

**FAMILY CAREGIVERS OF PALLIATIVE CANCER PATIENTS AT
HOME:**

THE PUZZLE OF PAIN MANAGEMENT

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ABSTRACT

Pain requiring treatment is experienced by many cancer patients at the end of life. When these patients stay at home, family caregivers are often directly implicated in pain management. There are few studies that examine the process that these family caregivers engage in when they take on the responsibility of pain management. This means we need information on whether or not these family caregivers are prepared for management to ensure proper support and optimal pain control.

The purpose of this qualitative study was to study the process used by family caregivers at home to manage the pain of palliative cancer patients using a grounded theory approach. A total of 24 family caregivers with differing relationships to the patient and differing lengths of caregiver experience participated. Family caregivers were recruited using purposeful then theoretical sampling. The data sources were taped, transcribed (semi-structured) interviews, field notes, and memos. Data analysis used Strauss & Corbin's (1998) suggestions for substantive coding: open, axial, and selective coding.

The results lead to the proposition of an explanatory theory titled "the puzzle of pain management," which include: 1) a frame of the process of "drawing on past experiences"; 2) puzzle pieces representing the process "strategizing a game plan" which include the sub-processes of "accepting responsibility," "seeking information," and "establishing a pain management relationship"; 3) puzzle pieces representing the process of "striving to respond to pain" which include the sub-processes of "determining the characteristics of pain," "implementing a strategy for pain relief," and "verifying if pain relief strategies were successful; and 4) "gauging the best fit," a decision-making process that joins the two pieces of the puzzle.

The realization that family caregivers assemble a puzzle of processes indicates that there are factors that nurses must be aware of before creating, teaching, and implementing interventions for pain management. Furthermore, the

results provide information to create and subsequently administer interventions based on caregivers' existing knowledge, identified needs for information and support, and current pain management regimens. The puzzle of pain management must be validated by further studies using this theory, in part, to help create interventions that will allow us to know how useful the theory is in practice.

Keywords: family caregivers, carers, pain management, palliative care, cancer pain, home care, grounded theory

RESUME

Les patients atteints de cancer en fin de vie éprouvent souvent des douleurs qui doivent être traitées. Lorsque ces patients demeurent à la maison, ce sont plus souvent les proches-aidants qui sont impliqués directement dans la gestion de cette douleur. Peu d'études existent sur le processus que les proches-aidants adoptent lorsqu'ils prennent la responsabilité de gérer la douleur. Il est donc opportun d'accroître nos connaissances afin d'outiller les proches-aidants à gérer de façon optimale la douleur et de mieux les soutenir dans leurs rôles.

Le but de cette étude qualitative est d'étudier le processus que les proches-aidants utilisent lorsqu'ils prennent soin à domicile d'une personne en fin de vie. Cette étude se base sur une approche de théorisation ancrée. L'échantillon de l'étude se compose de 24 proches-aidants ayant des types et des durées de relation différentes avec le patient. Les proches-aidants ont été sélectionnés selon une procédure d'échantillonnage à choix raisonné, suivi par une procédure d'échantillonnage théorique. Les données recueillies sont basées sur des entrevues (semi-structurées) enregistrées et transcrites, ainsi que sur des notes de terrain et des mémos. Les analyses de données ont été basées sur les recommandations de Strauss & Corbin (1998) pour le codage; c'est-à-dire codage ouvert, axial et sélectif.

Cette étude révèle que pour composer avec la douleur, les proches-aidants utilisent un processus complexe d'assemblage de différents sous-processus, similaire à un casse-tête. Cette étude a mené à l'élaboration d'un modèle intitulé « Le casse-tête de la gestion de la douleur », qui inclus: 1) le cadre du processus intitulé « l'apprentissage basé sur l'expérience passée »; 2) Un ensemble de pièces de casse-tête représentant le processus de « formuler le plan d'action », comprenant les sous-processus « d'accepter l'étendue de sa responsabilité », « rechercher de l'information » et « établir une relation intégrant la gestion de la douleur », 3) Un ensemble de pièces de casse-tête représentant le processus de « répondre à la douleur » comprenant les sous-processus de « déterminer les

caractéristiques de la douleur », « mettre en place une stratégie pour y remédier » et « vérifier si la stratégie adoptée est efficace », 4) « l'évaluation de la meilleure décision », le processus de prise de décision qui lie les deux ensemble du casse-tête.

Les résultats de l'étude et l'élaboration du modèle soulignent l'importance pour le personnel soignant de mieux comprendre les composantes de ce processus avant de créer, de former et de mettre en place une gestion de la douleur. De plus, les résultats de cette étude offrent une base d'informations pour mieux créer et administrer des interventions centrées autour des proches-aidants, en d'autres termes, des interventions basées sur leurs connaissances existantes, leurs besoins en information et en soutien, et finalement, leurs approches actuelles face à la gestion de la douleur. Ce modèle devra être validé par des études additionnelles, pour permettre de comparer la théorie à la pratique.

Mots clés: proches-aidants, soulagement de la douleur, soins palliatifs, douleur associée au cancer, soins à domicile, théorisation ancrée

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INTRODUCTION

Pain is experienced by a majority of cancer patients at the end of life. A worldwide review of cancer pain statistics revealed that half the patients with cancer at all stages reported pain, rising to over 70% of those with advanced cancer (Bonica, 1985). Several more recent studies and reviews show that patients with cancer continue to report the presence of pain (Rao & Cohen, 2004; Whitecar, Jonas & Clasen, 2000; Yates et al 2002). Patients with advanced cancer report a higher frequency and intensity of pain than those patients with cancers at an earlier stage, with 20%-34% experiencing severe pain (Davis & Walsh, 2004). These patients may also have many separate types of pain and pain that occurs at multiple sites (Lema, 2001; Portenoy, 1989; Twycross, Harcourt, & Bergl, 1996). In Canada, pain occurs in 67% of all patients with advanced cancer and 75% of those patients will have more than two different types of pain (Statistics Canada, 2003). Despite the fact that cancer pain is acknowledged, assessed, and intervened upon, it has been estimated that up to 25 million people throughout the world die of cancer in pain annually (Boffetta & Parkin, 1994; Foley, 1987). Pain can be controlled in 85-95% of patients with either pharmacological or non-pharmacological methods, yet poor pain relief is well documented (Abram, 1993; Lin, 1998; Mercadante, Casuccio, Pumo, & Fulfaro, 2000; Whitecar, Jonas & Clasen, 2000; Yates et al., 2002). This is of great concern for patients, families and health professionals alike (Carr et al., 2004; Davis & Walsh, 2004; Dobratz, 2001; Mehta & Ezer, 2003). In Canada, it is noted that pain caused by cancer can be completely or almost completely alleviated in at least 9 out of 10 patients (Statistics Canada, 2003). As a result, pain control becomes a central focus for advanced cancer patients at the end of life.

“Palliative care is an approach that improves the quality of life of patients and their families facing a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2007). Pain is one of the most frequently reported physical symptoms for

palliative (see p. 14 for definition) cancer patients (Coyle et al., 1990; Dobratz, 2001), and perhaps the most distressing (Davis & Walsh, 2004; Mercadante, Villari, Ferrera, & Casuccio, 2006). Furthermore, patients continue to increasingly prefer to receive end-of-life care in their own home (Aubin et al., 2006; Higginson, Wade, & McCarthy, 1990). This has become a possibility, especially if there is a family member who is willing and able to care for the patient at home. In fact the availability of a family caregiver is an important factor in the decision of a patient to die at home (Cameron, Shin, Williams, & Stewart, 2004; Tang, 2003). When these patients stay at home, it is the family caregivers who administer hands-on care to them and who ultimately become responsible for ensuring patient safety and comfort. This includes the responsibility of pain management.

Family caregivers are often directly implicated in the administration of medications and implementation of other pain relief strategies. This may be for the following reasons: the patient may be juggling multiple responsibilities and needs assistance to help manage them (Clark et al., 2006); the patient's disease may progress so they are incapable of being responsible for their own pain management (Doorenbos et al., 2007; Mazanec & Bartel, 2002) and the shift in care from hospital to home requires someone to assume some of the tasks and responsibilities of health professionals related to pain relief (Cameron, Shin, Williams, & Stewart, 2004; Given, Given, & Kozachik, 2001). Pain management often presents as one of the most challenging aspects of the caregiver role (Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). The pain they must witness and attempt to manage has a significant impact on these family caregivers. In fact, it is not uncommon for family caregivers to experience feelings of hopelessness, helplessness, and a sense of loss of control when observing their loved ones in pain (Ferrell, Grant, Chan, & Ferrell, 1995; Mehta & Ezer, 2003; Yates et al., 2004). As a result, an important goal for health professionals is to ensure that the family caregivers of palliative cancer patients at home are prepared for and supported in their responsibility of pain management.

In order for health professionals to provide assistance and offer the most appropriate support, more information is needed on how family caregivers are currently managing pain. This information is important for the following reasons because:

1. it provides information on alternatives and allows us to make suggestions if ineffective assessments are being done and ineffective interventions are being used;
2. it helps determine how to support and reinforce interventions that are effective for pain relief;
3. it helps to determine if family caregivers have received the necessary information they require to make informed decisions while managing pain at home, and provide information where it is lacking;
4. it helps us learn how to build on their current pain management regimen using what they already know and what they are already doing; and
5. it highlights the importance of individualizing the teaching we do to match the type, intensity, and frequency of the pain experienced by the patient.

Not all interventions done by family caregivers will be equally effective or appropriate for every patient. The information obtained from this study provides us with crucial information to create and subsequently administer interventions that are based on each family caregiver's existing knowledge, their identified needs for both information and support, and their current pain management regimen. It would be inappropriate to teach pain management interventions without acquiring this baseline information because a standard "recipe" does not take the family caregiver's and patient's individual needs into account. Nurses need to be aware of a variety of interventions appropriate for different family caregiver and patient needs so they can ensure a proper fit between what these clients need and what they are teaching and doing about pain.

The purpose of this study was to gather information on how family caregivers of palliative cancer patients managed pain at home, the problems they

faced, and how health care professionals could help them. The intent was to understand the pain management process for each family caregiver. If the way each caregiver manages pain differs, then it may become clearer how health professionals can individualize their teaching interventions and amount of support they provide. An understanding of how the pain management process may differ should help dictate how interventions directed towards supporting the pain management should differ as well. Patients were also included in this study, not in order to understand the family caregiver pain management process, but rather to see if the family caregiver processes that emerged were, in their opinion, helpful in the relief of their pain so that future interventions based on the results of this study will only incorporate processes that were successful for patients' pain management from the patient point of view as well.

The Study Question

This study focused on the following question: What is the process used by family caregivers at home to manage the pain of palliative cancer patients? Secondary questions were also explored: 1) What are the types of pain family caregivers of palliative cancer patients are managing at home? and 2) What are the interventions that family caregivers are performing at home? The answers to these secondary questions are not yet known, and were thought to have an influence on what the process of pain management may look like.

Definitions

Palliative in this study refers to the subset of patients whose treatment plan was no longer directed towards a cure, but rather whose primary treatment goal was to optimize the quality of life of the patient and the family.

A *process* is defined as “phases or clusters of activities in movement toward some goal” (Rodgers, 2000, p.109).

Successful pain management is defined as the effective treatment/control of cancer- related or non-cancer-related pain with either pharmacological or non-

pharmacological interventions while minimizing toxicity (Boisvert & Cohen, 1995; Paregeon & Hailey, 1999).

Family caregivers or “Informal Caregivers are family members, friends and neighbors who provide support or care for the dying family member, loved one, or friend” (Canadian Hospice and Palliative Care Association (CHPCA), 2002). In this study, most family caregivers were identified by the patients (see Inclusion Criteria).

LITERATURE REVIEW

A literature review must not necessarily precede a grounded theory. Strauss & Corbin (1990) stress the importance of beginning with an area of study and allowing what emerges as relevant to formulate the theory. However, a literature review can provide support and a context for a study. In this case, it provided evidence that little information could be found about the process of pain management at home as done by family caregivers. Furthermore, once a process grounded in data was developed, it was examined in light of the literature review to determine to what extent it reflected processes already described in the literature. Hutchison (1993) also notes that a literature review can also reveal gaps in the present knowledge and provide a rationale for the proposed research. The literature was examined in order to learn what is known about family caregivers who have the responsibility of pain management for palliative cancer patients at home. The literature search was also conducted to see how pain management by family caregivers of patients with cancer has been previously described and if the descriptions that exist are applicable to the palliative cancer population and to the way the caregivers are managing pain. Other factors that I suspected were involved in the pain management process were also identified and described. Therefore, another goal of the literature review was to find existing frameworks that could potentially explain or impact pain management.

Pain and Pain Management

The International Association for the Study of Pain (IASP) (2003) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. Pain is always subjective and the inability to communicate verbally does not negate the possibility that an individual is experiencing pain. Successful pain management is of concern in both acute and chronic pain. Family caregivers are managing all of the cancer patients’ pain, not just their cancer pain. It is for this reason that both chronic and acute pain will be briefly discussed prior to discussing cancer pain.

Acute pain is pain perceived immediately upon injury and experienced throughout the healing process, usually lasting no longer than 3 months (IASP, 1979). Acute pain is usually transient in nature, and can last several minutes, days, or weeks. It may not necessarily be associated with anxiety and overt pain behaviours (e.g. grimacing), depending on the intensity, predictability, and meaning of the pain (Jovey, 2002). There is a clear biological value to acute pain. It requires those experiencing it to take action to remove themselves from the situation causing the pain, and to rest and/or protect the damaged area to allow for healing. Unrelieved acute pain is a concern in the hospital (Musclow, Sawhney, & Watt-Wilson, 2002; Schoenwald & Clark, 2006) and also at home (Girdhari & Smith, 2006; McDonald, 1999; VanDenKerkhof, 2006).

Chronic pain is defined by the IASP (2003) as pain without apparent biological value that has persisted beyond normal tissue healing time (usually considered greater than 3 months). It may also be associated with a chronic pathological process or with a pattern of recurrence over months or years. Chronic pain is often also accompanied by emotional symptoms, activity limitations, and negative health perceptions (Breen, 2002; Jovey, 2002). It may be caused by such conditions as rheumatic disease and may include pains such as headaches and back pain (Abeles, Pillinger, Solitar, & Abeles, 2007; Davis, 1992). At least 70% of older adults experience some degree of chronic pain (Davis, Hiemenz, & White, 2002; Dewar, 2006). Such chronic pain may be treated in-hospital, but many people rely on pain management on an out-patient basis. Increasingly,

cancer pain may also evolve into chronic pain for the patient (Burton, Fanciullo, Beasley, & Fisch, 2007).

Chronic pain is a significant problem among community dwelling older adults and it was found that under-treated or poorly managed pain affected the physical, psychological, social, emotional, and spiritual well-being of older people (Dewar, 2006; Dunn & Horgas, 2004). This is of relevance because patients with cancer tend to be older, and may now have new pain added to chronic pain they were already experiencing. In fact, it has been predicted that over the next 20 years, about 70% of all cancers will be diagnosed in persons who are 65 years old or older. Despite the prevalence of cancer in the elderly, pain secondary to the cancer is more likely to be unrecognized and untreated in this population (Cancer Pain Release, 2004).

Cancer treatment may also result in either acute or chronic pain. In fact, treatment-related pain is often identified as a cancer pain syndrome (Chang, Janjan, Jain, & Chi Chau, 2006; Davis & Walsh, 2004). Surgery, radiation therapy, and chemotherapy can result in the affliction of acute pain or pain of a longer duration. Overall, cancer pain can often be a combination of both acute and chronic pain and remains under-treated (Turk, Monarch, & Williams, 2002; Vallerand, Riley-Doucet, Hasneau, & Templin, 2004).

Poor pain management results in under-treated pain, and as a consequence, pain is often unrelieved for many cancer patients. Unrelieved pain is a prevalent problem for the palliative cancer population, both in hospital, hospice, and at home (Aubin et al., 2006; Bostrum et al., 2004; Dobratz, 2001; Duggleby, 2002; Ferrell et al., 1993; Ferrell et al., 1991; Randall-David, Wright, Porterfield, & Lesser, 2003). Unrelieved pain is not without its consequences. Pain management is of prime importance not only for patient comfort but also because of secondary effects unrelieved pain has on family caregivers. Some documented consequences are anxiety and depression (Casten et al., 1995; Davis & Walsh, 2004; Jenson & Karoly, 1991; Yates et al., 2004), feelings of hopelessness and helplessness (Mehta & Ezer, 2000; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007), and a decreased quality of life (Clark et al., 2006; McMillan et al., 2005; Yates et

al, 2002). Sleep disturbances, poor nutritional status, tension, fatigue, and suffering are additional consequences that have been described as family caregiver reactions to watching their family member endure unrelieved pain (Yates et al., 2004). Due to the number of cancer deaths (72,700 estimated for 2007 in Canada alone, Canadian Cancer Statistics, 2007) such unrelieved pain is a public health care problem (Berry & Dahl, 2000; Randall-David, Wright, Porterfield, & Lesser, 2003).

Overall, palliative cancer patients may experience a combination of both acute and chronic pain. A search of the literature indicates that pain and pain control remains an important health care concern today. This concern is shared by both health care professionals and the family caregivers who must manage this pain at home.

Factors related to Pain and Pain Management

Types of Pain

Pain is a common symptom experienced by older adults for a range of different reasons (Gibson, 2007; Morone & Greco, 2007). A diagnosis of cancer often adds to the pain some of these people are already experiencing, particularly as their disease progresses. In comparison to patients who are in the early stages of their cancer, patients with advanced disease experience an increased frequency and intensity of pain (Davis & Walsh, 2004). These patients may experience many different types of pain. A survey done by Twycross & Fairfield (1982) revealed that most patients with advanced cancer reported that they experience more than one type of pain. Of these patients with advanced cancer pain, 34% also stated that they were dealing with three or more types. Patients continue to report more than one type of pain (Davis & Walsh, 2004). The pain may be caused by the neoplasm itself, its tendency to spread locally or distally, or due to anticancer treatment resulting in “typical pain syndromes” (Mercadante, Casuccio, Pumo, & Fulfare, 2000, p.28). The pain may also be the result of causes unrelated to the cancer (Portenoy, 1989; Turk, Monarch, & Williams, 2002;

Twycross & Fairfield, 1982). Pain may be mild or moderate to severe in intensity and may appear as “a number of distinct pains” (Davis & Walsh, 2004). Cancer pain has been described as “quivering, flashing, pricking, or gnawing” (Melzack, 1987). It may also present itself as more severe and debilitating when patients describe it as “splitting, punishing, piercing, or even killing” (Melzack, 1987). Home hospice patients with advanced cancer described their pain as “tiring and exhausting,” “troublesome and annoying,” “dull and aching,” and “nauseating and sickening” (Dobratz 2001 p. 296-97).

