, you know, she's kind of gone back working on call kind of shifts – but she had said at the beginning if you need any help with anything give me a call. So we

> called her and I told her what the problem was and, like, she came right over. And, we are very lucky we've had tons and tons of support from all kinds of different friends and people. And, uhm, it was really nice to have somebody like her to call and say we need some help and she just came right over and showed us how to use the feeding tube.

Another source of informal support that was particularly helpful for family caregivers was the support offered by others who were in a similar situation. Some caregivers were connected to this support through a peer mentorship program at CancerCare Manitoba, while others experienced chance encounters with other caregivers in waiting rooms during the course of their loved ones' treatment. Regardless of how they connected with others in a similar situation, family caregivers found the discussions with these individuals to be informative and a source of meaningful support:

> ...this couple that we hooked up with when they were going through this, and it has been helpful for me because she was the caregiver for him, so she was able to share a lot of her experience with me. And she talked about how difficult it was, as the non-sick person, trying to get food into him. And how upsetting it would be, you know, she said it would take 2 hours to get a bowl of soup down his throat and ... and whatever.

Formal Information, Communication, and Support

Family caregivers felt that health care providers were a helpful source of formal support. Specifically, they reported that health care providers were readily available to answer questions and provide information related to their loved ones disease and management of the feeding tube:

> And, uhm, like our family, we were all able to support each other but we were also able to get help and support from the CancerCare. From the nurses and the doctors and whoever we talked to ... the dieticians, whoever it was. They were very, very helpful.

One family caregiver acknowledged the formal support offered by health care providers but reported the help available to be too restrictive. In particular, she felt that having to wait for home care to arrive at an unspecified time within a broad window of time was extremely limiting in a situation that already controlled many aspects of their life. As such, this family caregiver did not always avail themselves of this help:

> When they said, well, you know, we can't tell you what time we'll come because we may be here at 8:00 in the morning, we may not be here till 11:00 and then at night we might be here at 6:00, it might be 9:00 o'clock at night. Well, this whole thing was already controlling our life and it's like, what are we going to do? Like, sit in the house the whole day waiting for these nurses to show up. So, I guess, in my opinion, you should be given the choice of dealing with it yourself or having these … because, trust me, if I can do this, anybody can because I don't have the stomach for this kind of stuff but I didn't have a problem with this at all. And we really … once we got … once my girlfriend came out and showed us what to do, we had no problem doing it. And I think a lot of people would find it very frustrating if they had to sit around all day waiting for nurses to show up. And it's not their fault, it's just that's the way the system is and there is a lot of elderly people out there or people on their own that need them and that's why the system is so backed up.

In relation to the formal support received by health care providers, family caregivers revealed that the provision of information was variable. Some of the family caregivers received pamphlets and written information about how to manage the feeding tube, while others received little or no written information to assist them in assuming their caregiving responsibilities. Similarly, some of the family caregivers were given practical demonstrations in relation to managing the feeding tube, and others were not shown how to carry out these responsibilities. Said this participant:

> There was really no training provided. Uh, there was a couple of information pamphlets on what to do. But no practical training, you know, to get you started.

Another participant said:

> I don't recall them sending any documentation or giving me any documentation. It was just, uh, sort of a visual demonstration on how to do it and then when the health care nurse was here, she again, demonstrated how to use it and, uh, how to get things going. I think a little pamphlet, uh, definitely would be helpful.

Family caregivers who did receive written information indicated that the depth and scope of information provided was insufficient and did not meet their information needs:

> ...we really were frustrated the first week or ten days after he had the tube put in ...at the ... this little information package. It had nothing in it. Like there was ... like I said it ... it ... I remember we commented ...on that at the beginning and (he) said, you know, that's one thing I would tell somebody, uhm, you know ...if I had the chance, is that you need to have more information when you have this thing put in about what to do with it...and what to look for and ...

Family caregivers readily identified the information and support that would be helpful to them. In general, caregivers reported needing detailed written information and hands-on practice to prepare them for and help them manage the feeding tube. More specifically, caregivers reported wanting to receive written information and training to prepare them for what to expect after the feeding tube had been inserted, how to do dressings changes appropriately, flush the feeding tube, administer medications, and administer the actual feeds. A trouble-shooting guide to address these issues throughout the course of managing the feeding tube was also identified as necessary. In addition, caregivers reported wanting information and training on how to assess and manage various symptoms, in particular pain. Said one participant:

> I think it just would have been a little more helpful having maybe a little bit more information up front about ... maybe somebody sitting down and saying, okay, here's what to expect after the surgery. You're going to have pain for a week. You're going to have some discharge. You should look for redness. Because, again, that's when I phoned my girlfriend who, uhm, is an R.N. and

then she came out and she was … she came out a couple of times, I guess and dropped by just looking for … like, I don't know what to look for. And … and, you know, she kind of said, well, you look for redness and this and that and the other thing.

Another participant said:

I guess a little bit of pictorial along with a, uhm, written description on, uhm, how to get the, uh … uh, the bag working. You know, filling the bag is no problem, but …you sort of … you … you've got to prime it a little bit..to, uh, make it work properly. And, uhm, you know, perhaps a little … a pictorial with a written description and, uh, uhm, perhaps a little troubleshooting guide, you know, if it's not … if it's not dripping. You know, what to do to get it going again. You sort of learn that as you go along.

And this participant said:

But if there had been some kind of mannequin that showed, like I said, so you could look on the backside of it and see where the tube is connected. Like, what … what … where … like, where does it go once it's in there? I'd love to know. Like, what we're … where we're we putting the food when it goes in, you know? Just kind of … so you can kind of see what's going on in the inside. And then, just have somebody demonstrate. Like, okay, if this was the tube, you know, if you have to use it, here's how you flush it out. Because all we had to do for the first … whatever that was, three weeks or month, was just flush it with water …twice a day. Well, I mean, that was like, okay, how do we do this? We had to kind of figure it out for ourselves. And, uh … and then when the … you have to use the … the liquid. But, you know, just to let people … okay, here, we'll demonstrate how to do it and then you try it. And then at least you'd have some … I mean I was terrified ... when he said, you know, I think … I think it's time to start using the feed … because, you know, we had been going along this path where he was eating really well and he was getting all this protein and he was putting weight on and whatever. And, I mean, we were making jokes about, well, gee, you know, isn't that too bad we did the feeding tube and, you know, wouldn't that be great if we could get through this whole thing without it. And it was literally overnight …that he couldn't eat anymore. Like, through his mouth. He was in a lot of pain. Well, I was terrified because, okay, well, now what do we do? And if it hadn't been for a friend of ours who is an R.N. …who I phoned and said, like, what do we do? And … and can we put stuff like … because we had been given some samples of Boost and Ensure. And I said, can we put that kind of stuff through? And she said, oh sure you can. So she came over and kind of showed us what to do. But it would have been less intimidating if there had been a bit of a demonstration …And, you know, where you could practice a little bit so that then you're kind of ready.

Family caregivers reported that they received information from a number of different sources. This piecemeal approach produced gaps in communication, which was confusing for caregivers and left them wondering whether they had received all of the information that they needed to adequately care for their loved one and manage the feeding tube. In addition, family caregivers reported being given mixed messages about how to manage various aspects of the feeding tube which was extremely confusing and frustrating for them as they assumed their caregiving responsibilities. As such, caregivers regularly reported the need for consistent communication from health care providers to support them in their caregiving role. One participant said:

> I think, a set of directions, like, from the very beginning from everybody. If everyone had the same message and … and …Yeah, I think it would have been a little bit clearer to us.

Another participant said:

> So I think – and I'm not sure if it normally would be like that – but everyone says, oh, you know, it's … it's minimized. And I don't know whether it's to … so you don't feel so scared going in to it, but I just … we just didn't seem to get everything that we needed to know. And either they don't think we'll understand it or it's … I don't know, but we are … we like to know exactly what's going on.

Said this participant:

> Well, I think we would need to have everyone saying the same thing. So, like, we talked about that, too. I think having that little standard form that all of them sign off. This is how you dress the bandage or … or the surgery. This is how you do this. This is what you can expect. That every one of them tells me the exact same thing. Like, you know, about whether there should be a gauze underneath or not and all these little types of …How tight it should be. Like everyone should be saying the same thing, I think. Or they should at least be in some sort of an agreement to give me some range but … you know, like, everyone has there own way of doing it. Maybe it works … you know, maybe it worked best for every one of those different people for different people they dealt with, those things that worked. But just some standard and they tell … you get told by one not to do it and the other person to do it, so I think … I think a standard form is what … and then also, knowing … like, I never thought about,

> you know, the complications of the pain. I think it was tube feeding that can cause these conditions. And I think they should have … we really didn't get any idea of what could happen. And I think that, you know, I'm assuming that maybe people would be less inclined to do it, if they heard that. But, I think it's important, you know, for everyone to … I think if you're more comfortable with what's going to happen, you're ready for it when it happens instead of finding out you're having these pains. It's, oh yeah, you know, that does happen, you know, when you have to go back for it. And that's … that's frustrating, I find.

Family caregivers also reported that they often received information about managing the feeding tube well in advance of needing to use it. At times, this information came when the caregiver was also receiving large amounts of information about other aspects of their loved ones treatment and care which was overwhelming for them. The family caregivers interviewed indicated that receiving too much information at once or receiving information about the feeding tube too far in advance of when they needed to use it was counterproductive. From the caregivers' perspective, information from health care providers regarding management of the feeding tube would be most supportive if it was given to caregivers in stages that matched their current use of the feeding tube:

> …if we had been shown a couple of days before the surgery how to flush it and whatever, I think that would have been very helpful. And then maybe they wait a couple of weeks and … because I think the timing of people needing to use the feeding tube is probably fairly close to the same for everybody, like, you know, the first two or three weeks are fine. So I mean, maybe two weeks into it, after you've had the feeding tube for a couple of weeks, where you've kind of settled into it and gotten used to flushing it and kind of mastered that. Then follow it up with, okay, if you need to use it. You know, here's … let's … let's … let's do practice. But just have something physically that you can practice on because we both found that very stressful to have to kind of wing it.