One of the most common types of pain a palliative patient faces is bone pain associated with metastatic solid tumors (Davis & Walsh, 2004; Grossman, Dunbar, & Nesbit, 2006). Almost 95% of cancer patients have bone lesions of some type, although not all are painful (Mundy, 1997). Huack (1986) found that one of every three patients with bone metastases experiences significant pain. However, one study looking at clinical problems and treatment strategies in vertebral metastases of prostate cancer found that from their sample of 119 patients with bone metastases, 93% experienced bone pain (Cerceda, Flechon, Droz, 2004). One third of advanced cancer patients experience neuropathic pain (Walsh & Davis, 2004). This results from damage to neural structures (e.g. by tumor infiltration, due to radiation therapy, or chemotherapy) and may be described as “shooting, lancinating, or burning” (Davis et al., 2001) or as “pins and needles” (Levy & Samuel, 2005). On the other hand, nociceptive pain is the result of ongoing tissue damage that activates the peripheral nociceptors. It may be the result of injury to somatic and visceral structures (Seaman & Cleveland, 1999). It may be described as “cramping, squeezing, stabbing, or throbbing” (Davis et al., 2001). More specifically, visceral pains are often described as “deep aches” and somatic pains may be explained as “sharp” and dependent on position and movement (Levy & Samuel, 2005, p.180).

Breakthrough or transient pain has also been identified as a concern for cancer patients. It is pain that “breaks through” the regular around-the-clock scheduled medications used to treat cancer pain (Payne, 2007). Breakthrough pain may occur in up to 93% of patients with persistent pain (Payne, 2007), and

can be unpredictable, come on quickly, and is often punctuated by intermittent exacerbations that may last for as long as an hour. It is often also quite severe (Zeppetella, O'Doherty, & Collins, 2001, p. 244). Transient pain induced by movement is often termed incident pain (Goudas, Gialeli-Goudas, & Carr, 2005). This pain can be further categorized as either somatic, visceral, and neuropathic pain (Petzke, Radbruch, Zech, Loick, & Grond, 1999).

As the above discussion suggests, advanced cancer patients experience at least one if not multiple types of pain in various parts of the body. Despite this fact, there is little information on the types of pain their family caregivers are trying to manage at home. Furthermore, they may be dealing with several sources of pain with different times of onset, and different durations. For example, pain may be intermittent or constant. It may also occur periodically, due to a triggering event such as a change in position. This is also important to note as many caregivers struggle with “managing new or unusual pain” (Schumacher et al., 2002). This new unfamiliar pain will need to be managed independently by the family caregiver until professional help can be obtained.

Finally, to fully understand the pain experience for the palliative cancer patient, the concept of ‘total pain’ is important to comprehend. Cicely Saunders, pioneer of the modern hospice movement, coined the term ‘total pain.’ ‘Total pain’ means pain with physical, psychological, social, and spiritual elements. Each of these elements will have an individualized impact on the ‘total pain’ resulting for the patient. Although not all elements may be present, or present to the same degree in a patient, all must be assessed and addressed in order to optimize pain control. A patient may not be capable of expressing the fact that the pain they are experiencing is a result of a combination of factors. For example, some patients with ‘total pain’ may be unable to distinguish exactly which element is causing their pain, as all they can express is that “they just hurt” (Storey, 1996). Easley & Elliot (2001) describe unrelenting pain at the end of life that extends beyond the physical realm into the psychological, social, and spiritual ones. The type of pain a patient experiences may be part of a ‘total pain’

experience and will have physical, emotional, social, and spiritual dimensions that interact and are expressed physically.

Types of Interventions

There are many different treatments for pain for cancer patients receiving care at the end of life. Radiation therapy, palliative surgery, palliative chemotherapy, and neural blockades are some examples of interventions that are being used in conjunction with a range of different medications (Chang et al., 2006). Patients also use alternative or complementary therapies in their attempts to relieve their pain. In fact, one study showed that as many as 91% of newly diagnosed cancer patients report having used at least one type of therapy other than medication (Yates et al., 2005). Some examples of these other therapies are prayer, relaxation, massage, and imagery. Nurses use both pharmacological and non-pharmacological interventions for pain control in their work with patients (Godfrey, 2005; Mobily, Herr, & Kelley, 1993; Snyder & Wieland, 2003). Non-pharmacological interventions used by nurses to decrease a patient's pain include such strategies as distraction, relaxation, and imagery (Mayer, 1985).

Also of interest is the fact that the type of pain often dictates the type of treatment. For example, incident pain and neuropathic pain are often quite challenging to manage (Davis & Walsh, 2004). Incident pain frequently requires medications outside of the prescribed medication regimen (Davis & Walsh, 2004). Neuropathic pain is often difficult to treat, reacting differently to opioid use or not responding to treatment at all (Mercadante et al., 2000; Seaman & Cleveland, 1999), although more recent work indicates that methadone (Gagnon, Almahrezi, & Schreier, 2003; Nicholson, 2004; Smith, 2004), gabapentin (Gilron, Bailey, Tu, Holden, Weaver, & Houlden, 2005; Smith, 2004), and pregabalin (Zareba, 2005) are useful for neuropathic pain. On the other hand, nociceptive pain can be targeted with different combined treatments such as opioids, electrical modalities (Seaman & Cleveland, 1999), or other medications. Overall, the type of pain experienced by the patient is of prime consideration in the determination of the management of the pain.

Family caregivers may also use a combination of interventions that involve both pharmacological and non-pharmacological methods (Ferrell, 1996; Given, Given, & Kozachik, 2001). In one study, family caregivers reported they had “a lot” of involvement in giving the patients medications and in reporting the patient’s pain to health professionals. Despite the fact the majority of interventions involved giving medications, they also reported feeling minimally involved in making decisions related to the giving of these medications (Yates et al., 2004). For example, they did not appear to make decisions related to the dose and the timing of the medication. This may imply that the caregivers are giving medications without an assessment or evaluation of the effects of these medications. This is unfortunate since successful cancer pain management often involves the continuous assessment of pain and the giving of breakthrough medications to complement the around-the-clock administration of prescribed opioids (Payne, 2007). Furthermore, effective pain management is often a result of a combination of both pharmacological and non-pharmacological interventions (McCaffery, 1990; Mobily, Herr, & Kelley, 1993; World Health Organization (WHO), 1990). These same caregivers also report the minimal use of non-pharmacological methods to relieve the patient’s pain (Yates et al., 2004). This is an important finding because the under-utilization of non-pharmacological interventions may actually contribute to the issue of pain and suffering among cancer patients (Zaza, Sellick, Willan, Reyno, & Bowman, 1998), or result in the need for increased use of analgesics, with associated increases in side effects. Non-pharmacologic methods for pain relief are vital as complementary treatment, however, should not be used to replace a prescribed medication regimen (Arderly, Herr, Titler, Sorofman, & Schmitt, 2003; Mobily, 1994). Present evidence is limited but suggests that family caregivers are learning about such interventions through trial and error (Given, Given, & Kozachik, 2001) or not using them at all. A more structured approach to the teaching and the implementation of non-drug strategies may be beneficial to both the patient and the family caregiver.

Rhiner, Rhiner, Ferrell, & Grant (1993) discuss an educational nursing intervention examining the role of heat, cold, massage/vibration, distraction, and

relaxation as potential interventions family caregivers can use. The study was done in the homes of 40 patients experiencing cancer pain. Patients and their family caregivers participated in a pain intervention program that included pain assessment, pharmacologic interventions, and non-pharmacologic interventions. The most frequently used interventions were heat (70%), massage/vibration (63%), distraction (50%), and cold (20%). Of interest to note was that distraction was rated as the most effective non-drug strategy. Schumacher et al. (2002) noted that family caregivers face difficulties in tailoring “prescribed regimens to meet individual need”, indicating that they are unsure how best to intervene to meet specific patient needs. Insight into this issue would help gain an understanding of how the caregiver makes pain management decisions. Understanding why they choose not to deviate from the prescribed plan may enable health professionals to reassure them and provide a rationale for why they might need to be flexible in their pain management roles. As a result, family caregivers should also have flexibility in the prescribed plan of care. The emphasis that each patient and often different pains in the same patient differ means that the interventions required differ as well. Teaching and support can help family caregivers recognize when alterations or adjustments need to be made to a prescribed pain regimen in order to best meet the patient’s needs.

Possible Barriers to Pain Management

Certain beliefs and/or attitudes on the part of the patient or the family caregiver may hinder effective pain management. For example, one study found that despite the fact that 88% of the sample of cancer patients reported their pain as greater than 5 on a scale of 0-10, they were reluctant to report discomfort. The results also showed that forgetfulness, stoicism and fatalism were other factors that may present as barriers in reporting uncontrolled cancer pain (Thomason, et al., 1998). Such barriers influence how the pain of the patient is managed and need to be understood.

Similarly it has been found that barriers to effective pain management in the cancer population include misconceptions about opioids and other drugs, non-

adherence to treatment regimens, poor communication about pain concerns to health care professionals, structural/organizational barriers, and the absence of formal assessment procedures (Berry & Ward, 1995; Pargeon & Hailey, 1999; Randall-David, Wright, Portefield, & Lesser, 2003; Yates et al., 2002). In other cases, concerns over the side effects of opioids, the fear of addiction, and lack of education about pain assessment and management also prevented caregivers from successfully controlling the pain for the patient (Aranda et al., 2004; Berry & Ward, 1995; Letizia, Creech, Shanahan & Hedges, 2004; Paregeon et al., 1999; Riley-Doucet, 2005; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007).

Discrepancies occur in the assessment of pain and pain intensity. Family members often report pain as higher than the patient perceives it to be. Many studies have shown that the family caregiver's perception of pain differs from the patient's in that they consistently estimate the patient's pain as worse than the patient does (Lobchuk & Vorauer, 2003; Paregeon & Hailey, 1999; Redinbaugh et al., 2002). Some other studies found that there was a high level of congruence between the patient and family caregiver ratings of pain (Lobchuk, Kristjanson, Degner, Blood, & Sloan, 1999; Yates et al. 2004). This is important because if the family caregiver is assessing incorrectly, the patient will not receive proper pain management. For example, if the patient is in greater pain than the family caregiver perceives, then the resulting medication or other intervention may not sufficiently alleviate the patient's pain. On the other hand, if the family caregiver overestimates the pain and medicates accordingly, it could result in unnecessary toxicity for the patient. Furthermore, given that the pain assessment differs, it may follow that the family caregiver may judge the success of a particular strategy differently than the patient. There were no studies found in a literature search examining the congruence in the perception of the success of pain interventions for people with advanced cancer. For future work that will use the results of this study to develop interventions, the patient's point of view is required to permit insight into the appropriateness of the assessment methods used and other related factors (e.g. communication between the patient and the family caregiver). More

research is needed in this area (but will only be briefly touched upon in this study).

Gender Differences

Although the majority of family caregivers are women, there are also men caregivers who take on the responsibility of caring for an ailing family member. Caregivers who are men are now increasingly involved in the care of sick family members, particularly their spouses (Ducharme et al., 2007). Gender differences have been found in several caregiver studies. Studies on role and gender differences in cancer-related caregiving stress revealed that the women caregivers scored higher on cancer-related anxiety, future uncertainties, and fear of recurrence and also suffered from symptoms of lack of well being, a decrease in psychosocial health and in overall self-rated health more often than the men (Chiou, Chen, & Wang, 2005; Mathews et al., 2003). In contrast, the men felt that the caregiving experience fostered individual growth, felt more satisfied with their experiences, favored more problem-focused interventions, experienced less burden, reported less stress secondary to their higher level of “caregiver esteem”, felt that they were more useful and had more meaning to their lives than did the female caregivers (Ekwall & Hallberg, 2007; Kim, Loscalzo, Wellisch, & Spillers, 2006, p.1087; Mathews, Dunbar-Jacob, Sereika, Schilz, & McDowell, 2004).

In relation to pain control, one study looked at the administration of medications for palliative patients where 64% had a cancer diagnosis (Letizia, Creech, Norton, Shanahan, & Hedges, 2004). These patients were either at home or in hospice. It was found that the caregivers who were men had greater concerns about reporting information about the patient's pain to health care professionals and administering medications (Letizia, Creech, Norton, Shanahan, & Hedges, 2004). They had a higher level of concern related to addiction, tolerance, and side effects of pain medications. Another study examined the concordance between patients and family caregivers in reporting patient symptoms, including pain, and found that the women caregivers had a higher percentage agreement with their

patients, and a higher level of association between patient and caregiver responses than men, uniformly for all symptoms (Kurtz, Kurtz, Given, & Given, 1996). Interventions aimed at improving agreement in symptom ratings may also prove beneficial in these cases so that both genders will be able to make accurate assessment for pain. These results suggest that gender differences may also influence the pain management process, and that women family caregivers may need closer monitoring for burnout and more support.

Assessment

Although a self-report of pain is considered the most reliable indicator of the presence and the degree of experienced pain, it is not always possible to obtain the information in this manner (Gelinass & Johnston, 2007). Patients at the end of life may not always be able to communicate their distress and discomfort to the family caregiver. This may be the case if the patients have another illness (e.g. dementia) or if they have become less responsive as a result of disease progression or the side effects of medication. This is a serious concern since the ability of patients to communicate that they are experiencing pain by both verbal and non-verbal methods is critical in facilitating the assessment of pain (Rodriguez, McMillan, & Yarandi, 2004). Pain assessment methods may need to be altered in order to meet the needs of the patient with poor or no communication abilities. As a result, in nonverbal patients who are unable to self-report, assessment involves observable behavioural and physiologic indicators (Herr et al., 2006; Kwekkeboom & Herr, 2001). Tools have been developed for assessing non-verbal pain indicators for the cognitively impaired and the intensive care unit populations (Ardery, Herr, Titler, Sorofman, & Schmitt, 2003; Gelinass, Fillion, Puntillo, Viens, & Fortier, 2006). Although developed for different populations, the above information may be applicable to the palliative cancer population as well since pain assessment at the end of life also requires that attention be paid to such non-verbal cues. Commonly used assessment tools such as the visual analogue scale or verbal descriptors may not be appropriate for this population and assessment may require a reliance on “behavioural signs such as agitation, or

even reports from the next of kin” (Black, Aveyard, & Schofield, 2007, p. 21). This often places the responsibility of accurate pain assessment on the family caregivers. These family caregivers can share valuable information on the non-verbal cues they are using for palliative cancer patients.

It is critical to note that it is still possible to verbally assess pain in some patients who are cognitively impaired. Some patients may not be able to recall and compare pain levels, however they are able to report their pain reliably at any given time (Turk, Monarch, & Williams, 2002). In these cases, frequent assessment is a necessity to determine if pain control is achieved (Turk et al., 2002). Some family caregivers who are responsible for pain assessment may find themselves trying to determine comfort levels for patients who are unable to verbally communicate their pain, while other family caregivers will be caring for those that can self-report. It may also be the case that patients who had been previously able to communicate their pain and comfort needs may no longer be able to do so as their disease progresses. Of interest is the fact that family caregivers are also communicating information about patient symptoms (e.g. pain) to health professionals even when patients are competent and able to communicate (Hauser et al., 2006). In one American random, national sample of 893 terminally ill patients and their caregivers it was found that only half the patients and family caregivers (52%) agreed on the assessed level of pain (Hauser et al., 2006). Furthermore, family caregivers are performing their pain assessments independent of the patient’s report on pain. There is no information on whether in these cases either verbal or non-verbal assessments are being done, or if a combination of both is being done by these caregivers.

Information about pain assessment is vital in understanding pain management. Despite the fact that many pain assessment tools exist, they are not all appropriate for the palliative care population. There is no consensus as to what family caregivers should be assessing and many of the tools and items are of limited relevance for patients with advanced cancer (Chang et al., 2006; Hølen et al., 2006). For example, although some tools do exist that include the assessment of non-verbal behaviour, they remain under-tested in the palliative cancer care

population (Feldt, 2000; Gelinas, Fillion, Puntillo, Viens, & Fortier, 2006; Gelinas & Johnson, 2007; Taylor, Harris, Epps, & Herr, 2005). Inadequate or inaccurate pain assessment can often be a reason for poor pain management, making a proper assessment key to good pain control (Davis & Walsh, 2007; Hølen et al., 2006; Whitecar, Jonas, & Clasen, 2000). The lack of an identified appropriate tool for pain assessment can therefore be a contributing factor to poor pain management.

Palliative Care in the Home

The history of palliative care demonstrates that the entire family unit has always been involved in the care of their family member. For example, families were, and remain, involved in such activities such as the administration of medication and the changing of dressings (Matzo & Sherman, 2001). Wright & Leahey (2005) point out that it was during the transition of health care from the home into the hospital that professionals began to take over some responsibilities from the family for major family events, such as the death of a family member. Today, this trend has since reversed and many aspects of palliative care now take place on an out-patient basis. In Canada, it is seen as important to provide patients who are terminally ill with the opportunity to spend their last days at home in the presence of their family and friends (Fainsinger, 2002). In North America the majority of home care for cancer patients is being provided by relatives and friends who assume such tasks as helping with activities of daily living, transportation, the negotiation of the health care system, and comfort care (Cameron, Shin, Wialliams, & Stewart, 2004; Houts et al., 1996; Schumacher et al., 2002; Skilbeck et al. 2005; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). More recently, the responsibility of pain control at home has also fallen to the family caregiver.

Family Caregivers and Pain Management

Family caregivers are responsible for many aspects of the patient's care, including their pain management (Aranda & Hayman-White, 2001; Lobchuk & Vorauer, 2003; Redinbaugh, Baum, & DeMoss, 2002). They play an integral role

in pain assessment, monitoring, and the delivery of complex therapeutic interventions (Aranda & Hayman-White, 2001; Chia-Chin, Lai, En-Chi, 2001; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007; Wilson, 1999). It has been noted that “if there is anything worse than being a patient in pain, it is being a family member in the position of observing a loved one in pain” (Ferrell, 2001, p.596). As a result, pain management is a great concern for these family members (Dar, Beach, Barden, & Cleeland 1992; Ferrell, Rhiner, & Ferrell; 1993, Hinds, 1985; Mehta & Ezer, 2003; Taylor, Ferrell, Grant, & Cheyney, 1993; Yates et al., 2004).