Levels of Negotiation

The family caregivers in this study negotiated a number of matters which needed to be facilitated by adequate information, communication, and support as they moved

towards a new normal. Negotiation transpired at the level of the individual family caregiver, the family caregiver-patient dyad, their social network, and the greater health care system. The various levels at which negotiation took place created the context within which the process of negotiating a new normal occurred. The process of negotiation that these family caregivers moved through was dynamic and ongoing and reflects the complexity of their caregiving experience.

Triggers for Re-negotiation

If caregivers were able to move through the process of negotiation successfully, they arrived at a new normal. However, any marked changes in the patient's status caused a disruption in this new normal and the process of negotiation began anew. For example, family caregivers reported that their new normal was disrupted when their loved one experienced a new symptom, or when caregiving responsibilities progressed from regularly flushing the feeding tube to administering actual tube feeds. These disruptions to caregivers' new normal served as a trigger for re-negotiation:

> Because we were convinced three weeks into his treatment – and all we were doing was flushing it twice a day – and three weeks into his treatments, we were going, well, it looks like this was a waste of time, like, you know, but I'm glad we had it done because imagine if we had to use it and whatever. And, uhm, we're thinking, you know, we're already halfway through the treatments and he's fine and doing great and able to eat and whatever…And I remember he had this … this breakfast this one morning … he had pancakes and he had eggs and he had toast and he had oatmeal. He had all this stuff. The next day he couldn't have any of it. It was literally … you know, we had this whole plan that he would go … kind of ease into liquids and … and all these things. But it ended and it was literally pretty much overnight he couldn't eat. Well, I was just frustrated because I'm going, oh come on! *(laughs)* You know, how could you have eaten all this stuff yesterday. You're not even trying… and he's just going, sorry but I can't eat it and that was the end of it…Yeah, so it was a little frustrating but, uhm, I guess my preference would have been for him to last longer eating orally. Uhm, I think just because emotionally it's … it … again, I'm not in the medical field so … And, uh, I think for me part of the thing was I felt a little panicky about, oh no, this is another … this is something new again.

> You know, like you're dealing with all these new things. Like you get diagnosed with cancer, that's something new. You have to have some … he had to have some, four teeth taken out. That was scary because, you know, I don't know, it just is. And then he has to have the stomach tube put in and that's kind of scary. And then you have to start the treatments and … and I remember we were … you know, when you're diagnosed, it's like, okay, we're not doing anything this afternoon can we just get on with the treatments and … and start getting through this but, of course, you have to wait two or three weeks because all these things have to happen. And I remember when he was … he phoned me and said, oh, guess what, I'm starting treatments next week. I mean we had been waiting and waiting – it seemed endlessly – to be told we'd start treatments and then as soon as he phoned me and said I'm starting treatments next week, I started to cry because I felt panicky and … and, oh no, like, here's something new again. And I think that's just want it was … it's like, you kind of get into this routine that all this tube is for is to flush a couple of times a day and then all of a sudden it's like, okay, I can't eat anymore, I need to start using it. And it's like, oh, no. And it's just like moving from, uhm, T3's to morphine, that's scary. And, you know, it's just all adjusting to something new. So, uhm, it was scary but I think that's why it was more … I didn't want him to move off eating orally because that would change another ... it would be just another change to add to the pile that of all these things that had changed in our life. And, uhm, again, I think if you were in the medical field where you're kind of more used to that kind of stuff maybe … you know, somebody else would probably react differently but, uhm, I would have preferred him to continue eating orally longer. But, uhm, that's probably more a denial thing than anything. But, it's like, okay, now we have to deal with the reality of him eating through a feeding tube.

Summary

This chapter presented the findings of the study. Demographic characteristics of the family caregivers and patients were provided. The essence of the family member caregiving experience, that of negotiating a new normal, was described in detail. The major themes and sub-themes emerging from the data were presented, supported by illustrative data exemplars. The levels of negotiation with which family members had to contend, in addition to the effect of changes in the patient's medical status were described as regards to their impact in triggering the renegotiation process. The

following chapter will present a discussion of the findings in light of extant work, and outline the implications of the study for nursing practice, education, and research.

CHAPTER FIVE: DISCUSSION

This chapter discusses the findings from the study as they relate to the proposed research questions, relevant empirical literature, and the sensitizing conceptual framework used in this project. The chapter concludes with a discussion of the implications of the study for nursing practice, education, and research.

Relationship of the Findings to the Research Questions

The purpose of this study was to describe the nature of the experience of caring for a dysphagic family member with advanced head and neck cancer who is either partially or totally reliant on tube-feeding. Three specific questions provided direction for the project and were addressed:

1. How does caring for a family member, who has advanced head and neck cancer and who receives enteral tube feeding, affect the family caregiver?
2. Do family caregivers of this particular patient population have specific needs related to their caregiving responsibilities?
3. What are the specific needs of the family caregivers as identified by the caregivers themselves?

Negotiating a New Normal

The experience of caring for a dysphagic family member with advanced head and neck cancer who is either totally or partially reliant on tube feeding means "negotiating a new normal". By definition, to negotiate is "to move through, around, or over in a satisfactory manner" (Soanes, Hawker, & Elliott, 2005). In the process of negotiating a new normal, caregivers moved through the disruption in their lives that was caused by the presence of a feeding tube, inserted as part of the patient's overall

plan of care. If they were able to move through this disruption in a satisfactory manner, caregivers arrived at a new normal.

The literature on negotiation is changing from a structuralist-rationalistic perspective to a contextual social process point of view. In the structuralist-rationalistic perspective negotiation is viewed as a rational, strategic, and calculated activity (Kramer & Messick, 1995). In contrast, the contextual social process viewpoint is focused on negotiation processes and outcomes (Kramer & Messick, 1995). From the perspective of a contextual social process, individuals are social decision makers focused on decisions, rules, behaviors, interactions, and self-awareness. As such, research from this point of view includes analyses of the social context and their effect on negotiation behaviors.

Morley (1986) described negotiation as a continual process of joint decision making used to address issues as they arise in particular social contexts. This ongoing negotiation process is used to manage change and it brings about sets of rules for the behavior of involved parties. As such, social order is considered a negotiated order. Understanding a negotiated social order does not require an analysis of or by both parties in the negotiation. Rather, the stories told by even one participant can be used to describe negotiated situations, processes, or outcomes.

As family caregivers in this study responded to the disruption in their lives and moved through the process of negotiating a new normal, negotiation happened at the level of the individual family caregiver, the caregiver-patient dyad, their social network, and the greater health care system. These levels at which negotiation took place, and the dynamic interaction between them, sets the context within which caregivers

negotiate a new normal. Akin to Morley's (1986) description, the process of negotiation that caregivers moved through was ongoing and was used to manage the disruption, or change, in their lives brought about by the presence of a feeding tube. The negotiation process also brought about behavioral rules for the caregivers, such as assuming a particular pattern of care, their loved ones, their friends and family, and the health care providers that were involved in this process of negotiation.

Effects of Caregiving on the Family Caregiver

This study identified that the act of assuming a caregiver role had multiple effects on the family caregiver. These effects will be discussed in light of extant literature.

Changing roles. The family caregivers in this study reported feeling that they were not given a choice about becoming a caregiver. Most of the caregivers expressed that assuming this role was something that "just had to be done". Stajduhar and Davies (2005) examined the perspectives of family members who provided care at home and found that the decision to provide care at home was characterized by one of three perspectives: an uninformed decision with little consideration for the implications; a decision made through negotiation with their ill family member; or an indifferent decision, whereby caregivers reluctantly agreed to provide care at home. The latter perspective most closely describes the caregivers in this study. This reluctance to assume the caregiving role has not been examined extensively in the literature. However, it is prudent to recognize that while some family caregivers may feel highly committed to caregiving, other caregivers will not be interested in caregiving, but will feel pressured by social norms and societal expectations to accept the role (Burridge et

al., 2007). Caregivers may feel obligated to uphold the wishes of their loved one concerning who provides care, which trumps their ability to make a choice about their role (Stajduhar, 2003). In addition, changes in the health care system aimed at maintaining people in the community make some caregivers feel exploited by the system and pressured to care for their loved one at home (Stajduhar, 2003). In any case, reluctance to assume a caregiver role may be hidden to avoid criticism (Burridge et al., 2007).

Family caregivers in this study indicated that in becoming a caregiver, their role in relation to their loved one had changed. Existing roles as "husband and wife", or "brother and sister", became redefined as "caregiver and patient". Such role changes inevitably affected the relationship between the caregivers in this study and their loved ones. This is congruent with the findings of an ethnographic study conducted by Stajduhar (2003) examining the experiences of family members providing palliative care at home. Stajduhar (2003) reported that many caregivers reinvent themselves to become "nurse-caregivers" by assuming responsibilities for the patient's personal care, assessing symptoms, monitoring the patient's health status, planning and coordinating care, and mediating family tensions.

Assuming a caregiving role alters family relationships in that caregivers have little time to maintain their core identities as spouses, children, or siblings. Furthermore, when the home becomes the site for the provision of health care, it is often turned into a hospital-like setting filled with equipment and supplies. As such, maintaining privacy and intimacy is difficult and family relationships change (Stajduhar, 2003). This type of situation is analogous for family caregivers providing

care for a family member who is dependent on tube-feeds. Indeed, family caregivers in this study reported that relationships with their loved ones revolved around the illness and their caregiving responsibilities. Having a family member dependent on tube-feeds altered those activities that the caregiver and their loved one would regularly enjoy together. Furthermore, relating to their loved one as a spouse or sibling was overshadowed by discussions concerning symptom management and the patients' needs.