Despite the family caregiver’s important role in pain management at home, one area of research that has received virtually no attention is the process of pain management by family caregivers of palliative cancer patients at home. This is an area of research that needs to be developed (McMillan et al., 2005; Riley-Doucet, 2005; Schumacher et al., 2002; Yates et al., 2004), because a caregiver plays an important role in the success or the failure of the pain management regimen for the patient (Vallerand, Collins-Bohler, Templin, & Hasenau, 2007; Yates et al., 2004). Also of interest is that pain management at home often involves constant interaction and communication between the patient and the family caregiver. Without this, differences in perceptions of pain and poor communication can influence pain assessment and pain management (Mazanec & Bartel, 2002). Importantly, in order to be able to be successful at pain management, family members and patients have identified that they require help with pain management (Porter et al, 2002; Riley-Doucet, 2005; Yates et al., 2004).

Nurses: Support for Pain Management

It is only through a thorough understanding of what these family caregivers are facing and managing that sufficient societal support, resources, and health care provider intervention can be provided. Health professionals need to target specific challenges caregivers may face in fulfilling their pain management role (Yates et al., 2004). Nurses and other health professionals are in a prime

position to address the specific needs of such family caregivers (Dobratz, 2001; Firth, 2006; Mazanec & Bartel, 2002; Whitecar, Jonar, & Clasen 2000), and in fact have a fundamental responsibility to ensure pain relief (Cahana, Arigoni, & Robert, 2007, p. 104). This is an important responsibility given that pain is one of the most commonly experienced and feared symptoms of advanced cancer (Davis & Walsh, 2004). More research is needed to increase our knowledge of pain and the pain management process (i.e. pain assessment and intervention) with palliative cancer patients and their family caregivers in order to meet these needs (Ferrell et al., 1995; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007; Yates 2004). There is also a lack of information on the types of pain the family caregivers are managing. To provide optimal pain management at home, it becomes critical then for healthcare providers to understand the types of pain family caregivers are managing and how they then decide to intervene. At present, interventions and family caregiver education programs are taught in the absence of this information, and are therefore not tailored to the needs of family caregivers of people at the end of life (Ferrell, Taylor, Grant, & Corbisiero, 1993; Keefe et al., 2005; Yates et al., 2004). If the information is not tailored to meet the individual needs of the patients and family caregivers, the interventions taught may be inappropriate ones that are not effective for the type of pain the patient is experiencing. There are different strategies that may work for different types of pain. While one intervention may work for a specific type of pain, it may not be successful for another. In the same way, an intervention that works for one patient may not work at all for another patient. The family caregivers are the primary caregivers when patients are cared for at home and as a result are present to monitor the effectiveness of interventions over time. They also have more intimate experience with insight into the pain management needs of the patients they are caring for, and can articulate these to the health professionals developing a plan for the patient. Despite this, family caregiver input is not often sought and the educational interventions are not always optimal for them. As a result, family caregivers are often not prepared to handle the responsibility of pain management and require help (Ferrell, 2001; Porter et al, 2002; Riley-Doucet, 2005; Taylor,

Ferrell, Grant, & Cheyney, 1993; Ward, Berry, & Misiewiswicz, 1996). This lack of preparedness and support may have serious consequences for the patients they care for (Clarke et al., 2006; Riley-Doucet, 2005; Yates et al., 2004) as well as for themselves.

Herr & Kwekkeboom (2003) note that assessment and treatment strategies that are used by nurses can be tailored to meet the needs of older cancer patients by taking into account the caregivers' willingness to participate. The authors state that home health nurses can educate both patients and family caregivers to actively manage pain through frequent pain assessment and the inclusion of non-pharmacologic interventions. However, without sufficient information on how these caregivers normally perform their assessments, determine possible interventions, and then follow up if they do so at all, the nurses cannot be certain they are providing the information that is appropriate and adapted to the pain management process already adopted by the family caregivers, or helping in the best way possible.

There has been previous success with the teaching of pain management interventions to family caregivers of cancer patients at the end of life that yielded positive results. For example, Ferrell et al (1995), using a quasi-experimental design, demonstrated that an educational intervention on pain (including pharmacological and non-pharmacological interventions) had a physical and psychological impact on family caregivers. With regard to quality of life variables, family caregivers showed more positive scores in the domain of physical well-being such as feeling strong. In terms of psychological impact, it was not uncommon for these family caregivers to express feelings of helplessness at being unable to provide the patient with comfort. In this case, the educational intervention was seen as offering them support. Caregiver scores improved over time on such quality of life variables as their ability to pay attention and their feelings of usefulness. What is important to note in this case is that, despite the fact that family caregivers used a variety of different interventions, it is unclear why certain interventions were selected. In another study, the caregivers, when

asked, had “no rationale for choosing heat versus cold” (Ferrell, Cohen, Rhiner, & Rozek, 1991, p. 1316).

The Ferrell et al (1995) study provides important information regarding family caregiver management of cancer pain at home. However, it is missing some information that is critical to designing a nursing intervention to help in this situation. What the previous study failed to do was explore the rationale that led to the decisions made by the family caregivers. Similar to the study by Yates et al. (2004), family caregivers were not articulating the reasoning underlining their choice of intervention. No attempt was made to have them think about or explain how they chose an intervention. Furthermore, there is no description of how these caregivers judge the success of their intervention. For example, “caregivers expressed satisfaction with the comfort massage seemed to provide” but did not explain how they judged the intervention as successful (Ferrell, Cohen, Rhiner, & Rozek, 1991, p. 1316). There is little information on the relationship between the type of pain the family caregivers identify and the nature of the intervention that is used. Not all family caregivers may feel comfortable assessing for types of pain, and then choose their interventions accordingly. This may mean inappropriate or detrimental strategies may be selected, making the difference between controlled pain versus uncontrolled pain.

Pain Management as a Possible Process

Pain management involves many components. Several authors describe it as a process, although there is a lack of description or consensus as to what the process may look like. For example, authors have referred to a “pain management process” (Wilson, 1999) and others have described pain management as “a complex process” (Dalton, 1995) or “an overwhelming process” (Ferrell, Jacox, Miaskowski, Paice, & Hester, 1994). One prospective Dutch study recognized that pain management could only be thoroughly assessed by health professionals if they looked at “process components”. They found that the major cause of sub-optimal pain treatment was flaws in the process of pain management which included such aspects as non-standardized clinical practice (de Wit, van Dam,

Vielvoye-Kermeer, & Abu-Saad, 1999). Dewar (2006) acknowledges that pain assessment may be an important component of a “process” that is needed to adequately understand a patient’s chronic pain, with no clear explanation on the rest of what the process may include. Furthermore, Lickiss (2001) recommended that health care professionals follow a logical process to ensure adequate pain relief. The literature suggests that pain management for health professionals requires attention to such “process” components. The possibility that pain management is a process should also be considered in attempts to understand the family caregivers’ experiences with pain management. Despite these suggestions that pain management is a process, there is not enough information to conclude if it is indeed such for the family caregivers, and what the process components may be.

Family caregiving processes that are described in the literature relate to things other than their pain management and do not adequately capture how a pain management regimen is put in place. How pain management unfolds at home is quite unclear as we know very little about how the family caregiver and the patient “put pain management regimens into practice after receiving a prescription and initial instructions” (Schumacher et al., 2002, p. 370).

Identifying Gaps

The literature review revealed the following gaps and showed that in order to successfully create pain management interventions to support family caregivers there is a need for more information on: 1) the actual involvement of family caregivers in pain management at home; 2) the types of pain and intervention selection based on this; 3) the knowledge, the skills, and the resources that a family caregiver requires to be successful in pain management at home; 4) how family caregivers intervene; 5) additional factors that may influence the pain-management process at home; and 6) the interaction between the patient and the family caregiver as pain is being managed at home.

The Actual Involvement of Family Caregivers in Pain Management at Home

While involvement of family caregivers in the management of the patient's pain is stressed, the nature of what this involvement should be is unclear. This is partially related to the fact that our understanding of what constitutes pain management itself is incomplete. It is important to know what family caregivers are doing and to ensure that they are able to manage the patient's pain safely and effectively. In some cases, family caregivers are unable to successfully take on all the required activities to ensure pain control and may have difficulty with making decisions and problem-solving (Given , Given, & Kozachik, 2001).

The previously described cross-sectional study of cancer out-patients and their family caregivers (Yates et al., 2004) acknowledged that only a limited number of studies examined pain in the family context, thereby reinforcing the need for their study which looked at the family caregiver involvement in and perceptions of cancer pain management for patients attending an out-patient oncology clinic. They state that pain management by family caregivers involves two major components. The first is the administration of pain medications. This involves the accurate assessment of pain, decisions concerning the most appropriate type and timing of medications, encouraging the patient to take medications, noting the conditions under which medications are given, and obtaining prescriptions. The second component important to pain management is that of providing pain relief using non-medicinal methods. These strategies are thought to involve the "same degree of assessment, planning, intervention, and evaluation as those associated with medication" (Yates et al., 2004, p.288). Although this does indicate that there seems to be an organized way that family caregivers involve themselves in pain management and that perhaps these components form a process that encompasses pain management for family caregivers, more information is needed to see if the steps described above are applicable to a palliative cancer population. Furthermore, what each of the steps entails for the family caregiver remains unclear. For example, the thought processes behind choosing different interventions need further study as does their description of how and when they assess their family member's pain. There is

also information lacking on the consistency of the experience and process across family caregivers of this population.

Types of Pain and Intervention Selection

Several studies have looked at the management of cancer pain at home (Dobratz, 2001; Ferrell et al, 1995; Riddell & Fitch, 1997, Schumacher et al., 2002; Vallerand, Collins-Bohler, Templin, & Hassenau, 2007). Palliative cancer patients often have many separate types of pain, varying in intensity and location (Davis & Walsh, 2004; Lema, 2001; Portenoy, 1989) and they also describe their pain in differing ways (Dobratz, 2001). The pain they experience may or may not be a result of their cancer or their cancer treatment (Davis & Srivastava, 2003; Turk, Monarch, & Williams, 2002; Twycross, Harcourt, & Bergl, 1996). Despite this fact, these studies do not examine the types of pain the family caregivers must manage or if their treatment differs depending on the type of pain. We also do not have enough information on which pains may be controlled by health professional interventions, are manageable for family caregivers at home, and which ones the patient may be able to manage independently.

Ferrell, Taylor, Grant, & Corbisiero (1993) did an exploratory study looking at “special problems associated with pain management at home.” Questions about pain, who helps with the pain, and what helps with the pain were asked to the family caregivers. Several non-pharmacological strategies were described (e.g. cold compresses, Scotch, and cigarettes), however the types of pain each strategy was used for was not elaborated. Furthermore, although patients felt some psychological strategies were successful for them (e.g. distraction and avoidance), their caregivers did not report the helpfulness of such strategies. These present a concern if family caregivers are responsible for managing the patient’s pain and are not using strategies the patient identifies as successful. In addition, we do not know if, and how, family caregivers validate the success of their interventions with the patient.

The qualitative study by Schumacher et al. (2002) looked at both the patient’s and the family caregiver’s experiences while putting pain management

regimens into practice at home. It was found that when a new or unusual pain was felt, both the patient and the family caregiver did not know how to respond to this. Due to their uncertainty, they did not change their pain management behaviour in response to the new pain. This suggests that the type of pain does not make a difference in the selection of strategies and family caregivers may be unprepared to handle different types of pain. Despite this, the types of pain that are being managed at home remain relatively unexplored.

Some recent studies have looked at educational interventions for family caregivers (Aubin et al., 2006; Keefe et al., 2005). Interventions delivered in the patients' homes were training sessions and often "manualized" (Keefe, et al., 2005, p.264) and it is unclear if the manual allowed for flexibility, for example in cases where family caregivers were managing different types of pain and may have needed different strategies. In fact, we do not know if the only type of pain the patients in this study were dealing with was pain caused by the cancer. It remains unclear whether the taught interventions were appropriate for managing the types of pain the patients were experiencing, particularly in light of the lack of pain reduction reported by the patients themselves (Keefe, et al., 2005). In the Keefe et al. (2005) study, the caregivers were asked "how certain they were that they could help their partner decrease his/her pain quite a bit" (p. 266) but were not asked if they knew for certain they had decreased the pain or how they determined if the intervention was successful or not. This reveals the need to understand how they evaluate the success of their intervention, or their evaluation process.

A clearer understanding of the pain management process family caregivers use will help to determine if they select an intervention on the basis of type of pain and how they determine the success of the intervention. This is important because family caregivers express "frustration related to being ineffectual in providing pain relief...and derive satisfaction" if their strategies for pain management are successful (Ferrell et al. 1991). This frustration, as well as other emotional responses to pain may also affect how the family caregiver approaches the pain management process. For example, feelings of distress and anxiety may

cloud judgment when attempting to determine if an intervention has worked or not. A family caregiver who unreasonably expects immediate relief and evaluates the intervention immediately upon delivering it may deem it unsuccessful. A further reason to understand why and how a family caregiver selects a particular intervention is that in some cases they select strategies based on a lack of knowledge. At times, they may act based on emotions and implement an inappropriate strategy that may compromise the patient they are caring for (Yates et al., 2004).

Knowledge, Skills, and Resources Required by a Family Caregiver

Information on what family caregivers know, what external support they have, and what they are doing and capable of doing are also important factors in a pain management regimen. There is a need to understand the knowledge, the skills, and the resources that a family caregiver requires to be successful at pain management (Yates et al., 2004). In observing how family caregivers take on the responsibility of pain management, nurses can explore what information these caregivers have received and are using. They can further assess if the family caregivers possess adequate and appropriate skills to take on the challenge of pain control at home. This is important primarily because often family caregivers “are untrained and inexperienced in providing medical care and detecting problems” (Houts et al., 1996). The availability and use of external resources is also an important factor that may play a role in pain management. Similarly, Berry & Ward (1995) point out that with time and the declining abilities of the palliative patient, the caregiver becomes the first line decision maker regarding the patient's care and treatment. They say that understanding caregiver perspectives is important for continued success with managing pain. Again, a solid understanding of any existing pain management process from the perspective of the family caregiver will assist in achieving this success.

Additional factors that may influence the pain-management process at home

Caregivers trying to manage pain have additional concerns regarding unrelieved pain. The understanding and use of pain medications, and the experimentation with non-drug interventions (Ferrell et al., 1991; Yates et al., 2004) are such examples. In addition, the impending death (Stetz & Brown, 1997) and fear of administering a fatal dose is a real concern for these caregivers. A family caregiver's previous experiences, values, and emotions may also influence how they will manage pain at home (Sims et al., 1992). Their personal insights into pain assessment, intervention, and evaluation may also influence their pain management. It is quite likely that there exist other factors that play a role in the creation and implementation of a pain management regimen for palliative cancer patients at home, and the results of this study may lend some insight into what these factors may be.

The interaction between the patient and the family caregiver

Furthermore, more information about the interaction between a patient and the family caregiver is needed. For example, Ward, Berry, & Misiewicz (1996), in their study of hospice patients, found that in a given patient-caregiver dyad, either person may have the greatest concerns about reporting pain or using analgesics. Concerns differed, highlighting the fact that attention must be paid to how patients interact with the family caregiver to relate what the most pressing concerns are for them. Similarly, the interaction the family caregiver has with the patient is of importance to understand how they are drawing conclusions about the patient's care. The authors conclude that it is critical that clinicians attend to both persons with respect to assessment and intervention.

Mazaneck & Bartel (2002) also note the importance of looking at how a patient and caregiver interact because it can provide information on why differences exist in the patient's and family caregiver's perceptions of pain, poor communication, and fears and misconceptions. These factors can influence the assessment and management of pain. The authors suggest that improving

communication between the patient and the family caregiver will enhance the success of pain management. Another study found that caregivers reported higher levels of patient pain and disability than did patients, lower caregiving needs, and different fears about the future (Hauser et al., 2006). The agreement between the patients' and their caregivers' responses ranged widely. When the responses differed, patients were more likely to express concern about domains that might impose on caregivers, while caregivers were more likely to express concern about the patients' physical suffering. The authors stated that these results suggest that interventions to improve communication between patients and their family caregivers are needed (Hauser et al., 2006). One possible way to accomplish this is to begin by observing existing communication patterns to understand how the patient and family caregiver interact with one another. Communication may be improved by understanding what they need to communicate about and how successful the communication between them is at present.

Without a doubt, family caregivers involved with any patient population take on a great responsibility and are subject to a range of different experiences. Pain management remains a challenge for those caring for family members experiencing pain. Of all patient populations experiencing pain, those patients with cancer and in the palliative phase of their illness have some of the greatest evidenced involvement from a family caregiver (Aranda, et al, 2004; Burns, Broom, Smith, Dear, & Craft, 2007; Ferrell et al., 1991). While there are several studies of family caregiver management of the pain of cancer or advanced cancer patients at home, this review of the literature found that the understanding of this situation remains at a relatively superficial level. It is for this reason that the goal of this study is to develop a framework or theory that may help understand the process components of the pain management experience for family caregivers through an in-depth study. Although several frameworks that may be applicable exist, it is unclear which ones may be most appropriate for this population.

Some Possible Approaches to Pain Management

The literature review revealed that the pain management process may involve several components. Because the manner in which a family caregiver manages a pain crisis or delivers routine comfort measures has not been formally described, the literature does not allow one to choose among existing frameworks that may be seen as appropriate to describe how pain management is approached. Coping, decision-making, and problem-solving will be briefly discussed as they have been shown to be important processes for family caregivers of cancer patients in the management of other issues. In the Discussion (Chapter 5) the data from this study is examined in light of these frameworks to evaluate the extent to which the family caregiver pain management process is different or similar to these frameworks, or if it contains a combination of elements from some or all of them.

Coping

A possible process that a family caregiver may use when managing pain in the home is a coping process. Lazarus & Folkman (1986) defined coping as thoughts and behaviours that people use to manage the internal and external demands of situations that they appraise as stressful. Emotion-focused processes or problem-focused processes are the two basic processes described when someone is coping with a stressor (Lazarus & Folkman, 1986). A family caregiver may see the patient's pain as a stressor, and the resulting behaviours may be the coping responses.