Despite changing family relationships, some of the family caregivers in this study considered their new caregiver and patient roles to be positive. Participants explained that caring for an ill family member strengthened their communication and helped them to foster appreciation for each other. Caregiving provided an opportunity for family members to spend time with the patient and allowed the caregiver to learn new things about themselves and the patient. This is consistent with the work done by Stajduhar (2003) which found that providing care at home was life-enriching for many caregivers in that it allowed them to spend valuable time with the patient and helped them to find meaning in the situation.

Family caregivers reported having to negotiate a caregiving relationship with the patient in their new "caregiver and patient" roles. One family caregiver assumed a standby role to support their loved one who was largely independent with their care activities. However, each of the remaining caregivers interviewed reported sharing care activities with the patient. Schumacher (1996) coined this caregiving relationship as a "pattern of care" and defined it as "the nature of the shared involvement in illness-related care by caregivers and patients" (p. 278). Furthermore, Schumacher and

colleagues (2006) describe three patterns of care that exist: the self-caregiving pattern, the collaborative care pattern, and the family caregiving pattern. The self-caregiving pattern, reflected by one of the participants and their loved one in this study, typifies patients who are mostly independent and require limited family member involvement. The collaborative care pattern characterizes the majority of the participants in this study and involves patients and caregivers sharing care activities in response to illness demands. Finally, the family caregiving pattern is characterized by patients being highly dependent on family caregivers to perform care activities (Schumacher et al., 2006). In this study the family caregiving pattern was not demonstrated.

Many of the family caregivers in this study carried out multiple roles simultaneously. A longitudinal study conducted by Kim and colleagues (2006) demonstrated that the multiple roles that are simultaneously carried out by caregivers are likely to compete with each other with respect to the caregiver's limited psychological resources, resulting in the caregiver feeling strained by the new caregiver role. A number of the caregivers in this study were employed at the time that they assumed their caregiving role. Some of the caregivers took time off from their paid employment in order to assume and enact their caregiving role. Other caregivers explained how they shifted their routines and organized their work and caregiving responsibilities simultaneously.

Intuitively, one would derive that maintaining employment while caring for an ill family member would be highly stressful. In fact, despite needing to juggle responsibilities between work and home, the caregivers in this study reported that spending time at work was a chance to escape from their caregiving responsibilities and

was seen as a way of coping. This is consistent with the findings from Kim and colleagues (2006) which revealed that family caregivers may benefit from being employed in that employment may operate as a respite for caregivers, providing them with opportunities to restore their psychological resources. That being said, the beneficial impact of performing multiple roles does not hold true for employed caregivers who also have a parental role. In fact, Kim and colleagues (2006) found that caregivers who were employed and took care of children while they provided care to relatives with cancer were particularly likely to experience psychological strain and have difficulty in finding meaning from their new role as a cancer caregiver. One caregiver in this study did have the added responsibility of taking care of children; however they were not employed outside the home. None-the-less, caring for an ill family member whilst simultaneously caring for children was demanding and placed added strain on this caregiver. The most advantageous combination and number of roles to facilitate optimal adjustment in family caregivers of patients with cancer remain unclear (Kim et al., 2006).

Family caregivers in this study were required to learn new skills and acquire unique knowledge in relation to providing nutritional care to the patients. Of utmost importance to the family caregivers in this study was ensuring that their loved one was receiving adequate nutrition. When an ill family member was no longer able to swallow, caregivers feared that their loved ones would starve to death and experienced frustration with trying to get their loved one to eat. This is consistent with the findings from a grounded theory study conducted by McClement, Degner, and Harlos (2003) in which many family members of advanced anorexic cachectic palliative in-patients

responded to their fears related to declining intake by adopting a perspective of "fighting back". In the process of fighting back, family members attempted various tactics to get extra calories into the patient, oftentimes creating tension between the family member and their loved one. In addition, family members petitioned health care providers for interventions such as enteral tube-feeding in an effort to ensure that their loved one received the best possible nutritional care (McClement et al., 2003; 2004). Similarly, the family caregivers in this study perceived the feeding tube to be an advantage because it reduced tension between caregivers and their loved ones and assisted the caregiver in providing their loved one with ample nutrition.

Family caregivers in this study also felt responsible for managing symptoms that the patient was experiencing. Symptom management and patient comfort have been identified as the primary concern of family caregivers in providing care for cancer patients at home (Kristjanson, 1986, 1989). Many of the symptoms that the caregivers in this study felt responsible for managing were related to complications of the feeding tube and were over and above any symptoms related to the patient's disease itself. Family caregivers reported dealing with discharge from the tube site, pain at the stoma site, and stomal infections requiring antibiotics, all of which are complications that are commonly documented in the literature as complications associated with percutaneous gastrostomy tubes (Crosby & Duerksen, 2005; 2007). Despite this, however, caregivers in this study reported that they had not been educated about the occurrence of these complications or taught about how to respond to them. This finding is troublesome from both a medical and psychosocial perspective. First, tube-related complications have been shown to be associated with significantly increased health care utilization (Crosby

& Duerksen, 2005; 2007). Second, not being provided with education regarding these complications resulted in family caregiver anxiety and not surprisingly, unscheduled contact with health care professionals.

Family caregivers in this study felt that they were responsible for providing emotional support to their loved ones. Caregivers provided this psychosocial support whilst simultaneously dealing with their own emotions, which they described to be extremely difficult. Thomas and colleagues (2002) describe the caregiving experience as being comprised of both care work and emotion work. Emotion work is a key aspect of the cancer caregiving experience and involves the emotional effort made by family caregivers to manage their own feelings and those of the patient (Thomas et al., 2002). Providing emotional support to their loved one was particularly distressing for one family caregiver whose loved one was experiencing low self-esteem in relation to weight loss. Visible weight loss symbolizes advancing disease and can have a negative impact on patients' sense of control (Hopkinson, Wright, & Corner, 2006). As such, weight loss not only has physical impacts, but psychosocial consequences for patients and becomes part of caregivers' emotion work. This is particularly important for caregivers of patients with advanced head and neck cancer who frequently experience difficulty swallowing and weight loss as part of their illness.

Family caregivers experience profound psychological (Braun et al., 2007; Cameron et al., 2002; Dumont et al., 2006; Kim et al., 2006; Payne et al., 1999), physical (Burton et al., 1997; Morse & Fife, 1998; Schulz & Beach, 1999), and financial burdens as a result of caregiving (Emanual et al., 2000; Grunfeld et al., 2004; McCorkle & Pasacreta, 2001; Morris & Thomas, 2001). Indeed, the family caregivers

in this study reported experiencing untoward effects in each of these domains as a result of their caregiving role. In particular, caregivers experienced emotional distress and disturbed sleep as significant burdens of care. Many of the caregivers in this study reported feelings of fear and concern in relation to filling their role adequately. This is consistent with the literature that describes caregiving responsibilities as evoking a considerable amount of anxiety in family caregivers (Braun et al., 2007; Grbich, Parker, & Maddocks, 2001; Grunfeld et al., 2004). As a result of the fear and anxiety, family caregivers in this study reported experiencing disturbed sleep. The anxiety imparted by overwhelming caregiver responsibilities often manifests in fluctuating sleep quality and increased reporting of depressive symptoms (Carter, 2002, 2003; Carter & Acton, 2006; Hearson, 2007).

The feelings of anxiety and disturbed sleep patterns that were experienced by the caregivers in this study are not surprising given the fact that the caregivers in this study did not feel prepared to assume their caregiving responsibilities. Caregivers' lack of preparedness is negatively associated with fatigue, confusion, and total mood disturbance (Schumacher et al., 2008). Many family caregivers who provide care for loved ones who are dependent on home care technologies such as enteral tube feeding receive no formal training, despite the recognition that providing technological home care is a complex task requiring specific skills (Silver & Wellman, 2002). Lack of formal instruction leaves caregivers unprepared for their caregiving responsibilities evoking heightened stress and anxiety (Silver & Wellman, 2002). As a result, the caregivers in this study reported feeling emotionally drained from the demands of their

caregiving responsibilities, a sentiment that is echoed in the caregiving literature (Stajduhar, 2003).

Altered lifestyle. The family caregivers in this study indicated that caring for a dysphagic family member who was dependent on tube-feeds included a major shift in their daily routines and a pronounced lack of freedom in their schedules. Many of the caregivers described how life happened "between feedings" in that the patient's tube feeds took priority and all other aspects of their day were scheduled around the feeding regimen. These findings are consistent with other studies in which caregivers describe feeling "stuck" or "tied down" in their caregiving role (Stajduhar, 2003).

In addition, family caregivers in this study assumed tasks and responsibilities that were normally outside of their role. These added responsibilities placed a large demand on caregivers' time and left little time for other activities. Caregivers who are limited in their ability to participate in valued activities and interests experience increased emotional distress and report greater depressive symptoms (Cameron et al., 2002).