Furthermore, coping is associated with the regulation of emotion, especially distress, throughout the stress process (Folkman & Moscovitz, 2004). For the family caregiver, witnessing their loved one in pain is a stressful situation. A threat to the patient is perceived, and a response on the part of the caregiver is required. This stressful encounter should be viewed as a dynamic, unfolding process, not as a static, unitary event (Lazarus & Folkman, 1986). Folkman, Chesney, & Christopher-Richards (1994) analyzed narratives of the caregiver partners of men with AIDS who had been asked to report the most stressful event related to caregiving. Within the general category of caregiving, narratives

revealed many different sources of stress, including adjusting to illness progression, the shifting of responsibilities from the patient to the caregiver, unexpected improvement in the patient's health, and role conflict. These insights were helpful in understanding the caregivers' perspectives regarding what they were actually coping with in their daily lives. The Lazarus and Folkman (1986) stress and coping theory has been used to “frame the family caregiver’s process of adapting to various stressful events” (Doorenbos et al., 2007, p. 271). This study of bereaved family caregivers found that one of the stressors identified was the patient’s increasing number and severity of symptoms at the end of life. However pain was not looked at as a specific trigger requiring a coping response.

Some examples of problem-focused coping are making a plan of action or concentrating on the next step. Examples of emotion-focused coping are engaging in distracting activities, using alcohol or drugs, or seeking emotional support (Folkman & Moscovitz, 2004). As a family caregiver manages pain, different forms of coping may be used in different parts of the process. What remains to be seen however, is whether or not family caregiver pain management is reflective of this, or if a different process exists.

Decision-making

Pain management has also been examined using a decision-making framework. Families and family caregivers are increasingly involved in decision-making at the end of life and the decisions they are faced with are increasingly difficult (Siminoff, Rose, Zhang, & Zyzanski, 2006). Therefore, it is not surprising that Ferrell & Dean (1994) state that family caregivers who are responsible for pain management have the implicit role of decision-maker in support of the patient in pain. Sims et al (1992) found that a family caregiver’s previous experiences, values, and emotions substantially shaped their decisions regarding home care. Furthermore, Blatt (1999), in her work with families regarding end-of-life decision-making about ‘Do Not Resuscitate’ orders, points out other variables that may factor into the decision-making portion of pain management. She includes the functional role of the patient in the family (e.g. a

grandmother whose role is matriarch of the family or the patient who is the family's main economic provider), emotional dependence on the patient, family problem-solving style, and ethnicity and religion as possible variables that may impact decisions made. Another study examined end-of-life decision-making of family caregivers of dementia patients. Using focus groups, it was found that the majority of family members made decisions within an emotional context of overwhelming burden and underlying guilt. They also based their decisions on their perceptions of death, their perception of their loved one's suffering, and their own values and goals regarding end-of-life treatments (Forbes, Bern-Klog, & Gessert, 2000). Pain management may involve a decision-making process similar to the ones used by these family caregivers caring for patients at the end of life.

Problem-solving

A third process that may be relevant for family caregiver management of pain is the process of problem-solving. Although pain control was not the focus of their work, Houts et al. (1996) proposed teaching family caregivers of cancer patients a problem-solving approach to deal with the many challenges they face. They describe problem-solving as the rational and systematic construction of a solution through the use of specific problem-solving skills: (1) problem orientation, (2) problem definition and formulation, (3) generation of alternatives, (4) decision-making, and (5) solution implementation and verification. They believe that this process is the same for family caregivers and for health professionals. They argue that elements such as information about the illness, about caregiving, and an orderly problem-solving approach for using information to address problems related to illness are likely part of effective family caregiving. The Home Care Guide for Advanced Cancer supported by the American College of Physicians (Houts et al., 1996) specifically highlights that "caregiving involves solving problems." Bucher, Trostle, and Moore (1999) stress the importance for health professionals to equip families with problem-solving skills specific to cancer pain. For example, family caregivers may have difficulty at any point in the problem-solving process. If it is at the beginning of the process,

they may require assistance in their assessment skills. On the other hand, it may be their evaluation of a pain intervention that needs further guidance. Houts et al (1996) also point out the importance of the role healthcare professionals have in giving expert information and guidance that contribute to the problem-solving process as applied to family caregivers. One study looked at problem-solving with family caregivers of patients with advanced cancer, describing problem-solving as one aspect of coping. Although they do not look specifically at pain management, the explanation that problem-solving uses a structured approach to manage the challenges that contribute to a stressful situation can certainly be applicable to pain management (Cameron, Shin, Williams, & Stewart, 2004).

A recent study used Houts et al.'s (1996) problem-solving training and their COPE (creativity, optimism, planning, and expert information) intervention for family caregivers to improve symptoms of hospice home care patients (McMillan & Small, 2007). They found that although the intervention did relieve some distress for both patients and family caregivers related to pain, the actual intensity of the pain for the patients was not diminished.

In this present study, what exists in the literature on coping, decision-making and problem-solving as possible explanations of how family caregivers manage pain in the home served only as a guide for the Discussion, to help in placing the theory that emerged from the data in the context of ways previously known to be used to deal with problems. The study was undertaken without these processes guiding the interviews, data collection, or analysis.

Summary

Overall, the literature review reveals the absence of in-depth and comprehensive knowledge on the way a family caregiver manages a palliative cancer patient's pain at home. Although we are aware of the different types of possible pain the patient may be experiencing, we remain unaware of the types of pain the caregivers are managing, how they are managing them, and how successful and confident they are. We can only speculate as to what factors influence and contribute to the pain management process for these caregivers.

This study was done in order to address this absence of information. The hope is that the information obtained from this study will make it possible to create nursing interventions that incorporate this knowledge so that family caregivers are being given the proper tools to manage the specific types of pain the patient is experiencing in the specific context that they are managing it. Understanding what factors influence the way family caregivers manage pain should also help to create interventions based on their own experiences, making it more likely that they will be used by the family caregivers with comfort. At present, interventions are being taught and implemented without differentiating between the types of pain the patient may be experiencing, the learning needs/styles of the family caregivers, or taking into account the past experiences or existing pain management regimen of the family caregivers. Inadequate and/or inappropriate interventions may result and sub-optimal pain management may be an undesired consequence. The results of this study should place nurses in a stronger position to increase caregiver competence and ensure that family caregivers have the appropriate skills to safely and confidently manage the patient's pain at home. Finally, for those family caregivers who feel helpless and without control (Mehta & Ezer, 2003; Milberg, Strang, & Jakobson, 2003), a clearer view of this process will highlight specific needs they may have related to the pain management process so the appropriate support can be provided.

METHODOLOGY

Study Design: Grounded Theory

Grounded theory was the methodology used in this study to gain an understanding of the process of pain management. Grounded theory is rooted in symbolic interactionism, meaning the researcher tries to determine the meaning certain gestures or words may have for a group of people as they interact with one another (Glaser, 1978). Symbolic interactionists emphasize the fact that people construct their personal realities from the symbols around them through their interactions. This means that people are active participants in creating meaning from a situation. Similarly, grounded theory seeks out social processes that are present in human interaction, hoping to discover patterns or processes to understand how people define their reality using their social interactions (Cutcliffe, 2000). McCallin (2003) stresses that grounded theory is the best way to discover the main concerns of patients and their families and to identify the process whereby these are managed. This has also now become “an important research methodology for the study of nursing phenomena” (Polit & Beck, 2004) and was deemed the most appropriate method to use in this study as available knowledge suggests that caregiver pain management in the home is a dynamic process.

The original premise of grounded theory is that this methodology seeks to construct theory about issues of importance in people’s lives (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Grounded theorists typically worked from a positivist ontology and epistemology, believing in a more concrete reality from which social processes emerge (Prasad, 2005). More recently, grounded theory has been seen as being more constructivist in nature, moving away from post-positivism (Charmaz, 2003, p. 250). Strauss & Corbin (1994) clearly state they do not believe in the existence of a pre-existing reality ‘out there’, stating their position is that truth is enacted. They have acknowledged the importance of a multiplicity of perspectives and “truths” and as such “have

extended and emphasized the range of theoretically sensitizing concepts that must be attended to in the analysis of human action/interaction.” They insist theirs is interpretative work that must include the perspectives and voice of the people who are studied. This is a relativist ontological position that leaves behind the traditional grounded theorists’ subscription to the discovery of the truth that emerges from data representative of a single reality experienced by all (Glaser, 1978).

For this study, the stance of the researcher in relation to the understanding of grounded theory is constructivist relativism. This approach differs from its positivist beginnings as it reaffirms the study of people in their natural settings, assumes the relativism of more than one social reality, recognizes that knowledge is the product of both the researcher and the participants, and aims towards an interpretive understanding of the participants’ meanings (Charmaz, 2003; Guba & Lincoln, 1994).

Although originally they co-authored the *Discovery of Grounded Theory* (1967) together, Glaser and Strauss have since diverged on their methodological suggestions. It is methodological rather than epistemological and ontological aspects that have been cited as the main source of divergence (Heath & Cowley, 2004). Glaser stresses the emergence of theory by data conceptualization with a less structured approach to “theoretical sensitivity”, whereas Strauss suggested a more structured approach to analysis through constant comparative technique. Glaser extended thoughts on grounded theory beyond the original text by explaining in more detail the concepts of theoretical sampling, theoretical coding, and theoretical memoing, but it was Strauss and Corbin (1990) who also focused on developing the analytic techniques and providing guidance to novice researchers (see pg. 51). It is therefore the coding framework of the latter that was used for analysis in this study.

Strauss & Corbin (1990) stress the importance of beginning with an area of study and allowing what emerges as relevant to formulate the theory instead of beginning with an existing theory and attempting to prove or disprove it. Theory development is a necessary goal of grounded theory, and in this case the overall

process of pain management was explored and explicated and the relationship it has to the existing theories concerning the processes of coping, decision-making, and problem-solving was examined. A theory consists of plausible relationships among concepts, or sets of concepts. Grounded theory research allows for conceptual density which refers to the richness of concept development and relationships (Strauss & Corbin, 1994). This relies on one being familiar with associated data pertaining to the phenomena under study and performing systematic verification and analysis with it (p.23). Grounded theory researchers are interested in “patterns of action and interaction” and in “discovering process” which is what are needed to appropriately answer the research question posed here (Strauss & Corbin, 1994).

The following sections will describe how this study was conducted using grounded theory to answer the research questions. The method of sampling, data collection, data analysis, and ethical considerations will be presented. In addition, a section on methodological rigour is included in order to justify the merit of this study.

Sample

Sampling for Family Caregivers

Family caregivers of the palliative cancer population manage pain that can be quite difficult to control, and involves increased and complex care, often in the absence of readily available health professionals (Dobratz, 2001; Tang, 2003; Yates et al., 2004). Pain can either be controlled, or not well controlled, and the family caregiver processes in both cases were of interest to be able to examine a range of pain management experiences. Family caregivers were sampled to answer the research questions posed.

The *primary* family caregivers were purposefully sought as they were identified as the most involved in the patient’s care. Sampling was limited to just one caregiver per patient for issues of practicality. English or French as spoken languages made for better comprehensibility of the interviews, since these were the spoken and written languages of the researcher. Family caregivers who were

looking after patients who were hospitalized (with no plans to be discharged) and in an environment where they could obtain immediate help were excluded as it was the pain management process at home where the caregivers were functioning independently that was of interest.

Inclusion criteria for family caregivers:

- Primary family or informal caregivers (male or female, of any relation to the patient) of patients that were receiving palliative end-of-life care for their cancer and who had pain control as part of their treatment plan, whether or not it was well controlled at the time of the study. The pain may have been a result of the cancer, the result of treatment received, the result of an additional pathological process, or another non-identifiable source.
- The person identified by the patient as that family member most involved with the management of the patient's pain at home. For the purposes of this study, only one family caregiver was studied per patient.
- Able to communicate orally in either English or French.

Exclusion criteria for family caregivers:

- Caring for a patient who was hospitalized and not expected to go home
- Deemed by patient's physician or nurse to be so distressed that participating in the study might be upsetting
- Under 18 years of age.

Patient Participation

Patients being cared for by the participating family caregivers were also interviewed, when possible, to obtain their perspective on the family caregiver's management of their pain. Although not integral to grounded theory, patients were also interviewed with the intent to see if the emerging family caregiver processes were successful at relieving their pain. This is valuable information for future intervention development as it would be difficult to justify basing interventions on the resulting theory of this study without having some idea of

whether they were effective for patients or not. The recruitment process was identical to that of family caregivers described above.

Inclusion criteria for patients:

- Cancer patients who were receiving palliative end-of-life care.
- Patients who had pain control as part of their treatment plan, whether or not it was well controlled at the time of the study. The pain may have been a result of the cancer, the result of treatment received, the result of an additional pathological process, or another non-identifiable source.
- Patients living at home or patients on a palliative care unit (PCU) who were admitted for symptom management and who were to be discharged home.
- Able to communicate orally in either English or French.

Exclusion criteria for patients:

- Patients who were unable to return home
- Deemed by patient's physician or nurse to be so distressed that participating in the study might be upsetting
- Physically or mentally incapable of providing informed consent and/or participating in the study
- Under 18 years of age.

The overall sample had 24 family caregivers and 8 patients. Since interviewing separately and together offered different advantages and drawbacks, both were initially seen as important for this study. The primary advantage to having the interviews conducted separately was to ensure the participants would be uninhibited in their conversations. For example, in a joint interview, a patient may hesitate to disclose an unsuccessful pain intervention done by the family caregiver, while the family caregiver may not feel comfortable sharing the uncooperative nature of the patient. The disadvantage in this case was that the interaction between the two may not have been observed. On the other hand,

patients and family caregivers were interviewed together, if they preferred. This permitted an examination of the nature of the interaction between the patient and the family caregiver. It was thought that the way the patient and family caregiver interacted may have been a part of the process of pain management. For example, if there was a smooth open communication process then that was taken as an indication that perhaps the process of pain management was a collaborative one without undue tension (See Table 1).

Purposeful and Theoretical Sampling

Purposeful and theoretical sampling of family caregivers was used in this study. Theoretical sampling is a key element to grounded theory research. It is important to recognize though that theoretical sampling does ultimately involve purposeful sampling during the initial stages of the study. This is because it is critical to begin the study with an effort to talk to those people who possess the most knowledge and information related to the research question (Coyne, 1997). In order to answer the research question: “What is the process used by family caregivers at home to manage the pain of palliative cancer patients?” it was decided that those family caregivers who met the inclusion criteria (see above) would be purposefully sampled at the onset of the study. The researcher selected these criteria to be able to sample for participants who will be the most “representative or informative” (Polit & Beck, 2004; Morse, 1991). It was felt that these caregivers would have information and knowledge that they could share, if willing, about the pain they were managing, the ways they were managing it, and the overall process of pain management taking place in the home setting.

Purposeful sampling is a non-probability sampling method. Although “personal judgment” was often used in this study, purposeful sampling was also based on theoretical findings in the literature. For example, family caregivers of different genders and who had different relationships with the patient were examples of those who were initially purposefully sampled. This was justified by the fact that women and men as caregivers assess and act differently as they

manage pain (see “Background” section). Family caregivers for cancer patients are often spouses (Bakas, Lewis, & Parsons, 2001; Chen, Chu, & Chen, 2004; Onishi et al., 2005). However, siblings and adult children are often also involved in caring for palliative cancer patients in the home (Bakas, Lewis, & Parsons, 2001; Weitzer, McMillan, & Jacobson, 1999). The relationship to the patient is critical to consider as adult children caregivers may feel abandoned at times, as well as experience a large disruption in the schedule of their lives (Given, Wyatt, Given, Sherwood, Gift, DeVoss, & Rahbar, 2004). This may be explained by the fact that unlike spousal caregivers, adult children may not live permanently with the patient, they are more likely to be employed, and may have their own families to take care of.

Grounded theory uses purposeful sampling at the beginning of data collection before the data or emerging theory begins to drive the sample (Backman & Kyngas, 1999). It is not uncommon for theoretical sampling to involve purposeful sampling (Coyne, 1997). In this study, purposeful sampling was then followed by theoretical sampling. Theoretical sampling differs from purposeful sampling (Polit & Beck, 2004, Cutcliffe, 2000) in that it “does not involve a calculated decision to sample a specific locale according to preconceived but initial calculated decisions” (Cutcliffe, 2000).

In this study, theoretical sampling began as the initial categories were being developed and it became clearer what subsequent areas of focus should be. For example, the category “developing a pain management relationship” encouraged sampling for family caregivers with different relationships with the patient. This was done when the theme of “role reversal” was recognized as daughters were caring for their mothers. In another example, the category “implementing a strategy for pain relief” showed that male caregivers tended to favor medications as an intervention, warranting the sampling of male caregivers to see if further interviews would yield data that would confirm this as part of the emerging theory. In theoretical sampling, the researcher seeks people to further interview to obtain information that may add to the richness of the data. In other words it involves the selection of people likely to further elaborate the theory,

confirm it, or disconfirm it. Furthermore, as was the case in this study, a sample can be maintained and additional data sought from it.

Recruitment

The nurses and physicians of the Supportive Care Team of a McGill University teaching hospital (The Sir Mortimer B. Davis Jewish General Hospital) and nurses from both the West Island and Montreal Victorian Order of Nurses (VON), or NOVA (previously the VON prior to organizational restructuring) were the ones who identified eligible people who were willing to be contacted by the researcher to have the study explained. An information session for staff was provided outlining the purpose of the study, the inclusion and exclusion criteria, and their expected/requested involvement in the recruitment process. The NOVA nurses identified family caregivers who were managing patient pain in the community and were appropriate candidates for the study. Similarly, members of the SCT from the hospital identified family caregivers of patients who were to be discharged into the community or who were already there. These clinical staff members then approached potential participants to inform them of the study and asked permission for the researcher to approach them to explain the study in detail. The health care professionals then passed on to the researcher the contact information for those who agreed to be contacted by her. The potential participants were then contacted by phone at home by the researcher to have the study explained in detail, have questions answered, and to verify if they consented to meet with the researcher. Written, informed consent was always obtained at the first meeting.

Sample size

In a grounded theory study, it is the emerging theory that dictates who will be sampled and how many: “sample size is a function of theoretical completeness” (Cutcliffe, 2000). Recruitment continued until no new information was being elicited. It was believed that saturation had occurred at this point. Saturation is when the collection of data reaches a point of “closure,” in that new data collected provides redundant information (Strauss & Corbin, 1991; Polit & Beck, 2004). In this grounded theory study saturation of categories was obtained

with 24 family caregiver interviews (Strauss & Corbin, 1998, p. 214). This was consistent with previous grounded theory studies with palliative cancer patients and their caregivers which found saturation with a range from 10-24 participants (Johnston & Abraham, 2000; McLane, Jones, Lydiatt, Lydiatt, & Richards, 2003; Mok, Chan, Chan, & Yeung, 2003; Harstade & Andershed, 2004). The decision that saturation had been reached was a judgment made by the researcher and her supervisor, based on examination of the richness of the emergent theory and the comprehensiveness of the data supporting it (i.e. no gaps).