Most notably, family caregivers in this study reported a vastly diminished social life as a result of caring for a loved one who was dependent on tube-feeds. Consistent with other qualitative research examining the impact of home enteral nutrition on the everyday life of patients and their caregivers (Brotherton et al., 2006; Liley & Manthorpe, 2003), the caregivers in this study explained how mealtimes and social occasions had changed dramatically for them and their loved one. Caregivers in this study grieved the fact that they were no longer able to go out for dinner, and explained how that even the engagement in mealtimes at home had changed. Many of the

caregivers found themselves cooking for one and eating meals alone. Even if their loved one was present during the meal, the dining experience was different in that the caregivers and patients could not enjoy a meal together. Rather, caregivers would be eating alone while their loved ones watched and received tube feeds. Moreover, family caregivers often felt guilty for eating around their loved one who was being tube-fed. Many of the caregivers in this study chose not to attend social functions because their loved one could not eat and they did not want to leave their loved one alone or explain to others why their loved one was absent. While research examining the impact of enteral tube feeding on daily life from the family caregivers' perspective is scant, a small number of qualitative studies have described mealtimes and social functions as important issues for family members who are caring for a loved one who is dependent on tube feeds (Brotherton et al., 2006; Larsson et al., 2003; Liley & Manthorpe, 2003). The findings in this study are consistent with existing literature that reports both the patient and the family caregivers experience negative psychological effects when they are unable to attend important social events due to others' reactions or the patients' inability to eat (Brotherton et al., 2006; Liley & Manthorpe, 2003).

Ways of coping. The family caregivers in this study found various ways to cope with their caregiving situation. Many of the caregivers expressed a sense of resignation in that caring for their loved one was just something that had to be done. The literature suggests that caregivers who accept their situation and find meaning in their caregiving experience are likely to improve their life satisfaction and reduce depressive symptoms (Kim, Schulz, & Carver; 2007). In addition, many of the caregivers in this study chose to maintain a positive outlook on their situation. Caregivers who tend to have a more

positive approach to life are better able to cope with the demands of their caregiving situation (Stajduhar, Martin, Barwich, & Fyles, 2008).

Another way that family caregivers in this study chose to cope with their situation was to avail themselves of informal support from family and friends. Caregivers appreciated having someone to talk to or provide physical help with tasks and responsibilities. This is consistent with the work of Stajduhar and colleagues (2008) who found that hands-on practical help and having someone to communicate with were important forms of social support and coping for caregivers.

Specific Needs as Identified by the Family Caregivers

The second and third research questions in this study examined whether or not family caregivers of patients with advanced head and neck cancer that are being tube-fed have specific needs in relation to their caregiving responsibilities, and delineate what those caregiving needs are.

Generally speaking, family caregivers in this study identified the need for information, communication, and support to facilitate the negotiation process. The absence of or inadequacy of these things hindered negotiation processes.

Informal support. Family caregivers in this study reported receiving most of their support informally from family and friends. The informal support offered from these sources was both emotional and task oriented in nature which the caregivers in this study found to be extremely helpful. Although caregivers often describe family and friends as providing extremely valuable help, it is frequently perceived by caregivers that these individuals simply do not understand the implications of the caregiving situation and therefore do not always respond appropriately (Wiles, 2003). While

practical physical help is always appreciated when given, caregivers often perceive the lack of appropriate social and emotional support by family and friends (Wiles, 2003).

An important finding in this study is that a source of informal support that was particularly helpful for family caregivers was that offered by patients and family caregivers who were in a similar situation. Caregivers found the discussions with these individuals to be informative and a source of meaningful support, reflecting their perceived need for emotional support from others who can fully understand the implications of the caregiving situation.

Family caregivers in this study found themselves negotiating new routines and an altered lifestyle in relation to their caregiving responsibilities. In so doing, they relied on their social network for assistance and support. The literature describes cancer caregivers as having significant unmet needs that cluster around managing daily life, emotions, and social identity. These unmet needs are likely to occur when family caregivers have other caregiving responsibilities or do not have friends or family to call on for help (Soothill et al., 2001). As such, it is important for health care providers to raise awareness of these issues with family caregivers and refer them to appropriate psychosocial care and sources of support as needed.

Family caregivers tend to put the needs and interests of their loved ones above their own self-care needs (Kristjanson, 1986; Morris & Thomas, 2001). Indeed, the caregivers in this study expressed that they felt all right if their loved one was comfortable and looked after adequately. As such, caregivers are not likely to take up support services aimed at their own needs if they view them as redirecting resources and attention away from the patient. In order to provide effective support to caregivers,

Duhamel and Dupuis (2004) suggest that health care providers need to acknowledge the existence of the family, acknowledge the family's experience with the illness, and acknowledge the family's expertise in their caregiving role. In addition, formal care providers need to reassure family caregivers that their needs are legitimate and worthy of intervention (Soothill et al., 2001).

Formal support. Family caregivers in this study felt that health care providers were a helpful source of formal support. Specifically, they reported that health care providers were approachable and readily available to provide information related to their loved ones disease and management of the feeding tube. Similarly, Soothill and colleagues (2001) described that caregivers of patients with cancer recognize the importance of good relationships with health care providers and the provision of honest information, and reported that few caregivers express dissatisfaction with these aspects of care. How professionals perceive family caregivers with respect to their caregiving responsibilities has an important bearing on their experiences of formal support. For example, family caregivers may be perceived as co-clients, co-workers or partners, or as background resources that are often taken for granted (Guberman, Lavoie, Pepin, Lauzon, & Montejo, 2006). While many contexts within which formal care is provided perceive family caregivers to be background resources, caregivers see themselves as co-workers and thus complementary to the formal support system and want to be supported in their role (Ward-Griffin & McKeever, 2000).

One family caregiver in this study acknowledged the formal support offered by health care providers but reported some facets of the help available to be too restrictive. For example, she felt that having to structure her day in relation to the unpredictable

schedule of the home care nurses was limiting. Despite the importance of home care nurses in providing helpful information, assisting in the assessment of patient's symptoms, and provide reassurance regarding the caring regimen (Kristjanson, 1986), the family caregivers in this study did not always avail themselves of this help. This suggests that the issue of flexibility in provision of care may be an important factor in family caregivers accessing existing supports.

Information and communication. That family caregivers of patients with cancer have information needs is well documented in the literature (Eriksson & Lauri, 2000; Harris, 1998; Morris & Thomas, 2002). However, caregivers' needs for information vary over time (Harris, 1998). Prior to moving through the process of negotiating a new normal, patients and family caregivers were confronted with decisions as regards whether or not to have a feeding tube inserted. The decision-making challenges that were experienced by the caregivers in this study were rooted in poor communication and lack of information from health care providers regarding those pieces of information things that were perceived by caregivers as necessary to make an informed decision. The literature identifies that caregivers feel that they need information and knowledge to participate in medical decision-making. Accordingly, the perception of receiving insufficient information contributes to stress, frustration, and uncertainty (Kirk et al., 2004; Steinhauser et al., 2001).

Once the decision was made to have the feeding tube inserted, family caregivers in this study moved through a process of negotiating a new normal and required new information to facilitate this process. Information is seen as vital in allowing caregivers to manage the cancer situation (Brown & Stetz, 1999). Caregivers require information

and communication about practical care skills, their own health, and social networks (Jansma, Schure, & deJong, 2005) as well as cancer pain and symptom management (Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004; Wong et al., 2002). Indeed, the family caregivers in this study identified needs primarily for information about how to deal with the patients' feeding tube and effectively manage pain and symptoms.

A key source of information for family caregivers is the formal health care system, which consists of those health care providers and organizations that are involved in the care of their loved one. Family caregivers in this study revealed that the information given to them with respect to managing the feeding tube was variable. Some of the family caregivers received written information or practical demonstrations about how to manage the feeding tube, while others received little or no information in this regard. Not surprising, caregivers felt ill-prepared to assume their caregiving responsibilities. This is consistent with the work of Silver and colleagues (2004) who found that of family caregivers managing home enteral nutrition, preparedness for caregiving scores were low and positively correlated with caregiver competence ($P<.001$) and self-rated caregiver effectiveness ($P=.004$). In the study by Silver and colleagues (2004), caregivers' need for information and training with respect to the technical and nutrition-related tasks of managing the feeding tube were greatest, a finding consistent with those identified by the family caregivers in this study. Silver and colleagues (2004) suggest that a high percentage of unmet training needs leaves caregivers unprepared for mastering skills related specifically to managing the feeding tube as well as unprepared for caregiving overall. That said, merely delivering information to family caregivers does not necessarily mean that caregivers can make

sense of that information. As such, it is prudent for health care providers to continually assess the extent to which people are able to make sense of, and interpret the information they are being given and respond appropriately (Rose, 1999).

Family caregivers in this study reported receiving information from a number of different health care providers and being given mixed messages about how to manage various aspects of the feeding tube. Caregivers explained how this was extremely confusing and frustrating for them as they assumed their caregiving responsibilities. Similarly, Kimberlin and colleagues (2004) found that caregivers of cancer patients who required pain management described their constant struggle to promote effective communication within the health care system. These caregivers described miscommunication between health care providers and between health care providers and caregivers, reminiscent of that described by the family caregivers in this study. Kimberlin and colleagues (2004) reported that the caregivers in their study described this miscommunication as being system-related where avenues to promote open communication were non-existent. Likewise, the caregivers in this study attributed communication problems to a greater system failure.

Relationship of the Findings to the Conceptual Framework

The Transactional Model of Cancer Family Caregiving Skill, developed by Schumacher and colleagues (2006), provided a sensitizing conceptual framework for this study. The purpose of the study was not theory testing and, as such, the researcher was not looking for the study data to fit the model. However, the concepts within this framework provided direction regarding aspects of the caregiving experience that could be explored, and a context within which to situate the study findings.

Schumacher and colleagues (2006) identified that family caregivers respond to a number of illness related demands by using various cognitive, behavioral, and interpersonal processes in relation to the pattern of care established by the caregivers and patients. Indeed, the family caregivers in this study reported experiencing a number of demands related to the illness situation. For example, caregivers responded to demands such as managing symptoms, providing nutritional support, and modifying usual activities for the illness situation. Recognizing that the demands these caregivers were facing are similar to those identified by Schumacher and colleagues (2006), the researcher was prompted to explore these particular illness demands in further detail.

The family caregivers in this study also reported using a variety of cognitive, behavioral, and interpersonal processes to respond to the demands of the illness. For example, caregivers in this study noticed symptoms that their loved one was experiencing, modified long-standing routines to accommodate the illness situation, and planned care jointly with the patient when possible to respond to specific demands of the illness. Again, recognizing that the processes that these caregivers used to respond to the demands of the illness were similar to those identified by Schumacher and colleagues (2006), the researcher was prompted to explore these particular processes in further detail.

Family caregivers in this study identified establishing a pattern of care with their loved one. For example, one of the caregivers explained how they assumed a stand-by role in relation to their loved ones' care because the patient was largely independent with their own care activities. The other caregivers in this study reported sharing care activities with the patient. Schumacher and colleagues (2006) defined these types of

relationships as the self-caregiving and collaborative care patterns respectively. When study participants identified a particular pattern of care during their interview, the researcher was impelled to explore these relationships further.

The model by Schumacher and colleagues (2006) provides a framework with which to describe the fit between the caregiving processes used and the context of care. For example, when care is skillfully provided, there is a fit between the caregiving processes used and the illness demands. In contrast, when caregiving responses do not match the demands faced, patients and caregivers experience distress (Schumacher et al., 2006). However, the mutually influencing nature of the relationships between each of these concepts suggests that caregiving is not straight forward, but rather, a highly complex and multifaceted situation. In addition to providing direction regarding specific aspects of the caregiving experience that could be explored, the model by Schumacher and colleagues (2006) sensitized the researcher to the dynamic and complex nature of the caregiving phenomenon.

Limitations of the Study

As with any research study, there are limitations that are placed upon this project. The findings from this study are not generalizable to all family members who are caring for a loved one with advanced head and neck cancer who is reliant on tube-feeding, due to the nature of a qualitative research design. Furthermore, all of the patients and five out of six caregivers in this study were Caucasian and the experience of family caregivers across varying cultures is not known. Finally, this study does not capture the longitudinal experience of caring for a family member who is reliant on

tuber-feeding and thus we do not know how the process of negotiating a new normal would evolve over time.

Implications of the Study for Nursing Practice, Education, and Research

The findings from this study have implications for nursing practice, education, and research. They include the following:

Implications for Nursing Practice

1. That the complexity of the family caregiver role is recognized.
2. That clinicians provide clear and consistent communication about the need for and implications of a feeding tube in order to effectively support caregivers and patients with their decision about whether or not to have a feeding tube inserted.
3. That caregivers' willingness and readiness to assume the caregiving role is assessed.
4. That caregivers' information and support needs in relation to enacting the caregiver role are assessed.
5. That detailed written information and hands-on practice in relation to managing the feeding tube is provided to family caregivers, including: what to expect after the feeding tube had been inserted; how to do dressings changes appropriately, flush the feeding tube, administer medications, and administer the actual feeds.
6. That the timing of information and instruction provided to family caregivers regarding management of the feeding tube is assessed and planned according to the needs of the caregivers.

7. That information and instruction provided to family caregivers regarding management of the feeding tube is consistent across disciplines and institutional departments.
8. That clinicians use the Transactional Model of Cancer Family Caregiving Skill (Schumacher et al., 2006) as a sensitizing framework to identify and assess the cognitive, behavioral, and interpersonal caregiving processes used by family caregivers in response to the demands of the illness situation and pattern of care. As such, clinicians can intervene when the caregiving processes used do not 'fit' the demands of the illness or pattern of care.
9. That clinicians have an empirical basis for the development of educational resources, enhancement of communication practices, and effective support of family caregivers.

Implications for Nursing Education

1. That the complexity of the family caregiver role is emphasized by nurse educators.
2. That lectures on the care of the patient with head and neck cancer are structured to include education about family caregivers and their need for information about how to manage a feeding tube and support to enact their caregiving role.
3. That educational support given to family caregivers includes detailed written information and hands-on practice.
4. That teaching material regarding management of a feeding tube includes what to expect after the feeding tube had been inserted, how to do dressings changes

appropriately, flush the feeding tube, administer medications, and administer the actual feeds.

5. That the information and instruction that are provided to family caregivers regarding management of the feeding tube should be consistent. Students need to be taught the importance of exploring with the patient and family the nature and source of the information previously received, and their understanding of it.

Implications for Nursing Research

1. That the findings from this study provide the foundation for future multidisciplinary psychosocial/educational intervention studies in the context of a randomized control trial. For example, the findings from this study provide an empirical basis for the development of educational resources and/or training for family caregivers with respect to managing the feeding tube. It would be prudent to design an educational intervention and examine it empirically for its effectiveness with respect to family caregivers' preparedness to assume their caregiving role and levels of anxiety.
2. That the needs of family caregivers of patients with advanced head and neck cancer who are dependent on tube-feeds may change over time and longitudinal research to examine the course of the entire caregiving experience needs to be conducted.
3. That the experiences of family caregivers across varying cultures are not known. Illness experiences and treatment decisions are culturally mediated. Further research is necessary to examine the experiences of individuals across various cultures.

4. That the nature of the communication that occurs between health care providers, patients, and family caregivers with respect to decisions about whether or not to have a feeding tube inserted is variable. Further research is necessary to examine the experiences of family caregivers related to decision-making regarding the insertion of a feeding tube.
5. That further research is needed to evaluate the role of peer support groups for information for patients who have advanced head and neck cancer and are tube-fed and their families.
6. That future work should include the family caregiving pattern of care identified by Schumacher and colleagues (2006) to more fully understand that facet of the caregiving experience.

Summary

Family caregivers of patients with advanced head and neck cancer who are either partially or totally dependent on tube-feeds assume an extremely complex caregiving role as they respond to the disruption in their lives and move through a process of negotiating a new normal. Family caregivers are significantly affected by caring for their loved ones and have specific needs for information and support to enact their caregiving role and negotiate a new normal. The health care team is in a key position to support family members caring for head and neck cancer patients receiving tube-feeding. The findings from this study provide a beginning understanding of the experiences of family caregivers of patients with advanced head and neck cancer who are reliant on tube-feeding and offer an empirical basis from which to begin to effectively support these caregivers in their roles.

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Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

Principal Researcher: Jamie L. Penner
Supervisor: Dr. Susan McClement

PATIENT CONSENT FORM

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, agree to participate in the above titled research project. The purpose of this study is to gain an understanding of what the experience is like for family members caring for patients who are receiving tube feeding from the caregiver's perspective. This study is being conducted by Jamie Penner as part of her graduate work in the Master of Nursing program at the University of Manitoba. Ethical approval for this study has been obtained from the University of Manitoba Education/Nursing Research Ethics Board (ENREB) and access approval secured from the Research Resource Impact Committee of CancerCare Manitoba.

If you agree to participate in this study, you will be asked to identify the individual that you consider to be your family caregiver and give them the family caregiver information sheet enclosed in the information package. Your family caregiver will be asked to be interviewed about their experiences in caring for a loved one who is receiving tube feeding. Family caregivers must be at least 18 years of age, and be able to read and speak English. Then, if both you and your family caregiver agree to participate in this study the researcher will contact you so that she may provide more information about the study, and answer any questions about your participation in it.

After both you and your family caregiver have given consent, your caregiver will be interviewed about their experience. Your family caregiver will not be interviewed unless you give consent.

If you agree to participate in this study the researcher will also have access to and obtain information from your chart at CancerCare Manitoba. The data obtained will be recorded on an information sheet and will include your age, gender, diagnosis, the treatment of your illness, and details regarding your feeding tube.

All consent forms and information sheets will be kept in a locked filing cabinet at the office of the researcher's advisor. As well, the information collected from your chart will be kept confidential. While results from the study may be published, your name will not be used in any reports about the study and only grouped information will be used. You will have the opportunity to receive a summary of the study once it is completed if you so desire by informing the researcher of your wishes.

This study poses no known risks to you.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you wish to withdraw from the study, you may do so by simply informing the researcher of your wishes. Your decision will in no way impact the care that you are receiving at CancerCare, or any care you may receive in the future. Should you choose to withdraw from the study, any data that has already been collected will be erased from the tapes and/or computer, and paper will be destroyed.

Principal Researcher: Jamie Penner
Supervisor: Dr. Susan McClement

This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

I agree to participate in this project.

_____

Participant's signature Date

_____

Researcher and/or Delegate's Signature Date

I would like a summary report of the findings:
Yes ___ No ___

Please mail a summary of the report findings to:

Name: _____

Address: _____

Postal Code: _____

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Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

Principal Researcher: Jamie L. Penner
Supervisor: Dr. Susan McClement

FAMILY CAREGIVER CONSENT FORM

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, agree to participate in the above titled research project. The purpose of this study is to gain an understanding of what the experience is like for family members caring for patients who are receiving tube feeding from the caregiver's perspective. This study is being conducted by Jamie Penner as part of her graduate work in the Master of Nursing program at the University of Manitoba. Ethical approval for this study has been obtained from the University of Manitoba Education/Nursing Research Ethics Board (ENREB) and access approval secured from the Research Resource Impact Committee of CancerCare Manitoba.

If you choose to participate in this study you will be asked to be interviewed about your experiences in caring for a loved one who is receiving tube feeding. Two interviews are planned. The initial interview will take approximately 1 ½ to 2 hours to complete. The second interview is estimated to last approximately 30-45 minutes, and its purpose will be to further discuss your experiences and verify discussion shared during the initial

interview. The interviews will be scheduled for a time and place that is convenient for you, such as your home. The interviews will be tape-recorded to allow the researcher to listen to you carefully. The tapes will later by typed out and any names mentioned on the tape will be replaced by fictional names. You will also be asked to fill out a short information sheet about yourself (eg. age, relationship to patient etc.), which should take less than 5 minutes to complete.