Data Collection

Interviews about Pain Management

Interviews are a central data collection method for grounded theory (Duffy, Furguson, & Watson, 2004). Family caregivers and, sometimes, patients and were interviewed. Most family caregivers were interviewed alone (16/24 family caregivers), 1 patient and family caregiver were interviewed separately as per their choice, and 7 patient and family caregivers were interviewed together as per their choice. Eight patients were interviewed. It was expected that we would only be able to recruit a few patients as the family caregivers we were seeking were caring for patients who were quite unwell. We did not ascertain in detail why patients chose to participate or not as their participation was not used to develop the grounded theory but rather to have information on how they felt about their pain relief.

The times for data collection were flexible in order to accommodate the study participants. Most caregivers were interviewed at two separate times approximately one week apart in order to discuss the findings, give them time to reflect, and ask clarifying questions as needed. Interviews were usually 45-60 minutes.

The interview process is critical in grounded theory and begins with the questions initially “exploring the issue, then progressing towards discovering the conditions related to the issue, the precursors, context, and finally the consequences” (Brink & Wood, 1998). Unstructured interviews, while successful

at engaging both the researcher and the participants in conversation as a result of open ended questions being asked, do not allow the interviewer to use a set framework for the interview. This means the interviewer usually must follow the lead of the participants (Moyle, 2002). On the other hand, semi-structured interviews allow for the freedom for both the interviewer and respondent to follow new leads (Bernard, 2002). We believed that the most effective method of interviewing for this study was semi-structured interviews, which were used in data collection.

Interviews were audio-taped and transcribed verbatim. Hudson (2004) noted that all health professionals should remain open to conducting interviews separately or together. He concludes that they should be sensitive to the needs of caregivers who “wish to speak openly about their concerns without the [patient] present if they choose (p. 63).” If either the patient or the family caregiver wanted to be interviewed alone, they were interviewed separately. Family caregivers were asked after they signed the consent form if they preferred to be interviewed together with or separately from the patient if the patient had agreed to participate. Patients were also asked to sign consents and share their preferences for interviews together or apart. The researcher was aware that it was also possible that a conflict may have occurred during a joint interview if patient and family caregiver opinions or concerns differed. If this was to have happened, then an attempt would have been made to resolve this in a three-way discussion. Such conflict did not occur. At all times, if the researcher felt further intervention would have been required, if permission had been granted, the clinical team involved in their care would have been notified.

Interview guides for both family caregivers and patients were developed (Appendices II, III). The interviews began with questions related to the types of pain the caregivers said they were managing, how they knew when it was time to intervene, the strategies they used to reduce each type of pain, how they chose a strategy, and how they evaluated the success of their interventions (Appendix II). Recognizing that pain may not just be limited to physical implications, and keeping in mind that the IASP (2003) defines pain as “an unpleasant sensory and

emotional experience associated with actual or potential tissue damage, or described in terms of such damage,” questions addressing the entire nature of the pain experience were asked. Acknowledging the importance of ‘total pain’ was an important part of the interview, however family caregivers focused on pain manifested physically. The questionnaire guide simply used the word “pain” and the participants were free to describe and define pain as they wished. Overall, the management of the physical pain the patient experienced was the prime focus (described further in Chapter 4: Results)

Questions asking the patient how they think the family caregiver knew they were in pain and what kinds of cues they gave these caregivers that they were in pain were asked. Questions to determine successful strategies and those that were ineffective were also part of the interview guide. This was meant to collect information towards the eventual development of pain management interventions for family caregivers. The patients were also asked questions similar to those asked of the family caregiver related to their pain management experience based on the initial idea that this information would be helpful in informing the creation of a future intervention (see Appendix III).

A second interview took place 1-2 weeks following the initial interview in order to see how things evolved, if new thoughts had emerged, if new strategies had been tried and how these were being evaluated. This second interview also provided an opportunity for them to explain things they were unable to in the first interview and were asked to reflect upon until the second interview. The second interview also served as a check for the interpretation of the data from the first interview, which was reviewed by the researcher in between the two interviews by listening to the audiotape.

Demographic data

A short demographic interview was developed and administered to collect some basic socio-demographic information on the participants in order to describe them on these variables. Questions about age, civil status, patient diagnosis and length of time since diagnosis, description of the types of pain experienced/being

managed, and previous caregiving experiences are some examples of the type of information collected (see Appendix I).

Table 1: Interview Format and Rationale

Interview Format	Rationale	How interview data was analyzed
Family Caregiver Alone (Patient unable to participate or unwilling to)	<p>Advantages:</p> <ul style="list-style-type: none"> -Provide insight into what indicators the family caregivers using to monitor these unresponsive, non-communicative, or very feeble patients -Assessment and evaluation of pain interventions may vary when the patient cannot express the type, intensity or location of the pain or indicate if it has been relieved. <p>Disadvantages:</p> <ul style="list-style-type: none"> - Unable to assess patient's participation in pain management process or obtain patient viewpoint. 	Interview, field note data analyzed individually, since no patient data is available. Data compared to other data across cases
Family Caregiver and Patient (together)	<p>Advantages:</p> <ul style="list-style-type: none"> -Interaction between the two was observed. Similar interaction may be a part of the process of pain management. -The combined perception of both the patient and the family caregiver is helpful to gain an understanding of the pain management process -Respect preference of family caregiver/patient if they preferred being interviewed together <p>Disadvantages:</p> <ul style="list-style-type: none"> -Either participant may not have disclosed important information in consideration of the other's presence. For example, the patient may have hesitated to disclose an unsuccessful pain intervention done by the family caregiver, while the family caregiver may not have felt comfortable sharing the uncooperative nature of the patient. 	Interview and field note data analyzed as a unit
Family Caregiver and Patient (separately)	<p>Advantages:</p> <ul style="list-style-type: none"> -Respected preference of family caregiver/patient if they preferred being interviewed alone. -Participants may have been uninhibited in their conversations. <p>Disadvantages:</p> <ul style="list-style-type: none"> -Unable to obtain a combined perception of both the patient and the family caregiver. 	Interview and field note data analyzed as a unit, despite the interviews having been done separately.
Second Interview (one week after initial interview)	<ul style="list-style-type: none"> -To see how things evolved, if new thoughts emerged, if new strategies were tried and how these were evaluated. - allowed for a check of interpretation of data from the first interview. -provided an opportunity for patient and family caregiver to explain things they were unable to in the first interview and were asked to reflect upon until the second interaction. 	Interview and field note data was compared to interview data/field notes from Interview I and across cases.

Field Notes

Bernard (2002) notes that most field notes are descriptive and stem from watching and listening. Field notes were taken after each interview and included information on the environment, the interactions between family caregiver and patient, and facial expressions and non-verbal cues (See Appendix IV). A further purpose of field notes, in this study, was to provide the researcher with an opportunity to record self-reflections. Such self-reflection is critical in qualitative studies. Frank (1997) encourages the use of self-reflection to enrich studies by lending new insights and deeper understandings to the data collected. This documentation permitted the researcher the opportunity to review thoughts and ideas that may have been present during the interactions. While Strauss & Corbin (1998) recognize that it is not possible to be completely neutral as a researcher and therefore free of all biases, it is important to be aware if any exist and that they may influence our thinking. The field notes taken during this study served as a check and a way to continuously monitor if the researcher's thoughts and/or feelings were influencing the interactions or the analysis. These field notes also helped the researcher be aware on an ongoing basis of any preexisting values or biases that may have had the potential to influence either the data collection or its analysis.

Field notes were taken if possible by the researcher during the interview, however the majority of the field notes were written and completed immediately following the interview. They were reviewed and reflected upon within 24 hours after the interview. This was to prevent a long delay between the observations and field note preparation, which may have led to a greater risk of "losing or distorting data" (Polit & Beck, 2004).

Although participant observation is also often used by grounded theory researchers (Polit & Beck, 2004) it was not used in this study. Participant observation "involves getting close to people...so that you can observe and record information about their lives" (Bernard, 2002). In this study, the researcher had the unique opportunity to enter into the homes of palliative cancer patients and their families. However, she was not there for a long enough period of time to

directly observe as the family caregiver proceeded to assess, intervene or communicate with the patient regarding pain. Participant observation would have required longer periods of time spent in the home by the researcher which would have presented an additional burden on the patient and family caregiver. It was felt that the information that would be added via this method of data collection, while valuable, did not justify this added burden in this study. Furthermore, the requirement added by participant observation that the researcher be in the home for a significant amount of time at this difficult period may not have been acceptable to many patients and family caregivers, therefore interfering with the sampling process. It is for this reason that participant observation was not included as part of the data collection despite the fact that participant observation might have allowed for direct observation of the process that is used by the caregivers, which would have added further depth in describing the process of pain management. On the other hand, observations made during the interviews added an important dimension to the data, and were recorded in the field notes.

Data Analysis

Timing of Data Analysis

The data analysis was ongoing as the data was collected and continued afterwards. Comparative analysis or what is also called the constant comparative method is central to grounded theory. This means that data was constantly being compared to what had already been uncovered. This allowed the researcher to identify patterns and relationships between these patterns (Eaves, 2001). It also enabled the researcher to make decisions related to theoretical sampling and helped the continuous reviewing and revision of the interview guide (See Figure 1).

Unit of Analysis

There were a total of 24 cases analyzed for this study. Most family caregivers were interviewed alone (16/24). In these cases a constant comparison to data collected from other family caregivers was done. The family caregiver was asked to speculate as to what the patient might say regarding the success of her/his

interventions. For example, one family caregiver was asked if she thought her husband would agree that she was successful in her attempts at pain relief, and she said she “*thought*” he would (008:269). Only 1 patient and family caregiver were interviewed separately as was their choice. In cases where both interviews were done together and separately, if a family caregiver felt their pain assessments were accurate or if they described a particular intervention as being successful, the analysis of the patient interview added valuable information such as confirmation of information. There were also 7 patients and family caregivers that were interviewed together. In these cases, the patient and family caregiver data were analyzed together, as a unit. This means that they were coded as if it were one transcript. In these cases, the patient was asked during the interview to add their opinion regarding the information the family caregiver provided. For example, one family caregiver stated that “nothing worked” for her husband’s pain (005), and her husband agreed with this statement since he was also participating in the interview. Overall, a case was considered to be the family caregiver data, the patient data, and field note data pertaining to each family caregiver in this study (Ayres, Kavanaugh, & Knafl, 2003).

Substantive Coding

It is important to note that despite the existing differences in thinking between Glaser and Strauss & Corbin, there remain, however, important similarities in data analysis. They both suggest to: 1) label the data, and create categories, 2) find the relationships between categories, and 3) find core categories. The only difference is that Strauss & Corbin named ‘open coding’, ‘axial coding’, and ‘selective coding’ and Glaser did not. The analysis of this study was done using the verbatim transcripts from the audio-recorded interviews and the field notes. Strauss & Corbin’s coding framework was used to guide the coding for this study. Open coding, axial coding, and selective coding will be described as part of substantive coding.

Open Coding

Open coding is the analytic process through which concepts are identified and their properties and dimensions are discovered in the data (Strauss & Corbin, 1998, p. 101). The goal was to discover the largest number of concepts and categories possible. A concept is a “labeled phenomenon” or “an abstract representation of an event, object, or action/interaction” (Strauss & Corbin, 1998, p. 103). A category is a grouping of concepts that are similar that represent a phenomenon: that is a problem or issue, event, or a happening that is being defined as significant to the respondents (Strauss & Corbin 1998, p.124).

Open coding begins by coding for all possible categories that might fit and for all examples that will fit into these categories. This type of coding is critical because it allows the researcher to anticipate the direction in which the study is heading, and provides some guidelines for further (theoretical) sampling. Furthermore, the data were analyzed sentence by sentence so that each sentence was constantly being coded. Overall, open coding fractures the data and allows for the identification of categories, their properties, and dimensional locations (i.e. where, along a continuum, a property is located).

Axial coding

Axial coding is the process of relating categories to their subcategories, called “axial” due to the fact that the coding revolves around the axis of a category (p. 123). A subcategory answers questions about the phenomenon such as when, why, where, who, how, and with what consequences. Subcategories give categories further clarification and specification. This gives the concept more explanatory power (Strauss & Corbin 1998, p.101, 125). The main objective here is to establish relationships between the identified categories.

Strauss & Corbin (1990) define axial coding as a set of procedures whereby data are put back in new and different ways after open coding is done. They suggest a coding paradigm involving conditions, context, actions/interactional strategies and consequences. In other words, connections are made between a category and its subcategories. For this study then, axial coding

began by the specification of a particular category (e.g. pain assessment by a family caregiver) in terms of the conditions that give rise to it (e.g. patient saying he/she is in pain, or noting non-verbal cues). The context in which it is embedded or specific set of properties as well as the action/interactional strategies by which it is managed was also of importance. Finally, the consequences of these strategies were also coded. This was of particular relevance for examining pain management as it was anticipated that a process may emerge. It was these specifying features of a category that gave it precision and gave rise to the different subcategories (Strauss & Corbin, 1990, p. 97).

Selective Coding

The third level of analysis is selective coding and is the process of integrating categories and refining the theory (p. 143). Selective coding (Strauss & Corbin, 1990) is the last coding processes in grounded theory methodology and involve the selection of a core category. After open and axial coding, several key variables were identified. These variables were the ones that were selected for closer examination and were seen as most critical for the development of the theory. They were central to the phenomenon of study and occurred frequently in the data. Selective coding is when the researcher begins to limit the coding to only those variables that relate to the key variable in significant ways. Strauss & Corbin (1990) define it as systematically relating the main categories to other categories, validating those relationships, and filling in categories that need further refinement and development. These are considered the substantive codes. This analysis further led to a description of how the substantive codes related to each other as hypotheses. These were then examined which allowed for the development of the theory.

Memos

The “memoing of ideas” was also seen as an important part of the analysis for this study. Memos are a record of the researcher’s analysis, thoughts, interpretations, questions and directions for further data collection (Strauss & Corbin, 1998, p. 110). They are the theorizing and write-up of ideas about codes and their relationships that the researcher sees as important as the coding

progresses. Theoretical memos refer to the descriptions of important categories of the theory being generated and include their properties, dimensions, relationships to other categories, and their context (Strauss & Corbin, 1990).

Analysis of the Interviews and Categories that Emerged

The qualitative software NVIVO was used to help organize concepts (*free nodes*). These concepts were then analyzed and compared until a list of conceptual categories was created (Strauss & Corbin, 1990, pp. 61-74). The qualitative software was enlisted to help visualize the relationships between the categories and to create subcategories. The following section will demonstrate how the analysis was applied to this qualitative study.

Open coding

Open coding was done by assigning a code to anything that was relevant to the research questions. The purpose was to identify as many concepts and categories possible (Strauss and Corbin, 1998). Open coding resulted in 752 codes, for example: “Advil,” “be proactive,” “location of pain moves around,” and “patient agitated if pain not relieved” (Full list in Appendix V). These open codes were then examined for commonalities such as similar ideas or themes. These were then grouped together as a category which was comprised of codes that were linked together and all “shared common properties” (Strauss & Corbin, 1998, p. 103). For example, the codes of “looked at face for pain,” “held his back when in pain,” “laid there like a dead dog,” and “body language as a cue” were grouped together initially as ways family caregivers were assessing (e.g. what actions/cues they used) for pain. They formed the “axis” around which axial coding would then commence.

Axial coding

Patterns began to emerge as the analysis continued. The concepts were organized based on commonalities of conditions or context between them to form categories (sets). For example, the first research question addressed what family caregivers did and how they managed pain at home. This often involved

discussions about how they determined their family member was in pain. If family caregivers stated they assessed the patient's pain by looking at the patient, their description of what they did was coded "assessment by looking" (e.g. 001, 008, 012, 013, 015). Another area of interest was the types of pain they were managing. Some examples of such codes are "bedsore pain" (e.g. 003, 010, 020), "general pain" (e.g. 001) and "dull pain" (e.g. 13). These categories, or processes were called "sets" using the NVIVO software, and there were 33 that were developed (Appendix VI). Some examples are "family caregiver interventions," "family caregiver feelings," "communication," and "pain controlled." For example, sub-categories for "family caregiver interventions" were "pain medication" or "non-pharmacological interventions."

Strauss & Corbin (1990) define axial coding as a set of procedures whereby data are put back in new and different ways after open coding is done. This was done, as mentioned above, by making connections between categories. In other words, connections were then made between a category and its subcategories. For this study then, axial coding began by the specification of a particular category or process (e.g. pain assessment by a family caregiver) in terms of the conditions that give rise to it (e.g. patient saying he/she is in pain, or noting non-verbal cues). It was at this stage that diagrams of the relationships between categories and concepts was also used, and found to be extremely helpful (for examples, see Appendix VII). This permitted a visualization of relationships between categories and sub-categories (Strauss & Corbin, 1998), and allowed for connections, interactions, and patterns to be seen.

Memos were also critical in developing and refining the categories selected. This became particularly evident when axial coding was being done. An example is provided below for the category "using past experience with pain management".

The family caregiver has caregiving experience, both professionally and as a family member. She is a wife and is a nurse. She has strong assessment skills (asks, but relies on own assessment more). Actually looks at the TYPE of pain and matches the pain intervention to this. She experiments

with different strategies-very comfortable with medications and with using non-pharmacological strategies (eg. Positioning, hot bath....)

Also not afraid to seek help, can be “aggressive” about it if need be! (Is this because of her nursing background? Part of her personality?). She also has past experience caring for her mother who died IN pain and at home so she has prepared herself: (She says this past “bad” experience affects the way she cares for her husband). It seems to me that her experience as a nurse AND her past experience caring for a dying parent in pain and at home has given her “tools” and the experience necessary to “successfully” manage her husband’s pain (Interview 001, “Memos to myself”, May 2007).

A category stands for a phenomenon or process that is a problem or issue, event, or a happening that is being defined as significant to the respondents (Strauss & Corbin 1998, p.124). The “sets” or categories created were then analyzed and throughout the analysis, categories were compared. For example, when looking at the category of *“implementing a strategy for pain relief,”* it was noted that distraction was one of the non-pharmacological interventions employed. It was recognized that not all family caregivers used this strategy and when it was used, it was used in different situations and in different ways. As a result, the use of distraction was compared across cases. It was found that family caregivers used distraction under different conditions such as when medications failed or as complementary treatment, to avoid the use of medications, to relieve mild to moderate pain, or depending on the time of day. It was also found when compared across cases that distraction was influenced by different factors as well. For example, the availability of family members and friends played an important part in the ability of the family caregiver to be able to carry out some of their distraction strategies.

Selective coding

Selective coding is the process of integrating and refining the theory (Strauss & Corbin, 1998). Certain categories were selected for closer examination and were seen as the most critical for the development of this theory. First these will

be described in detail, and then their relationship to each other will be described. However, during the analysis the description of the categories and their relationship to each other were elaborated simultaneously. The main categories or processes identified were: **drawing on past experience with pain; accepting responsibility for pain management; establishing a pain management relationship; seeking information on pain management; determining the characteristics of pain; implementing a strategy for pain relief; verifying if pain relief strategies were successful; and gauging the best fit.** It is how they fit together as a theory that resulted in the final “puzzle of pain management” that was the final result of selective coding.

Analysis of field notes

The field notes were reviewed and analyzed to check for any patterns or themes that may relate to the data obtained from the interviews. Field notes were also used to help “visualize analytic points being made” as the categories were being created from the interview data (Strauss & Corbin, 1998, p.283). For example, when the category “establishing a pain management relationship” emerged, the field notes were reviewed to see if the behaviours recorded by observing the family caregivers and patients reflected the relationship that was being described and coded in the interview data.

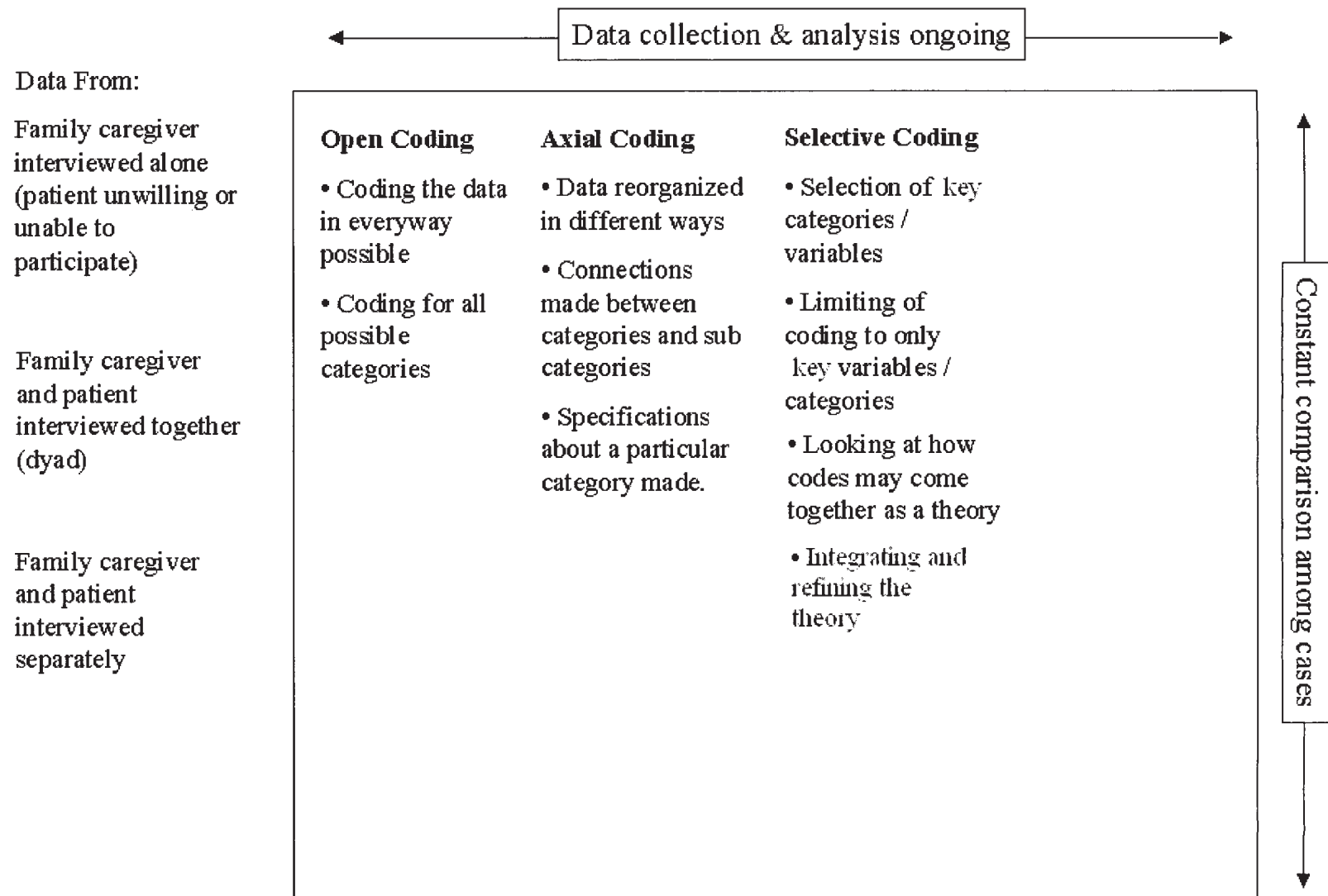


Figure 1: Data Analysis

Methodological Rigour

The terms reliability and validity used in quantitative research are not the same as those used in qualitative research. However, methodological rigour is of equal importance. In order to ensure that the present study met the criteria of rigour for a qualitative study, Sandelowski's (1986) suggested criteria of rigour for qualitative research were ensured: auditability; credibility; fittingness; and confirmability.

Auditability refers to the ability of another researcher to follow the methods and conclusions of the original researcher (Chiovitti & Piran, 2003). In other words, a clear decision trail concerning the study from beginning to end is needed (Sandelowski, 1986). In this study, this has been done by providing a clear description, explanation, or justification of purposes, methods, analysis, and conclusions. The progression of events are clearly articulated and the decision trail concerning the study (including sample selection and coding) are thoroughly documented and readily attainable. The field notes containing personal thoughts and feelings, as well as the memoing done also served to contribute to the dependability or transparency of the research process.

Credibility is how accurate and vivid the description provided is, and it contributes to the truth value and how believable the study findings are (Beck, 1993; Sandelowski, 1986). This means that the study will be credible if it presents "such faithful descriptions or interpretations of a human experience" (Sandelowski, 1986) that others with the same experiences will recognize it "as their own" (Chiovitti & Piran, 2003) after reading about it in the study. Family caregivers were asked to verify something that emerged from their previous interview, or as the study progressed some participants were asked to validate interpretation of the data collected to date. For example, in one instance the researcher asked a family caregiver if he also experienced the feeling of "flying blind" when it came to pain management, and the caregiver agreed that this statement echoed some of what the experience was like for him. Both auditability

and credibility lend to our ability to “trust” the study results, (Chiovitti & Pavin, 2003; Clarke, 1999) creating a study that is trustworthy in nature.

Glaser & Strauss (1967) allude to the fact that in grounded theory the credibility of the theory that is being developed is highly dependent on the constant comparison method, which was also used in this study. The emerging ideas and categories were continuously compared to each other and guided the ongoing research. They make the suggestion that as a result of this process, credibility is inherent to this method.

The “fittingness” of qualitative research findings refers to how applicable or “transferable” the findings are to other situations (Carnevale, 2002; Sandelowski 1986). Throughout the research process, and in the writing up of this study’s results, detailed and accurate descriptions of the situations and the contexts of each interview were written, and the participant’s own words were used such that others reading this work would be able to feel a resonance with their own experiences.

Another way to ensure methodological rigour in qualitative research is by triangulation (Mays & Pope, 1995). This is a suggested way to ensure credibility and fittingness as it attempts to see if the data collected is congruent across the data sources used in the study (Sandelowski, 1986). Interviews and the observations noted in the field notes provided different methods of studying the phenomenon (methodological triangulation). A further manner of achieving both credibility and fittingness is to “obtain validation from the subjects themselves” (Sandelowski, 1986, p. 35). The second interviews often served the purpose of validating emerging ideas, themes, and categories.

Neutrality refers to “the freedom from bias in the research process and product” (Sandelowski, 1986, p.33). Confirmability is the suggested criterion of neutrality and is achieved when auditability, truth value, and applicability (through fittingness) has been established (Sandelowski, 1986, p. 33). It is evident that grounded theory research “inevitably involves interaction between the researcher and the world [being studied]” (Cutcliffe, 2000, p. 1479). While it was acknowledged that it was impossible to conduct this research without having

some personal thoughts, feelings, and beliefs that would color data collection, analysis, and interpretations, every attempt was made to remain aware of this possibility. The field notes taken were key to this awareness.

The field notes that were written immediately after each interview included the researcher's personal experiences, thoughts, feelings, or beliefs as influenced by the study. It involved the researcher making a conscious effort to understand and integrate these into the study (Lamb & Huttlinger, 1989). This process prompted the researcher to be aware of her own preconceptions, beliefs and values throughout the research process. This contributed to the scientific rigour of this grounded theory, and hopefully to the accuracy in the identification of [social] processes identified (Cutcliffe, 2000).

The researcher's supervisor, Dr. Robin Cohen, read all transcripts on an ongoing basis during the analysis. This was an important means of "cross checking the coding strategies and interpretation of data by independent researchers" (Barbour, 2001). Regular meetings were held between the researcher and her supervisor to discuss discrepancies in understanding and coding that may have occurred, and new directions to be followed based on the data. This process is extremely useful so that different eyes look at the data and at the emergent "coding frameworks" (Barbour, 2001). The student's thesis committee was also consulted to keep them abreast of the study's progress and the themes, categories and preliminary findings that were emerging, and the committee members helped to guide the theoretical sampling and changes to the interview guide. This is also known as peer debriefing and contributes to the trustworthiness of the study (Ingleton & Seymour, 2001).

Furthermore, one of the main advantages of audio-taping is that the tapes offered an opportunity for subsequent analysis by both the primary researcher and the others involved in the study (Mays & Pope, 1995). As previously mentioned, the ongoing external examination of data by the supervisor, and ongoing dialogue with the thesis committee, helped to ensure that the selection and interpretation of themes emerging from the data collected were grounded in the data. This enhanced credibility.

Ethical Considerations

Approval was obtained from the Research Ethics Board at the S.M.B.D. Jewish General Hospital, and this approval along with review for context- and population-specific ethical issues was accepted by the other organizations where participants were also recruited (NOVA West Island and Montreal), which did not have their own Research Ethics Boards (See Appendices VIII and IX). Written informed consent was obtained from all participants. Family caregivers and patients who were interviewed were told they were able to receive a copy of the study results if they wished, however there have not been any such requests. Palliative patients are a vulnerable population, experiencing pain, fatigue and other distressing symptoms. At times, family caregivers may object to participating in research if they feel it taxes them or takes away from their spending time with the patient (Addington-Hall, 2002; Jubb, 2002). Sensitivity to these issues was always considered before they were asked to participate and re-evaluated on an ongoing basis both during and between interviews. Each case was assessed individually and often to observe for any undue burden or stress placed on either the family caregiver or the patient. If they appeared burdened during the course of the study, they were reminded that they were free to withdraw from the study at any time, free of consequences (Tri-Council Policy Statement, 2002). It has been shown however, that some family caregivers benefit from the research experience and enjoy their interactions with researchers (Hudson, 2003).

The introduction of the researcher as a nursing student may have influenced the expectations of the patients and their family caregivers. On occasion, they did ask for advice or support during the interactions, which was considered inappropriate for the researcher to provide. It is for this reason that the term “researcher” was used instead of “nurse researcher.” The understanding is that the role of the researcher should not be clouded with that of a nurse, and that the information received was to be kept confidential in light of that responsibility. If it was observed that the patient or family caregiver was in need of clinical support, it was suggested they contact their homecare nurse or physician. This occurred in two instances. If the case would have arisen where they did not have

such support, the researcher was prepared with a list of contact numbers that could be provided.

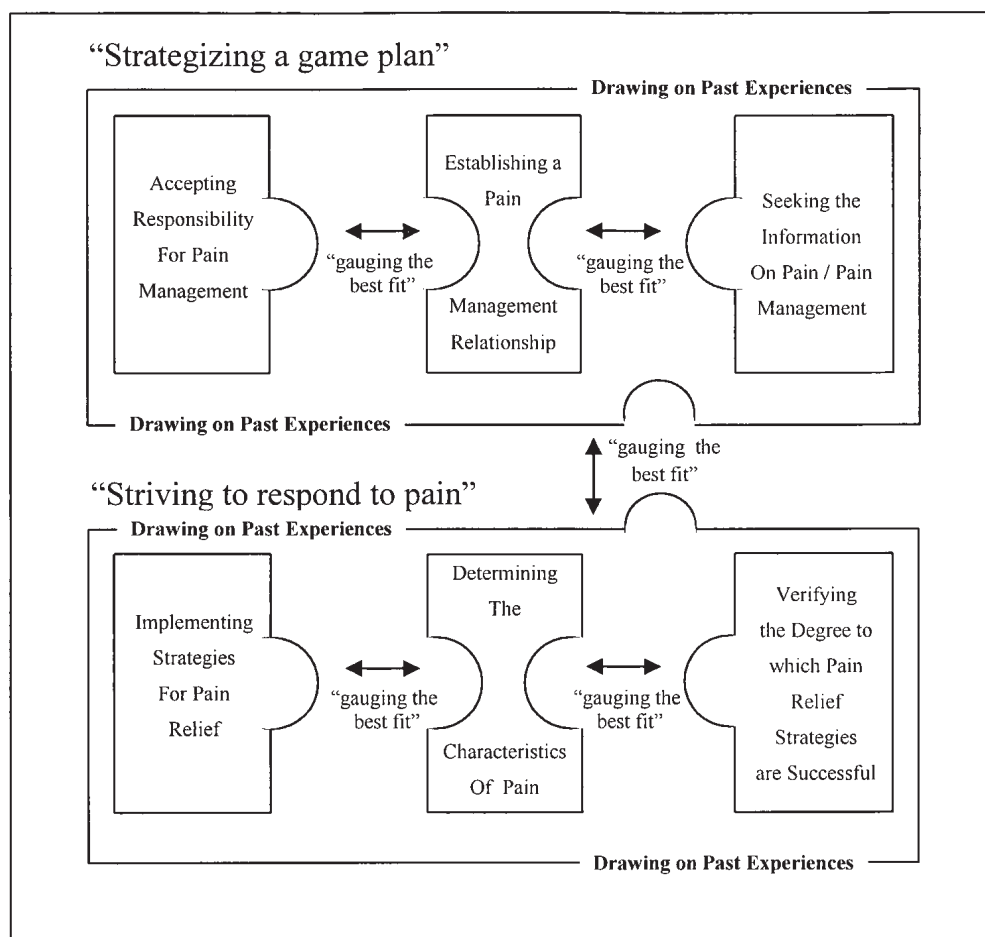
A master list was generated with participant names and study ID numbers. This information, the transcripts, and all data collected is kept safe in a locked cabinet in a locked office, with only the researchers having access to them, and all information remains confidential. There is no identifying information on either the interview tapes or the transcripts. For the single interview where the individual family caregiver and patient were interviewed separately, confidentiality was ensured and no information regarding the contents of the family caregiver interview was disclosed to the patient and vice versa. For five years after the completion of the study, the data will be stored in Dr. Cohen's locked office in a locked cabinet. After publication or these five years (whichever is later), the data will be destroyed.

RESULTS

The first section of this chapter describes the family caregivers and the palliative cancer patients they were caring for that comprised the study sample. The second part of this chapter presents the results of the analysis of the interviews conducted, transcribed, and coded. It begins with the core category **“chasing the pain”** and explains its selection. The major processes (categories) and their properties and dimensions are then presented. The core category and the main processes were labeled using the words of the family caregivers to capture the true essence of the experiences and processes they were describing. The analogy of a puzzle (an idea borrowed from Melzack (1973) who used it to describe pain), is used to explain the complex relationship between the core category and the processes of pain management. A model using the metaphor of a puzzle is proposed to capture the process elements necessary to assemble the **“puzzle of pain management”** (Figure 2.).

Four main processes emerged to form the **“puzzle of pain management”**: 1) a frame (or border) that is formed by the process of **“drawing on past experiences”** which provides the context within which the family caregivers assemble their individual puzzle pieces; 2) puzzle pieces which together represent the process **“strategizing a game plan”** which included the sub-processes of **“accepting responsibility”**, **“establishing a pain management relationship”**, and **“seeking the information”**; 3) puzzle pieces which together represent the process **“striving to respond to pain”** which included the sub-processes of **“determining the characteristics of pain”**, **“implementing a strategy for pain relief”**, and **“verifying if pain relief strategies were successful;”** and 4) **“gauging the best fit”**, a decision-making process that represents the joining of two pieces of the puzzle and determines how it fits with the other pieces.

**Figure 2: The Puzzle of Pain Management:
The Pain Management Process at Home by Family Caregivers**



The last part of the chapter presents the analysis of the relationships between the identified processes as pieces are joined when family caregivers “gauge the best fit” for their process puzzle pieces. The theory proposed describes the process pieces “strategizing a game plan” and “striving to respond to the pain” and the critical joining of these two pieces in order for family caregivers to “assemble” a process of pain management that explains family caregivers’ perceptions of how they manage the pain of palliative cancer patients at home.

Study Sample

There were a total of 24 family caregivers interviewed for this study. Demographic details are given in Table 2. The mean age was 69, with a range

from 25 years to 90 years. Sixteen family caregivers were women. Of the total number of family caregivers, 16 were spouses of the patient. The mean length of family caregiving experience was 2.2 years, with a range from 2 weeks to 20 years. There were 8 patients who were interviewed. The patient mean age was 69.8, with a range from 52 years to 89 years. These patients had differing cancer diagnoses. There were participants from a variety of different ethnic backgrounds.

Seventeen of 24 caregivers and 6/8 patients were interviewed twice with a mean of 7.8 days apart, 7 interviews were done only once for different reasons. Four family caregivers did not meet a second time because the patient was sicker or admitted to the hospital. In one case the researcher felt during the interview that the family caregiver was highly distressed, so to prevent the risk of adding further distress,¹ there was no second interview scheduled. In another case the patient and family caregiver opted out of participating since the patient was beginning chemotherapy and was anticipating side effects including weakness. There was also one case where the patient died and one where the family caregiver had to return home to another province.