All consent forms, tapes, and information sheets will be kept in a locked filing cabinet at the office of the researcher's advisor. As well, the information collected from you during the interview will be kept confidential. While results from the study may be published, your name will not be used in any reports about the study and only grouped information will be used. You will have the opportunity to receive a summary of the study once it is completed if you so desire by informing the researcher of your wishes.

This study poses no known risks to you. However, speaking about the experiences of being a family caregiver to a relative with advanced head and neck cancer who is receiving tube-feeding may evoke feelings and emotions in you. In the event that a family member becomes upset during the interview, the investigator will stop the interview and the participant will be given the option of ending the interview, and rescheduling for another time. You may find that participating in the study raises some issues and concerns for you. Counseling services are available through the Department of Psychosocial Oncology at CancerCare Manitoba. You are encouraged to contact them at 787-2109 if you would like to discuss these issues further. While the study offers no direct benefits to you, family members are frequently appreciative of having the opportunity to share their stories, with someone who is genuinely interested in what they have to say.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you wish to withdraw from the study you may do so by simply informing the researcher of your wishes. Your decision will in no way impact the care that you and your loved one are receiving at CancerCare, or any care you or they may receive in the future. Should you choose to withdraw from the study, any data that has already been collected will be erased from the tapes and/or computer, and paper will be destroyed.

Principal Researcher: Jamie Penner
Supervisor: Dr. Susan McClement

This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

I agree to participate in this project.

_____

Participant's signature Date

_____

Researcher and/or Delegate's Signature Date

I would like a summary report of the findings:

Yes ___ No ___

Please mail a summary of the report findings to:

Name: _____

Address: _____

Postal Code: _____

Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

Interview Guide

Main Research Question:

What is the nature of the experience of caring for a dysphagic family member with advanced head and neck cancer who is either partially or totally reliant on tube-feeding?

Initial Question to begin interview:

Can you describe in as much detail as possible, the experience you are having caring for your family member who is receiving tubefeeding?

Additional questions/probes to be asked after the initial description if this information is not disclosed:

1. Can you describe how caring for your family member affects you?
2. Do you recognize any immediate physical/emotional responses or effects?
3. Do you recognize any effects this experience has on your relationship with the loved one you are caring for?
4. Do you recognize any effects of this experience in other areas of your life?
5. How do you deal with the effects that this experience is having on you?
6. What does this experience mean for you as a spouse? daughter/son? parent? etc.
7. What is particularly difficult about caring for your loved one?
8. Is there anything positive about caring for your loved one?
9. Has there been anything that has been helpful to you in caring for your family member?
10. Is there anything that you feel would be helpful to you in caring for your family member?
11. What have you learned throughout this experience of caring for your family member?
12. Have you gained any insights as a result of being in this caregiving situation?
13. What would you like to tell other family caregivers who may find themselves in a similar type of experience?

Generic prompts to be used as needed:

Is there anything else?
How do you feel about that?
What do you think about that?
Could you tell me more about that?

Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

Demographic Form - Patient

ID Number: _____

1. Age (in years): _____

2. Gender: Female _____ Male _____

3. Diagnosis: _____

4. Treatment received: _____

5. Date feeding tube inserted: _____

Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

Demographic Form – Family Caregiver

ID Number: _____

1. Age (in years): _____

2. Gender: Female _____ Male _____

3. Relation to patient:
   Spouse/Partner_____ Child _____ Parent _____ Sibling _____ Other _____

4. Do you live in the same household as the patient?
   Yes_____ No _____

   If no, how often do you see the patient? (eg. daily, 2x/week, weekly etc.)
   _____

5. When did you start managing the care of the feeding tube (partially or totally) for the patient? _____

6. Please identify the pattern of care that best describes your situation:
   _____ Patient is mostly independent and family caregiver has a "standby" role
   _____ Patient and family caregiver share care activities
   _____ Patient is unable to perform care activities independently and extensive family caregiver involvement is needed

7. Have you ever been a caregiver for another person requiring tubefeeding?
   Yes _____ No _____

   If yes, please describe (eg. relation to patient, amount of care given etc.)

8. Do you have professional caregiver training?
Yes _____ No _____

If yes, please describe (eg. type of training, length of training etc.)

9. Have you ever received formal training regarding tubefeeding?
Yes _____ No _____

If yes,
when did you receive this training? _____
where did you receive this training? _____

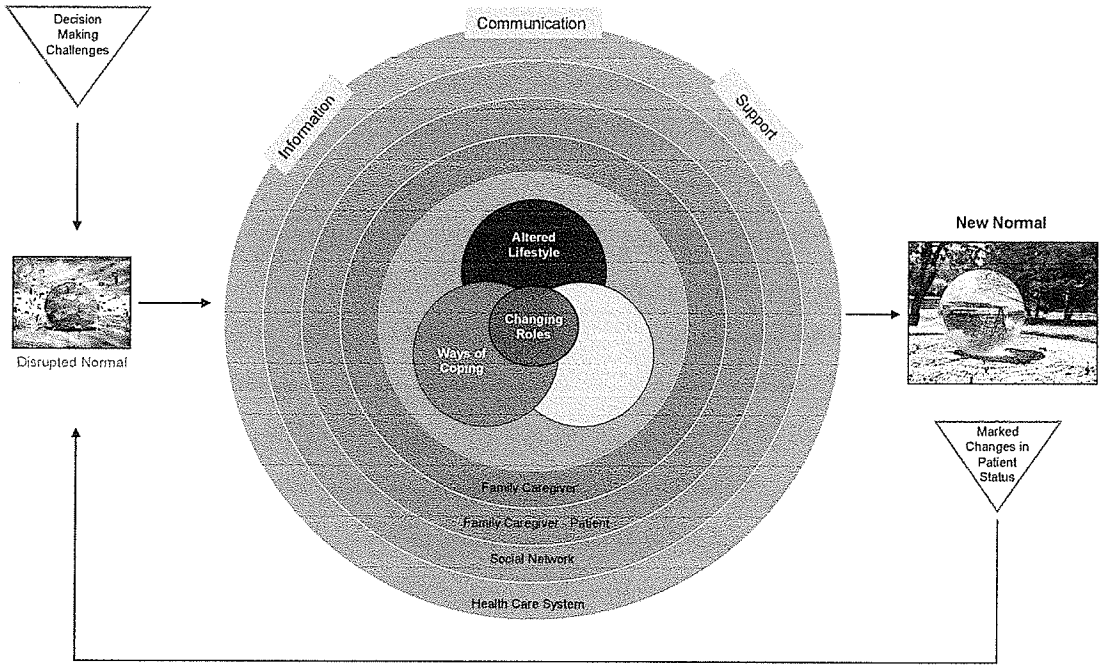
Please describe (who provided the training, did you receive verbal training, written instructions etc., what did the training entail etc.)

Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding

decision making challenges

NEGOTIATING A NEW NORMAL							
Matters of Negotiation				**Facilitators of Negotiation**		**Levels of Negotiation**	**Triggers for Re-negotiation**
Changing Roles	Altered Lifestyle	Meaning of Feeding Tube	Ways of Coping	Information/ Communication/ Support		Family Caregiver Caregiver-Patient Dyad Social Network Healthcare System	Marked Changes in Patient Status
Becoming a Caregiver Caregiving Responsibilities Effects of Caregiving Caregiver Self-efficacy	Shifting routines Diminished social life Changes at work	Presence of cancer Illness/ suffering vs. life/hope	Adopting a certain mindset Psychosocial support Distraction	Informal Family and friends Others in a similar situation	Formal Healthcare providers		

Experiences of Family Caregivers of Patients with Advanced Head and Neck Cancer Receiving Enteral Tube Feeding



Negotiating a New Normal

References

Anis, M.K., Abid, S., Jafri, W., Abbas, Z., Shah, H.A., Hamid, S., et al. (2006). Acceptability and outcomes of the percutaneous endoscopic gastrostomy (PEG) tube placement – patients' and care givers' perspectives. *BMC Gastroenterology, 6*, 37-41.

Arcuri, M.R., & Schneider, R.L. (1992). The physiological effects of radiotherapy on oral tissue. Jo*urnal of Prosthodontics, 1*(1), 37-41.

Baghi, M., Wagenblast, J., Hambek, M., Radeloff, A., Gstoettner, W., Scherzed, A., et al. (2007). Demands on caring relatives of head and neck cancer patients. *Laryngoscope, 117*, 712-716.

Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: spouse caregivers. *Journal of Clinical Oncology, 25*(30), 4829-4834.

Brotherton, A., Abbott, J., & Aggett, P. (2006). The impact of percutaneous endoscopic gastrostomy feeding upon daily life in adults. *Journal of Human Nutrition & Dietetics, 19*, 355-367.

Brown, M.A., & Stetz, K. (1999). The labor of caregiving: A theoretical model of caregiving during potentially fatal illness. *Qualitative Health Research, 9*(2), 182-197.

Burridge, L., Winch, S., & Clavarino, A. (2007). Reluctance to Care. *Cancer Nursing, 30(*2), E9-E19.

Burton, L.C., Newsom, J.T., Schulz, R., Hirsch, C.H., & German, P.S. (1997). Preventive health behaviors among spousal caregivers. *Preventive Medicine, 26*, 152-169.

Cameron, J.I., Franche, R.L., Cheung, A.M., & Stewart, D.E. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer, 94*(2), 521-527.

Canadian Society of Otolaryngology. (http://www.entcanada.org/public2/patient14.asp) accessed September 17, 2008

CancerCare Manitoba. (http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/ccmb_and_you/) accessed October 28, 2008

Carter, P.A. (2002). Caregivers' descriptions of sleep changes and depressive symptoms. *Oncology Nursing Forum, 29*(9), 1277-1283.