Patient Results

It is important to note that the decision to include patients in the study was based on the fact that a future goal is to utilize the results of this grounded theory to help create and implement pain management interventions for family caregivers of palliative cancer patients at home. The patient data was NOT collected to inform the development of the theory itself, but rather its future use. In the end, all patients agreed with the family caregiver description of their pain management and the success of their strategies.

¹This family caregiver was overwhelmed, felt he would die when his wife did, and cried often throughout the interview. He also felt that spending time with healthcare professionals was time they could/should be spending with his wife, and time he could be spending with her. The physician caring for his wife was informed (with the family caregiver's consent) about his high level of distress and his concerns in order to follow-up with him.

The Study Participants

Table 2: Sample Characteristics

FAMILY CAREGIVERS

Mean Age (range)	69.0 yrs (25-90)
Mean length of caregiving experience (range)	2.2 yrs (2 weeks-20 years)
Median length of caregiving experience	1 year
Gender (male/female)	8/16
Relationship to patient	
Wife	10
Husband	6
Daughter	4
Son	1
Brother	1
Sister in-law	1
Niece	1
Self-described ethnic background of family caregiver	
Jewish	4
“WASP”	4
Scottish	3
French-Canadian	2
Italian	2
Egyptian	2
British	2
Irish	2
Portuguese	1
French	1
“European”	1
Family caregivers who were health professionals	3

PATIENTS BEING CARED FOR

Mean age (range)	69.8 yrs (52-89)
Type of cancer	
Pancreatic	4
Breast	4
Prostate	3
Colon	2
Lung	2
Other (only 1 of each type)	9
Gender (male/female)	12/12

Core Category: “Chasing the Pain”

The core category identified was “**chasing the pain.**” In essence, it is “what the research is all about” (Strauss & Corbin, 1998). It also fulfilled Strauss and Corbin’s (1998) other criteria for a core category in that: it occurred frequently in the data; the explanation that emerged by relating the core category to the other categories was logical; the name or phrase selected was sufficiently abstract; it was able to explain variation in the data; and the thorough analysis of this core concept permitted the theory to grow in depth and explanatory power (p. 147).

The core category “chasing the pain” is related to each of the main processes and the sub-processes identified as they all capture some element of the family caregiver responding to pain in the patient with attempts to “chase” it away. These responses to pain lead the family caregiver to different interactions with the pain. This core category was seen frequently throughout the data, and in every interview the family caregiver was chasing the pain in some manner.

Pieces of the Pain Management Puzzle

All family caregivers interviewed described a pain management process, although not all used all the processes and sub-processes in the same manner. Categories are concepts that stand for phenomena or processes (Strauss & Corbin, 1998, p. 114, 123). Evidence of family caregiver experiences as related to the categories will be described with some of their properties and dimensions. *Properties* are the general or specific characteristics or attributes of a category while *dimensions* represent the location of a property along a continuum range (Strauss & Corbin, 1998, p. 117).

The next section of the results begins with a discussion of the frame of the pain management puzzle: “drawing on past experiences with pain management.” This is followed by presentation of the process pieces of “strategizing a game plan” and “striving to respond to pain.” Finally, the important process of “gauging the best fit” is presented as the critical process occurring as the other process pieces are being put together by the family caregivers.

The Frame: Drawing on Past Experiences

Properties and Dimensions

Family caregivers who had past experiences working with pain, or with pain medications used for other purposes, tended to draw on these experiences to help shape their pain management regimen. There were four different properties of past experiences that will be described below. These were generalized experiences with pain, past experiences as health professionals, past experiences caring for others with pain, and pain as part of their own lives. The dimension for all of these ranged from none to many past experiences under each characteristic.

Generalized experiences with cancer, pain, and/or pain management

Many family caregivers had had some previous exposure or experience with either knowing someone who had cancer (e.g. 009), cancer pain (e.g. 014), other pain (e.g. 003), taking pain medication (e.g. 003) or knowing someone who took pain medication (e.g. 017). These experiences all had some effect on the shape of the pieces of the pain management process for each family caregiver. For example, family caregivers who knew others who had abused pain medication or had seen the patient react badly to pain medications were fearful of repeating past experiences, and maintained minimal involvement in actually giving pain medication (017), or monitored the dose and reactions closely (008). These more general experiences in some cases explained family caregiver concerns about pain medications, and also provided information for them to which they could compare their present situations.

Past experiences as health professionals

Some family caregivers were able to draw on their past experiences as health professionals in dealing with pain. Some caregivers were retired nurses and used their “*experience that [they] had in nursing*” (001: 139-141) and knowledge “*from work*” to help manage the patients’ pain (013: 161)². Another family caregiver said that her training as a nurse’s aide and her past work experience

² All quotes are referenced by the transcript number and the lines that describe the concept.

helped her prepare for the responsibility of managing her mother's pain. She said the following:

"...I'm very fortunate to have taken the courses that I've taken because it's prepared me probably better than somebody who had never taken those types of courses. It's given me that extra, you know what to expect. You learn to look for the things that... a family member who hasn't had any kind of experience wouldn't look for. I think that's...where I'm very fortunate because I have that background...So...I feel safe when I make decisions (010: 230-237)."

Across cases, these family caregivers drew on information and experiences they had in their professional lives to help structure the way they handled pain as a family caregiver. Their professional experiences gave them confidence, sources of information, and a sense of preparedness managing pain

Previous experiences caring for others

Several family caregivers were not new to the caregiving experience and had dealt with pain before. For example, one family caregiver's previous experience caring for a family member helped her make the link between good pain control and a good quality of life:

"...I took care of my mother-in-law; I took care of my aunt. My aunt was in pain like you wouldn't believe because three months before she died she signed a release of having no more medicine. So she was in very strong pain, very strong pain and I couldn't do anything for her because she refused all kinds of medicine... She said: "I have no more quality of life, I wanna go"...I took care of a lot of people that had pain in their life (015: 269-280)."

Another couple felt they didn't need any more information on pain or pain control because both their children had had cancer, and so they had *"been through this twice before (011: 232)."*

Past experiences caring for others in pain contributed in different ways to how family caregivers now dealt with or perceived pain management. Across cases, such past experiences explained the relationship the family caregiver had with the patient, the reasons pain management was critical (e.g. impact on quality of life: 011), and the information and expectations they had in relation to pain management.

Pain as part of their own lives

Family caregivers who had managed their own pain were able to articulate empathy about the importance of pain control and borrowed pain management strategies from these experiences. For example, one family caregiver said her pain created an understanding of the patient's pain experience, and helped her determine what interventions (e.g. distraction) she could use:

"Because I've dealt with pain all my life myself...I sort of sympathize with her and my goal is to keep her out of pain because I can't handle it sometimes and I don't want her to handle it... If I'm in bad pain, I'd be doing something so I'm not thinking totally of what's happening unless it's really bad... She's really into her stories... I ask her to spell...the words keep her [distracted]... (003:265-50-52, 592-593)."

Personal experiences with pain and pain management helped explain the selection of some interventions and the family caregiver's feelings toward the patient.

In sum, past experiences are important factors in pain management regimens. They shape the way family caregivers may understand pain, the way they treat pain, and what they know about pain. The experiences may be of a personal nature: either their own or with family members. For some, past experiences in the health field also contributed to family caregiver knowledge and comfort level with pain control. Overall, drawing on past experiences sets the context for the pain management process. When the complete pain management puzzle is assembled, it is the past experiences that family caregivers have that provide the backdrop with which each process piece has an important relationship. These relationships help illustrate the interaction between the processes of "drawing on past experiences with pain management" and the other processes.

"Strategizing a Game Plan"

The sub-processes that make up the process of "strategizing a game plan" are as follows: 1) "accepting responsibility for pain management"; 2) "establishing a pain management relationship"; and 3) "seeking information on pain and pain management." **Accepting the responsibility for pain management**

is the first critical process that family caregivers must engage in, and therefore becomes the first piece of the pain management puzzle. Then, and in no particular order, are the sub-processes of **“establishing a pain management relationship”** with both the patient and the healthcare team, and **“seeking information on pain and pain management.”**

Once family caregivers are faced with the knowledge that they will be the ones responsible for the care of their family member at home, they engage in several processes. An important part of their responsibility includes the management of the patient’s pain, and the process of “strategizing a game plan” includes the above mentioned sub-processes that are critical for the development of a pain management routine.

It is important to note that while all these sub-processes contribute to a family caregiver’s preparation for pain management at home, the process of “strategizing a game plan” does not necessarily have to precede the process of “striving to respond to pain.” As indicated in the diagram of the puzzle, either process piece may be assembled first by the fitting together of the relevant sub-processes. The separate pieces may also be assembled simultaneously before the final assembly of the puzzle. The following example illustrates this point:

“...we could have used more [information] when the medications were given to us because we...ask a lot of questions...And even now I don’t understand completely why some things only work for certain period of time and why they change. And like the Decadron, why the switch, why upping with like...I still have questions yes...[mainly related to medication](020:276-280, 283).”

In the above example, the family caregiver was still “strategizing a game plan” (e.g. seeking information) while engaging in the sub-process of “striving to respond to pain” (e.g. giving pain medications). In this case, she was involved with different sub-process pieces belonging to both the “strategizing a game plan.” and “striving to respond to pain” at the same time as she was assembling her pain management puzzle.

Accepting responsibility: the first essential piece

Properties and Dimensions.

Level of Responsibility

An important property of accepting responsibility for pain management was the level of responsibility that pain management entailed. All family caregivers described having to come to terms with the fact they were now responsible for the comfort of their family member. Their level of responsibility (dimension) ranged from: *“It’s a 24/7 job”*, to *“I’m not too involved, I just observe.”*

Some family caregivers did not have a large responsibility for pain management at the time of the interviews (e.g. 009, 017). Others felt a tremendous level of responsibility:

“And I had to call to make sure that she got her pain killer; her hydromorphone 24 mg at 9:00 pm. If I didn’t call, she wouldn’t have got it. ...So that’s a big problem for me... that’s a stress that I can’t rely on anyone fully (014:297-301).”

This family caregiver felt that pain management was still her responsibility even when she wasn’t there. One wife stated that being *“on call 24 hours a day”* was at times *“frustrating, (001: 160)”* and that she gets mad when her husband says: *“You don’t have to do it...You’re not obliged to do it” (001: 161)*. Her statement demonstrates that pain management is an ongoing job and that she accepted the responsibility.

Attitude towards Responsibility

Another property was the family caregiver’s attitude towards accepting such responsibility where the range in dimension was from: *“I’m choosing to do this”* to *“It’s like prison.”* One family caregiver commented that *“the obstacle is my freedom, it’s gone for now”* but *“...I’m sticking to it. I made a promise I wouldn’t send her to the hospital (003: 214, 35-36).”* She felt she had to be present at all times and she used prison as a metaphor for her situation. Despite this view, she was determined to be successful at pain management to prevent a hospitalization due to pain (003: 088).

When comparing across cases, family caregivers who were caring for patients with greater pain concerns felt that their involvement with pain control was around the clock. For those who were less involved, there were two main reasons. In some cases, the patient's pain was well controlled during the time of the interview. In others, it was because they did not live with the patient or lived out of town and therefore were not always present enough to take on a greater responsibility for pain management. Furthermore, those family caregivers who felt they were freely choosing to care for the patients often described very close relationships prior to the onset of illness and the accompanying concerns: "... *because we've always been such a close family that watching her suffer bothers me (010: 132-133).*" For the few that described feeling at times constrained, it was often related to other specific circumstances, such as moving from a previous caregiving situation straight into the present one, or having active lives prior to accepting this responsibility and feeling limited in what they could do: "*Because really it's a 24/7 job...I can't work. I started and I couldn't do it. It was impossible (014: 244-246).*"

In sum, despite the limitations the responsibility for pain management may have placed on the family caregivers, they all acknowledged that their ongoing support and presence was essential for the patient's successful pain control. The amount of responsibility and their attitude towards it was critical in how family caregivers developed relationships with the patients and with the healthcare team.

Establishing a pain management relationship with the Patient

Family caregivers described establishing relationships specific to pain management both with the patients they were caring for and with the healthcare team. These relationships were identified as part of the pain management process the family caregivers engaged in.

Properties and Dimensions

Nature of the relationship

The nature of the relationship between the caregiver and the patient was an important property that determined the establishment of a pain management relationship between them. Family caregivers discussed how their relationships either stayed the same or had changed.

Although the family caregivers were not questioned specifically on their pre-diagnosis relationships with the patients, there were some family caregivers who explained their present relationship with the patient in light of their previous relationship. When asked if the responsibility of pain management affected their relationships with the patients, many family caregivers felt there was no change (e.g. 009, 010, 011, 012, 013, 018). For example, one family caregiver felt that he and his wife were still as intimately connected as before her diagnosis and subsequent pain concerns. Despite her sleeping in a specialized hospital bed, he said: *“And I sleep in our bed and we hold hands... We’re still connected. Very strongly (022:44-47).”*

Maintaining or building on an existing strong relationship made it easier for patients to trust in the family caregiver when they assumed the responsibility of pain control. This permitted accurate pain assessments by the family caregivers since these patients had no hesitations in reporting their pain, and had faith in the family caregiver’s ability to treat it. If family caregivers and patients had close relationships prior to the patient’s cancer diagnosis, it was seen during pain management. They drew on the strengths of their existing relationships and incorporated them into the pain management regimen. In fact, one family caregiver summarized this point nicely when he mentioned that after fifty years of marriage, there is nothing that has to be changed (004).

There were also family caregivers who felt that their relationship changed by becoming stronger. Some felt that becoming responsible for pain management brought them closer to their family member (e.g. 019, 021). For example, the

pain management experience, dealing with a cancer diagnosis, and the realization of an impending death *“brought [them] a lot closer together (017: 156-157).”*

In comparing across cases, it was seen that the creation of pain management relationships was done collaboratively with the patients by those family caregivers who were caring for patients who wished to maintain their independence or whose independence they wished to encourage (e.g. 003, 009, 016, 017). In some of these cases the family caregiver felt the need to set limitations with the patient on their involvement so that they did not take control away from the patients who wished to remain as independent as possible (e.g. 009, 018). There were also some family caregivers in this study who assumed total responsibility for pain management, rendering the patients dependent on them in the pain management relationship that they established:

“If I’m not to be there, he wouldn’t take the pill. He would not. He wouldn’t...even remember that. He depends on me....And... I look after his welfare in the house and everything else (006: 437-439).”

In turn, the patient’s dependency on them meant that family caregivers acknowledged that the patient’s successful pain relief is ultimately up to them: *“I have to be here. I cannot depend on someone else (023:42).”* This patient dependency on the family caregiver and the corresponding acceptance of the role of the one who brings pain relief created a changed relationship (e.g. because of dependency) that is part of the pain management process.

In a few cases, the pain management relationship involved a reversal of roles. There were adult children or nieces caring for a parent who had assumed roles and responsibilities that are consistent with parental ones, comforting the family members who had previously comforted them. (e.g. 003, 019, 020). In response to the question about how pain management altered her relationship with the patient, one family caregiver said: *“It’s an interesting place to be because I’ve been the daughter. It’s usually my mommy who would always take care of me when I was sick (019: 359-361).”* There were also several influencing factors that affected the establishment of the pain management relationship the family caregiver developed with the patient. These factors were: 1) the availability of the

family caregiver (“... *thank God I’m able to do it. I happen to have jobs that are very flexible (014:237-238);*” and 2) the passage of time, improving familiarity (“*You see that I’ve been with her for six years. I pretty well know all the aspects of her pain and what she’s going through (007:538-540).*”).

In summary, the pain management relationship the family caregiver established with the patient was done in the context of past experiences, and the existing relationship they had. Family caregivers felt that their relationships had either remained the same, or had strengthened. None felt their relationships had deteriorated. The relationships they held during the course of this study were “pain management” relationships because they were impacted by the responsibility of pain management. Over time, changes in the patient’s pain, how it is managed, and the family caregiver’s role may also change. This may result in changes in the relationship between the family caregiver and the patient.

Establishing a pain management relationship with the healthcare team

Properties and dimensions

Efforts of family caregivers

The amount of effort a family caregiver invested in trying to establish a relationship with the healthcare team was seen as important to the process of actually creating a relationship with its members. Some caregivers described themselves as proactive, while others didn’t make an effort to develop or strengthen the relationship with the patient’s doctors and nurses. For example, one daughter said:

“I’m much more proactive with ...the nurses that come and the doctors. I’ve gotten involved with everything because I felt disconnected for a while from it. I knew she was in pain and I was frustrated to not be able to do anything. But once you have as many answers as you can get, and you know and you understand what’s going on, it makes it easier too (020: 146-151).”

Despite the challenge in establishing a comfortable relationship with the healthcare team, she made the effort and as a result felt more comfortable with how her mother’s pain was being managed. Another family caregiver felt the healthcare team was not very available to her or her husband: “... *the medical*

community only exists from Monday to Friday from 9 AM to 5 PM. And it's [patient's pain] just not that way (012: 290-294)." She felt she needed to be active in trying to establish a relationship with the healthcare team. She said she did this by meeting with them regularly, keeping meticulous records of her husband's pain and medications, and keeping herself informed:

"...so that from day one I ask all the questions that need to be asked. I deal with all the doctors. I'm very informed. In terms of what changed with me, the pain, I've always tried to seek some kind of solution (012: 62-64)."

This resulted in the creation of a relationship with the team in which they realized and recognized her contribution to the patient's care, valued her assessments, and kept her involved (012).

It is important to note that all the family caregivers in the study were already receiving support in various forms from palliative care services (NOVA Montréal or the Supportive Care Team of the Jewish General Hospital), or both, at the time of the study. Since a relationship already existed by virtue of this fact, the efforts made to establish a relationship referred to their efforts to create a trusting and secure relationship with the team. For example, one family caregiver described the homecare nurses as her "friends." She described an honest and open relationship with the healthcare professionals. *"I don't hide anything from ...the nurse... So it has to be an open book, otherwise, there's no use. We can't lie... (015: 262-264)."*

Some family caregivers did not focus on trying to establish a relationship with the healthcare team. It was felt that such attempts might disturb the team members (*"... I can't always disturb the team (024: 63-64)"* or *"[I] cannot depend on someone else (023: 242-243)"*), that such a relationship was not needed because the family caregiver was managing sufficiently well, or that they could not trust the care that would be provided. Across cases, those family caregivers that did not make an effort to strengthen the relationship described themselves as more independent or "hands on" (e.g. 002, 012) in the care and in their pain control efforts.