Carter, P.A. (2003). Family caregivers' sleep loss and depression over time. *Cancer Nursing, 26*(4), 253-259.

Carter, P.A., & Acton, G.J. (2006). Personality and coping: Predictors of depression and sleep problems among caregivers of individuals who have cancer. *Journal of Gerontological Nursing, Feb*, 45-53.

Chen, M.L., Chu, L., & Chen, H.C. (2004). Impact of cancer patients' quality of life on that of spouse caregivers. *Supportive Care in Cancer, 12*, 469-475.

Clark, M.M., Rummans, T.A., Sloan, J.A., Jensen, A., Atherton, P.J., Frost, M.H., et al. (2006). Quality of life of caregivers of patients with advanced-stage cancer. *American Journal of Hospice and Palliative Medicine, 23*, 185-191.

Crosby, J., & Duerksen, D. (2005). A retrospective survey of tube-related complications in patients receiving long-term home enteral nutrition. *Digestive Diseases and Sciences, 50*(9), 1712-1717.

Crosby, J., & Duerksen, D. R. (2007). A prospective study of tube- and feeding-related complications in patients receiving long-term home enteral nutrition. *Journal of Parental and Enteral Nutrition, 31*(4), 274-277.

Czreninski, R., & Kaplan, I. (2005) Oropharyngeal cancer: An update on diagnosis, treatment, and the impact of treatment on oral functions. *Topics in Clinical Nutrition, 20*(3), 229-42.

Donalek, J.G. (2005). The interview in qualitative research. *Urologic Nursing, 25*(2), 124-5.

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*, 131-142.

Duhamel, F., & Dupuis, F. (2003). Families in palliative care: Exploring family and health-care professionals' beliefs. *International Journal of Palliative Nursing, 9*(3), 113-119.

Dumont, S., Turgeon, J., Allard, P., Gagnon, P., Charbonneau, C., & Vezina, L. (2006). Caring for a loved one with advanced cancer: Determinants of psychological distress in family caregivers. *Journal of Palliative Medicine, 9*(4), 912-921.

Dunbrack, J. (2005). The information needs of informal caregivers involved in providing support to a critically ill loved one. Retrieved October 3, 2007 from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2005-info-caregiver-aidant/2005-info-caregiver-aidant_e.pdf

El-Deiry, M., Funk, G.F., Nalwa, S., Karnell, L.H., Smith, R.B., Buatti, J.M., et al. (2006). Long-term quality of life for surgical and nonsurgical treatment of head and neck cancer. *Archives of Otolaryngology Head & Neck Surgery, 131*, 879-885.

Emanuel, E.J., Fairclough, D.L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L. L. (1999). Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *The New England Journal of Medicine, 341*(13), 956-963.

Emanual, E.J., Fairclough, D.L., Slutsman, J., & Emanual, L.L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine, 132*, 451-459.

Eriksson, E., & Lauri, S. (2000). Informational and emotional support for cancer patients' relatives. *European Journal of Cancer Care, 9,* 8-15.

Ferrario, S.R., Cardillo, V., Vicario, F., Balzarini, E., & Zotti, A.M. (2004). Advanced cancer at home: caregiving and bereavement. *Palliative Medicine, 18,* 129-136.

Given, B.A., Given, C.W., & Kozachik, S. (2001). Family support in advanced cancer. *CA A Cancer Journal for Clinicians, 51*, 213-31.

Goldstein, N.E., Concato, J., Fried, T.R., Kasl, S.V., Johnson-Hurzeler, R., & Bradley, E.H. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care, 20*(1), 38-43.

Grbich, C., Parker, D., & Maddocks, I. (2001). The emotions and coping strategies of family members with a terminal cancer. *Journal of Palliative Care, 17*(1), 30-6.

Greene, F.L., American Joint Committee on Cancer, & American Cancer Society. (Eds.). (2002). *AJCC cancer staging manual/American Joint Committee on Cancer*. (6th ed.). New York: Springer-Verlag.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., & Earle, C.C. et al. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal, 170*(12), 1795-1801.

Guberman, N., Lavoie, J., Pepin, J., Lauzon, S., & Montejo, M. (2006). Formal service practitioners' views of family caregivers' responsibilities and difficulties. *Canadian Journal of Aging, 25*(1), 43-53.

Hanna, E., Alexiou, M., Morgan, J., Badley, J., Maddox, A.M., Penagaricano, J., et al. (2004). Intensive chemoradiotherapy as a primary treatment for organ preservation in patients with advanced cancer of the head and neck. *Archives of Otolaryngology Head & Neck Surgery, 130*, 861-867.

Harding, R., & Higginson, I.J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic review of interventions and their effectiveness. *Palliative Medicine, 17,* 63-74.

Harris, K.A. (1998). The informational needs of patients with cancer and their families. *Cancer Practice, 6*(1), 39-46.

Health Canada. (2004). A 10-year plan to strengthen health care. Retrieved on October 3, 2007 from http://www.hc-sc.gc.ca

Hearson, N.B. (2007). Sleep disturbance in family caregivers of community-dwelling advanced cancer patients. Unpublished master's thesis, University of Manitoba, Winnipeg, Manitoba.

Higginson, I.J., & Sen-Gupta, G.J.A. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine, 3*, 287-300.

Hopkinson, J., Wright, D., & Corner, J. (2006). Exploring the experience of weight loss in people with advanced cancer. *Journal of Advanced Nursing, 54*(3), 304-312.

Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing, 10*(2), 58-66.

Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology* (D. Carr, Trans). Evanston IL: Northwestern University Press.

Jansma, F.F.I., Schure, L.M., & deJong, B.M. (2005). Support requirements for caregivers of patients with palliative care. *Patient Education and Counseling, 58*, 182-186.

Jemal, A., Siegel, R., & Ward, E. (2006). Cancer Statistics, 2006. *CA A Cancer Journal for Clinicians, 56*, 106-130.

Jo, S., Brazil, K., Lohfeld, L., & Willison, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care, 5*, 11-17.

Keating, N., Fast, J., Frederick, J., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: context, content and consequences*. Ottawa: Statistics Canada: Housing, Family and Social Statistics Division.

Kim, Y., Baker, F., Spillers, R.L., & Wellisch, D.K. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology, 15*, 795-804.

Kim, Y., Schulz, R., & Carver, C.S. (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine, 69,* 283-91.

Kimberlin, C., Brushwood, D., Allen, W., Radson, E., & Wilson, D. (2004). Cancer patient and caregiver experiences: Communication and pain management issues. *Journal of Pain and Symptom Management, 28*(6), 566-578.

Kirk, P., Kirk, I., & Kristjanson, L.J. (2004). What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ, 328*, 1343-1349.

Koop, P.M., & Strang, V.R. (2003). The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research, 12*(2), 127-144.

Kramer, R.M., & Messick, D.M. (1995). Preface. In R.M. Kramer & D.M. Messick (Eds.), *Negotiation as a social process* (pp. vii-x). Thousand Oaks, CA: Sage.

Kristjanson, L.J. (1986). Indicators of quality of palliative care from a family perspective. *Journal of Palliative Care, 1*(2), 8-17.

Kristjanson, L.J. (1989). Quality of terminal care: Salient indicators identified by families. *Journal of Palliative Care, 5*(1), 21-30.

Kristjanson, L.J., & Aoun, S. (2004). Palliative care for families: Remembering the hidden patients. Canadian Journal of Psychiatry, 49(6), 359-365.

Kristjanson, L.J., Nikoletti, S., Porock, D., Smith, M., Lobchuk, M., & Pedler, P. (1998). Congruence between patients' and family caregivers' perceptions of symptom distress in patients with terminal cancer. *Journal of Palliative Care, 14*(3), 24-32.

Kristjanson, L.J., Sloan, J.A., Dudgeon, D., & Adaskin, E. (1996). Family members' perceptions of palliative cancer care: predictors of family functioning and family members' health. *Journal of Palliative Care, 12*(4), 10-20.

Kulbersch, B.D., Rosentahl, E.L., McGrew, B.M., Duncan, R.D., McColloch, N.L., Carroll,W.R., et al. (2006). Pretreatment, preoperative swallowing exercises may improve dysphagia quality of life. *Laryngoscope, 116*, 883-886.

Larsson, M., Hedelin, B., Johansson, I., & Athlin, E. (2003). Eating problems and weight loss for patients with head and neck cancer. *Cancer Nursing, 28*(6), 425-435.

Lazarus, C.L. (1993). Effects of radiation therapy and voluntary maneuvers on swallow functioning in head and neck cancer patients. *Clinical Communication Disorders, 3*(4), 11-20.

Lazarus, C.L., Logemann, J.A., Pauloski, B.R., Rademaker, A.W., Larson, C.R., Mittal, B.B., et al. (2000). Swallowing and tongue function following treatment for oral and oropharyngeal cancer. *Journal of Speech, Language, and Hearing Research, 43*, 1011-1023.

Lazarus, C., Logemann, J.A., Song, C.W., Rademaker, A.W., & Kahrilas, P.J. (2002). Effects of voluntary maneuvers on tongue base function for swallowing. *Folia Phoniatrica et Logopaedica, 54*(4), 171-176.

Liley, A.J., & Manthorpe, J. (2003). The impact of home enteral tube feeding in everyday life: A qualitative study. *Health and Social Care in the Community, 11*(5), 415-422.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lobchuk, M.M. (2006). Concept analysis of perspective-taking: Meeting informal caregiver needs for communication competence and accurate perception. *Journal of Advanced Nursing, 54*(3), 330-41.

Lobchuk, M.M., Degner, L.F., Chateau, D., & Hewitt, D. (2006). Promoting enhanced patient and family caregiver congruence on lung cancer symptom experiences. *Oncology Nursing Forum, 3*(33), 273-82.

Lobchuk, M.M., McClement, S.E., Daeninck, P.J., & Elands, H. (2007). Caregiver thoughts and feelings in response to different perspective-taking prompts. *Journal of Pain and Symptom Management, 33*(4), 420-33.

Lobchuk, M.M., McClement, S.E., Daeninck, P.J., Shay, C., & Elands, H. (2007). Asking the right question of informal caregivers about patient symptom experiences: multiple proxy perspectives and reducing interrater gap. *Journal of Pain and Symptom Management, 33*(2), 130-145.

Lobchuk, M.M., & Vorauer, J.D. (2003). Family caregiver perspective-taking and accuracy in estimating cancer patient symptom experiences. *Social Science & Medicine, 57*, 2379-2384.

Lopez, K.A., & Willis, D.G. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qualitative Health Research, 14*(5), 726-735.

Matthews, B.A., Baker, F., & Spillers, R.L. (2004). Family caregivers' quality of life: Influence of health protective stance and emotional strain. *Psychology and Health, 19*, 625-641.

McClement, S.E., Degner, L.F., & Harlos, M.S. (2003). Family beliefs regarding the nutritional care of a terminally ill relative: A qualitative study. *Journal of Palliative Medicine, 6*(5), 737-748.

McClement, S.E., Degner, L.F., & Harlos, M. (2004). Family responses to declining intake and weight loss in a terminally ill relative. Part 1: Fighting back. *Journal of Palliative Care, 20*(2), 93-100.

McClement, S.E. & Woodgate, R.L. (1998). Research with families in palliative care: conceptual and methodological challenges. *European Journal of Cancer Care, 7*, 247-254.

McCorkle, R., & Pasacreta, J.V. (2001). Enhancing caregiver outcomes in palliative care. *Cancer Control, 8*, 36-45.

McPherson, C.J., Wilson, K.G., Lobchuk, M.M., & Brajtman, S. (2008). Family caregivers' assessment of symptoms in patients with advanced cancer: Concordance with patients and factors affecting accuracy. *Journal of Pain and Symptom Management, 35*(1), 70-82.

Meyers, J.L., & Gray, L.N. (2001). The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncology Nursing Forum, 28*, 73-82.

Moran, D. (2000). *Introduction to phenomenology*. Routledge: London.

Morley, I. (1986). Negotiating and bargaining. In O. Hargie (Ed.), *A handbook of communication skills* (pp.303-324). New York: New York University Press.

Morris, S., & Thomas, C. (2001). The carer's place in the cancer situation: Where does the carer stand in the medical setting? *European Journal of Cancer Care, 10*, 87-95.

Morris, S.M., & Thomas, C. (2002). The need to know: Informal carers and information. *European Journal of Cancer Care, 11,* 183-7.

Moustakas, C. (1994). *Phenomenological Research Methods.* Sage Publications, Thousand Oaks.

Morse, S.R., & Fife, B. (1998). Coping with a partner's cancer: adjustment at four stages of the illness trajectory. *Oncology Nursing Forum, 25*(4), 751-760.

Newman, L.A., Vieira, F., Schwiezer, V., Samant, S., Murry, T., Woodson, G., et al. (1998). Eating and weight changes following chemoradiation therapy for advanced head and neck cancer. *Archives of Otolaryngology Head & Neck Surgery, 124*, 589-592.

Nguyen, N.P., Frank, C., Moltz, C.C., Vos, P., Smith, H.J., Karlsson, U., et al. (2005). Impact of dysphagia on quality of life after treatment of head-and-neck cancer. *International Journal of Radiation Oncology, Biology, & Physics, 61*(3), 772-778.

Nijboer, C., Tempelaar, R., Triemstra, M., van den Bos, G.A.M., Sanderman, R. (2001). The role of social and psychologic resources in caregiving of cancer patients. *Cancer, 91,* 1029-1039.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & van den Bos, G.A. (1999). Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer, 86*, 577-588.

Northouse, L.L. (2005). Helping families of patients with cancer. *Oncology Nursing Forum, 32*(4), 743-750.

Osse, B.H.P., Vernooij-Dassen, M.J.F.J., Schade, E., & Grol, R.P.T.M. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing, 29*(5), 378-388.

Pauloski, B.R., Rademaker, A.W., Logemann, J.A., Stein, D., Beery, Q., Newman, L., et al. (2000). Pretreatment swallowing function in patients with head and neck cancer. *Head & Neck, 22*, 474-482.

Payne, S., Smith, P., & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. *Palliative Medicine, 13*, 37-44.

Penner, J.L., McClement, S.E., & Sawatzky, J.V. (2007). Management of dysphagia in advanced oropharyngeal cancer. *International Journal of Palliative Nursing, 13*(5), 206-212.

Polit, D.F., & Beck, C.T. (2004). *Nursing research: Principles and methods.* Philadelphia: Lippincott Williams & Wilkins.

Rickman, J. (1998). Percutaneous endoscopic gastrostomy: Psychological effects. *British Journal of Nursing, 7*(12), 723-729.

Rose, K.E. (1999). A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing, 8,* 81-8.

Ross, M., MacLean, M., Cain, R., Sellick, S., & Fisher, R. (2001). End of life care: the experience of seniors and informal caregivers. *Canadian Journal on Aging, 21*, 137-146.

Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Journal of American Medical Association, 282*, 2215-2219.

Schumacher, K.L. (1996). Reconceptualizing family caregiving: family-based illness care during chemotherapy. Research in Nursing & Health, 19(4), 261-271.

Schumacher, K.L., Beidler, S.M., Beeber, A.S., & Gambino, P. (2006). A transactional model of cancer family caregiving skill. *Advances in Nursing Science, 29*(3), 271-286.

Schumacher, K.L., Stewart, B.J., Archbold, P.G., Caparro, M., Mutale, F., & Agrawal, S. (2008). Effects of Caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum, 25*(1), 49-56.

Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-oncology, 14*, 102-114.

Sherwood, P.R., Given, B.A., Doorenbos, A.Z., & Given, C.W. (2004). Forgotten voices: Lessons from bereaved caregivers of persons with a brain tumour. *International Journal of Palliative Nursing, 10*(2), 67-75.

Silver, H.J., & Wellman, N.S. (2002). Family caregiver training is needed to improve outcomes for older adults using home care technologies. *Journal of the American Dietetic Association, 102*, 831-836.

Silver, H.J., Wellman, N.S., Galindo-Ciocon, D., & Johnson, P. (2004). Family caregivers of older adults on home enteral nutrition have multiple unmet task-related training needs and low overall preparedness for caregiving. *Journal of the American Dietetic Association, 104*, 43-50.

Soanes, C., Hawker, S., & Elliott, J. (Eds.). (2005). *Pocket Oxford English Dictionary.* (10^{th} ed.). New York: Oxford University Press Inc.

Soothill, K., Morris, S.M., Harman, J.C., Francis, B., Thomas, C., & McIllmurray, M.B. (2001). Informal carers of cancer patients: What are their unmet psychosocial needs? *Health and Social Care in the Community, 9*(6), 464-475.

Souhami, R.L., Tannock, I.., Hohenberger, P., & Horiot, J.C. (Eds.). (2002). *Oxford Textbook of Oncology.* (2nd ed.). New York: Oxford University Press Inc.

Speziale, H.J.S., & Carpenter, D.R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative* (4th edition). Philadelphia: Lippincott Williams & Wilkins.

Spiegelberg, H. (1975). Doing phenomenology. Martinus Nijhoff, Dordrecht, Netherlands.

Stajduhar, K.I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19*(1), 27-35.

Stajduhar, K.I., & Davies, B. (2005). Variations in and factors influencing family members' decisions for palliative home care. *Palliative Medicine, 19,* 21-32.

Stajduhar, K.I., Martin, W.L., Barwich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing, 31*(1), 77-85.

Statistics Canada. (http://www40.statcan.ca/l01/cst01/demo07a-eng.htm) accessed October 28, 2008.

Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., Granbow, S., Parker, J, et al. (2001). Preparing for the end of life: Preferences of patients, families, physicians and other care providers. *Journal of Pain and Symptom Management, 22,* 727-37.

Thomas, C.L. (Ed.). (1997). *Taber's cyclopedic medical dictionary.* (18th ed.). Philadelphia: F.A.Davis Company.

Thomas, C., Morris, S.M., & Harman, J. (2002). Companions through cancer: the care given by informal carers in cancer contexts. *Social Science and Medicine, 54*, 529-544.

Verdonck-de Leeuw, I.M., Eerenstein, S.E., Van der Linden, M.H., Kuik, D.J., de Bree, R., & Leemans, R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope, 117*, 238-241.

Vickery, L.E., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck, 25*, 289-296.

Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: Partners in Care? *Advances in Nursing Science, 22*(3), 89-103.

Wennman-Larsen, A., & Tishelman, C. (2002). Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scandinavian Journal of Caring Science, 16,* 240-247.

Wiles, J. (2003). Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community, 11*(3), 189-207.

Winterling, J., Wasteson, E., Glimelius, B., Sjödén, P., & Nordin, K. (2004). Substantial changes in life: Perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nursing, 27*(5), 381-388.

Wong, R.K.S., Franssen, E., Szumacher, E., Connolly, R., Evans, M., Page, B., et al. (2002). What do patients living with advanced cancer and their carers want to know? – A needs assessment. *Support Care Cancer, 10*, 408-415.

Zorowitz, R.D., & Robinson, K.M. (1999). Pathophysiology of dysphagia and aspiration. *Topics in Stroke Rehabilitation, 6*(3), 1-16.