Perception of the healthcare team's availability

The perception a family caregiver holds of the healthcare team was another important property of establishing a pain management relationship. Some family caregivers saw their professional caregivers as never available while others felt they were “always available.” Availability in these cases meant accessible for help, support, or advice. For example, some family caregivers felt the healthcare team was “*close minded (002)*” or “*mean (004)*” and not easily accessible. Some caregivers thus felt no need or desire to establish a relationship with the healthcare team, and explored treatment options elsewhere (e.g. 002) or lacked information (e.g. 004). In other instances it meant the family caregiver made a greater effort to establish a relationship with them, in others it led to the family caregiver not wishing to invest in a relationship with them at all.

In contrast, there were family caregivers who felt the healthcare professionals were accessible to them. The following caregiver described the comfort she felt knowing the physician was available to her:

“And we can go there anytime...that’s a relaxing good feeling because Dr. W always says: “Anytime”, he said, “Give me a call”. And you call and he says: “I’ll be available. I’ll be there for you (013: 193-196)”.

The fact that she saw the doctor as being available to her meant that she could establish a secure relationship with him, and call him with questions about her husband’s pain without hesitancy. In this case, the pain management relationship was established knowing she had someone available with whom to establish that relationship. Similarly, family caregivers who felt their team was available and accessible to them had relationships with the healthcare professionals characterized by trust and security (e.g. 010, 015). Overall, the availability of the healthcare team and the efforts family caregivers invested were important elements in the process of establishing a pain management relationship with the healthcare team.

Seeking Information on Pain and Pain Management

Properties and Dimensions

Helpfulness of the information

An important property of collecting information was the helpfulness of the information collected. Family caregivers determined whether the information was helpful or not helpful. Family caregivers used the information they obtained to set up a pain management regimen of their own as they cared for their family members at home. For example, one family caregiver mentioned how she found the information she wanted from books and that she found it helpful:

“...I have a drug compendium...so we’ve read up on all the medications and we know what to do with them. And we have them all tabbed and at easy access so that we know all the signs of overdose or whatever... I don’t want her to be taking too much breakthrough pain management because her mouth is very dry... And it’s, as time as progressed, it’s easier because I know the properties of the drugs and what they’re actually doing and how she’s reacting to them (019:218-228).”

This shows that she feels sufficiently knowledgeable not only to give the prescribed medications but to adjust the frequency of the breakthrough medications.

There were also family caregivers who felt that information received from health professionals or found independently was not helpful. For example, partial information was often given, and not appreciated by family caregivers. This was typically around teaching done about pain medication. Often a brief description was given as to what the medications were for, but no explanation about the side effects:

“So there are things that perhaps you should be told and will happen a lot. For example, if you’re on a medication that can cause side effects, they don’t tell you the side effects because the side effects do not necessarily occur in every person. And then when the side effects do occur, what are you supposed to do? You don’t know about it (012: 92-97).”

Similarly, others mentioned they knew the purpose of the medications, but did not have information on how they were supposed to alter the doses depending on the level of the patient’s pain (e.g. 019, 020). Receiving partial or incomplete

information left family caregivers feeling “helpless” (002) or “inadequate” (005) when faced with the responsibility of pain control for their family member. When comparing across cases, it was seen that all family caregivers had information needs. It was the type, sources, reasons, how collected, and the timing related to the collecting of the information that differed.

Type of information needed

Many family caregivers in this study stated that the information they needed the most was related to the side effects of the pain medications (e.g. 008, 019). They also felt they required information on the nature of the pain. In particular they needed to know the course of the pain (e.g. 002, 019), and their course of action should the patient’s pain worsen and to control it become increasingly difficult (e.g. 012, 024). Finally, they wanted information on what to do in an urgent pain crisis (e.g. 010, 017, 018).

Of interest is the fact that family caregivers mentioned they needed more information and support, and they needed it earlier on in their experience as caregivers responsible for pain control (e.g. 009, 012, 018). In comparing across the cases, all family caregivers stated they wanted more information on pain and pain medications, and all the male caregivers, as well as a couple of female family caregivers (e.g. 012, 019), also expressed a desire to have had more information on what to expect from the cancer and what types of pain would result.

Sources of information

Family caregivers sought and received information from a variety of different sources. Examples of such sources are family members and friends (e.g. 006, 012, 016, 017), the internet, books (e.g. 003, 012, 019), and health professionals (e.g. 002, 008, 015). For example, the internet proved to be a popular source of information for many of the family caregivers in this study. It was cited by several of them as a valuable tool in their search for knowledge about the pain experience (e.g. 002, 008, 015, 018). Of interest to note was that this was the case regardless of age, as a 90 year old caregiver talked about the vital role the internet played for him as he tried to understand his wife’s illness

and associated pain (005). One family caregiver mentioned that: *“the only information [she] got was from the internet (019:121).”*

Some family caregivers used more than one source of information to gather the information they needed. One said the following when asked about where she got her information on pain medications and on the type of pain her husband was experiencing:

“Well, it’s a multilevel question...I do...read up. That’s number 1. Number 2, one of my sons is a doctor. So that helps me a lot. And number 3 when I speak to doctors here or nurses or anybody in one of the professions here, I try to prepare in advance the questions that I’m going to ask (012: 82-85).”

In one case the family caregiver chose to use alcohol in an attempt to relieve her husband’s neuropathic jaw pain, yet when asked what the source of information was for her, the family caregiver replied: *“Nowhere. I just know that alcohol...when you keep it in your mouth it...freezes up (006:161-164).”* She was unable to explain where she had obtained the information.

In looking across all the data, it was found that family caregivers had different ways they could collect information on pain and pain management, and at times would need to rely on more than one source of information. The analysis revealed that this was a result of the fact that there was not always a consistent or readily available source of information for the family caregivers (e.g. 002, 005).

Reasons for seeking the information

The main reasons family caregivers were intent on having information were so that they could better understand the pain experience (*“... to make sure [they] fully understand (020: 202-207)”* and so that they could know *“what...to expect... when maybe something wrong will come. I don’t know when but I am aware of that [it will happen] (023: 68-71).”*

Information and a better understanding seemed to allow the family caregivers more freedom in their pain management regimen that stemmed from being confident and at ease with making decisions related to pain control. For example, one daughter caring for her mother mentioned her feelings about being adequately informed:

“I think it’s important to understand fully what all the medications that the patient is being given are for so that you understand the behaviour that you see, that you might not otherwise understand... We’ve been told we can adjust it a little bit. So in somebody starting out you need to sort of understand medication (020: 342-344, 348-350).”

This caregiver was comfortable changing the doses of the patient’s medication if she felt the need to. Another mentioned that the more information she had, the higher her level of comfort was with being responsible for pain management (012: 75-76). Overall, family caregivers had different reasons for gathering their information about pain, but the ultimate goal was optimal pain control.

How the information is sought and sorted

In the above discussion on “sources of information,” it is clear that family caregivers are able to find information on pain and pain control from a range of different places. How they proceed to gather the information from these sources is also of interest. Many said that it was a matter of asking health care providers many questions and asking them persistently. The following example shows one family caregiver’s actions to collect information as well as her motivations:

“By asking an awful lot of questions... if someone said something that I would talk to like at the oncologist at the [hospital]. I went and spoke to her separately after my parents were gone... I’ve spoken to both the nurses at the VON and the CLSC. I have made phone calls after their visit to talk to them to make sure I fully understand (020: 202-207).”

In some instances, when the sources of information were numerous and family caregivers were asking questions to many people, the information they received became overwhelming. For example, one family caregiver noted that she got her information by asking. She stated that she sorted through all that information and retained what she chose to:

“Oh, I think we get the information. If we’re asking we’ll get the answers. But if we’re not asking we won’t get the answers. And we tend not to listen to everybody because everybody has their point of view. So we are very leery about people volunteering this and that. So we will just decide on our own (009-149-153).”

In sum, family caregivers collected their information by asking questions of either health professionals or others who are in or had been in similar situations. They also gathered information by sorting through what they had received and retaining what they felt was applicable to their own family member’s situation. Many family caregivers felt that they received little or no information on the patient’s pain and the prescribed pain management regimen. As a result, they were unclear on how to develop their own pain control practice and had to pursue sources of information on their own initiative (e.g. 005).

When the information is sought

A critical finding was that while it might have been suspected that the relevant information would have been obtained prior to the family caregivers becoming responsible for the patient’s pain control, this was often not the case. The search for information about the pain experience of the patient is an ongoing one. Family caregivers were seeking information constantly about the types of pain the patient had, about the medications, and about the side effects. New issues and concerns led to new questions and needs for information. Many family caregivers were articulating the fact that their need for knowledge about pain and pain medication was most salient at the beginning of their experiences as caregivers responsible for pain control:

“And it was just, I think at the very top when we needed the most information, there was none available...And I know for myself, if I were ill, I would like to have as much information as possible right up front. (019: 119-120, 348-349).”

Another family caregiver said that receiving information earlier on would have been appreciated so that she could anticipate things, in particular with her husband’s pain medications:

“I find that what happened in the medical community in general is that you’re totally on an ‘as you need to know’ basis. So there are things that perhaps you should be told and will happen a lot. (012: 91-94).”

Another caregiver mentioned that information and resources both need to be put into place sooner rather than later to help make pain management successful (018). As the family caregivers continue to care for the patients, they realize how much more information is still required (e.g. 014, 019, 024).

Overall, while some caregivers felt well informed, others felt the information they received was insufficient and they were not fully prepared to take on the responsibility of the patient’s pain management. They got their information from different sources and felt that the more they knew about pain and medications the more comfortable they were caring for their family members. The data revealed that although family caregivers were soliciting and searching for information at various points of their experience, it was at the immediate onset of their responsibility for pain control that information about pain and its management was required. Finally, all male family caregivers interviewed felt they had not received enough information on either the cancer, or how they were expected to treat the resulting pain. In contrast, only two of the female family caregivers expressed this thought, one of whom had been a caregiver for only 2 weeks (014). The female family caregivers were also obtaining information from a greater variety of sources, having both personal and professional experiences upon which to draw.

“Striving to Respond to Pain”

This process involves the sub-process pieces of **“determining the characteristics of pain,” “implementing a strategy for pain relief,” and “verifying the success of pain relief strategies.”** Together, this portion of the puzzle represents the processes family caregivers actively engage in with the patient as they work towards obtaining pain relief for the patients. As previously mentioned, these pieces may be assembled at the same time family caregivers are putting together the pieces for “strategizing a game plan.”

Determining the characteristics of pain

Properties and Dimensions

Quality of pain

Family caregivers qualify the patient's pain by stating its intensity such as whether it is a *"tolerable pain (013, 016)"* or at the other extreme, where it can be described as *"agony (007, 010)"* or *"excruciating (005, 010, 011, 014, 019)."* Family caregivers often used such descriptive words such as *"burning (007)," "stabbing (001)," "sharp (019)," "throbbing (007, 018)," "scratching (019),"* and *"tingling (014, 017)"* to describe the nature of the pain the patient is feeling.

Duration of the pain

There are also descriptors that the family caregiver uses to describe how long the pain lasts. This can range from *"lasting a few minutes (001)"* to the pain lasting *"24 hours long (003, 006, 007, 012)"* for the patient.

Frequency of the pain

The frequency of the pain refers to how often the pain occurs for the patient. Some family caregivers said that the pain was always occurring and that it was constant (e.g. 006, 007). It was also described as intermittent: *"it comes and goes (001, 004, 017),"* while there were some who felt the frequency of pain had decreased to the point where the patient had no pain at the present time (e.g. 008, 009).

Location of pain

The family caregivers also felt that it was important to note the location of the pain. The dimensions ranged from pain localized in one area for some patients, to pain that actually moved around for others. This differed depending on the type of cancer and whether the pain was related to the cancer or attributed to another underlying cause. There were also instances where there was more than one location for the pain (e.g. 001, 006), and instances where different areas were

painful at the same time (e.g. 003, 007, 010, 019). Often, these different pains can occur simultaneously.

Type of pain

Another finding is that the family caregivers are managing more than one type of pain and, as mentioned above, pain in multiple locations:

*“...She has different types of pain. She has the pain that starts in her stomach like sometimes when she can’t digest certain foods. So we just avoid them altogether. So if she does happen to have something gritty like a grainy piece of toast that falls into her stomach, she has an excruciating sense of a rock sitting in her stomach, which is not very good. She has these **sharp little needle pains in her liver area** and the pain that radiates from her stomach area down her left side into her back. And her back, her back pain is quite, like a **scratching type of pain** and it’s pretty much, it was pretty much just the lower back that was affected. Now it’s pretty much spread throughout her back... Because she had stopped taking her laxatives and her stool softeners and I guess it was just a question of her bowels not moving at all...**It’s hard to distinguish between the bowel pain and the cancer pain.** But the cancer pain is definitely the lesser of the two (019: 3-12, 26-27).*

The above statement highlights the fact that the types of pain may be related to the cancer or the side effects of medications. In some cases it is unrelated to cancer or its treatment. Some caregivers were describing the pain they manage in a variety of different ways. Not only does the family caregiver use descriptors that were discussed previously, some also described the pain in relation to the cause of the pain (e.g. cancer pain, bowel pain).

Pain due to the cancer

The majority of family caregivers and patients described the pain caused by the cancer itself as the main type of pain that they were trying to manage. This pain was related to the primary tumor itself, the compression of the nerves resulting in neuropathic pain, and/or to the pain caused by the spread of the cancer to other parts of the body. Metastases often resulted in bone pain. For example, one family caregiver stated:

“ His general pain is just when he complains of pain on his back or that he has pain in his arms and, you know, because he has multiple areas or several areas

where the metastases are. But most of his pain is in his smaller back. So, the shooting pain is the nerve pain. The stabbing pain is usually just in his lower back when the pain starts stabbing at him (001:18-022)."

As she was managing these types of pain, her husband then had a fall as he was going to the bathroom. This resulted in an additional new pain on "one side" where he landed as he fell. As in this example, a new pain often presented itself, either as a result of disease progression, or an event that resulted in injury. This new pain was then added to already existing pain the family caregiver was trying to keep under control.

Other Types of Pain

In addition to pain caused by an accident or injury, "other pain" can come from a variety of different sources. For example, in one case, the patient had a large wound secondary to an infected bedsore on his hip. This wound required dressing changes with packing and the family caregiver described a "mild pain" for the patient as a result of this twice a day intervention (017). Another patient referred to the pain caused by the ulcerations on her coccyx as "*pure agony*" and mentioned that the dressing changes "*kill [her] for the rest of the day (007:27, 29)."*

Pain could also be a result of the treatment for cancer and/or the treatment of cancer pain. Some of the family caregivers felt that the pain that the patient was experiencing was a result of treatment being received to treat the cancer. For example, one family caregiver felt quite strongly that the chemotherapy her mother received intensified her pain:

"When they were giving her chemo, she went almost into a type of coma. And the pain was just excruciating the first couple of days all she kept saying is: "I shouldn't have done it." So you know that the pain must have been a lot worse... (010:224-229)."

Other types of pain are possible consequences of the medications used to treat the initial cancer pain. One example is constipation. The son of one woman with pancreatic cancer said his mother compared the pain associated with a bowel

movement to the pains of giving birth. In her case, even the medication to ease the constipation caused a great deal of discomfort:

“She just can’t take that kind of...bloating and just the actual contraction that the laxatives cause. She feels like she’s giving birth. She’s actually mentioned that. It’s a huge contraction... It’s terrible (019:18-21).”

Finally, in one case, the family caregiver mentioned “*terrible emotional pain*” as being one of the types of pain that both she and her husband experienced because the diagnosis was so difficult to accept (008: 3-4). In no other cases was reference made to non-physical pain.

Overall, the data revealed that although pain from a tumor was often the main source of distress and the focus of much of the pain management, patients were experiencing a range of differing pains caused by different sources. As a result, the family caregivers found themselves responsible for managing these different types of pain as they cared for the patients at home.

Assessing the characteristics of pain

Verbal Assessment

In some instances, the patient will say when he/she is in pain and describe the pain without prompting. This is one way that the family caregiver is able to determine the characteristics of the patient’s pain. For example, one family caregiver talked about how she and her husband determined how he would communicate his discomfort:

“He tells me when he’s not feeling well. If there’s pain, if there’s a headache that has come on or something, he will mention it. Because that’s the way we’ve decided to deal with it. I think it’s the fact that we can communicate... (009: 9-14).”

In other instances, it is the family caregiver that must initiate a line of questioning directed towards obtaining more information on the pain their family member is experiencing. The frequency of use of verbal questioning and communication to inquire about a patient’s pain ranged from always used, sometimes used, to rarely used. There were no instances where verbal assessment was never used as all family caregivers attempted to elicit information from the patient regarding their

pain by asking them. The following statement is an example of a family caregiver always asking the patient to ascertain if pain was a concern to her:

“...we’re just constantly talking to each other. And she shared very fully how she felt. And I inquired very frequently...Is she getting any better? Any worse? (005:74-76).”

The frequent and successful use of verbal questioning can be explained by the fact that when patients were able and willing to communicate pain, their family caregivers were more easily able to assess their pain verbally.

Communication was key to pain assessment, however not all family caregivers used verbal assessment at all times to determine the characteristics of the patient’s pain. In some cases, it was only used sometimes: “[I use] my own judgment and with sometimes asking” (023: 112);” “...he will not tell me just spontaneously [if he’s in pain] (015: 74);” while another said his father was “a poor communicator (017: 183).” In these cases, the family caregivers had more confidence in their instincts since they were not able to either trust what the patient communicated or they were caring for patients who did not communicate information regarding their pain. Furthermore, some patients sometimes did not want to tell their caregivers they were in pain (e.g. 003, 013, 022), or had difficulty with their speech when they were in pain (e.g. 024). Some reasons patients would not always communicate pain were: a fear of hospitalization (e.g. 003); a reluctance to show their discomfort (e.g. 015); or a hesitancy to complain (e.g. 007, 009, 011, 013, 020). It was in these instances that verbal assessment was rarely used and pain assessment relied on the family caregiver’s observations of non-verbal cues.

Across cases, it was noted that the passage of time was an important factor that influenced a family caregiver’s use of verbal pain assessment. Family caregivers stated that over time they could just “read” their family members to know when they were in pain (e.g. 001, 012).

Non-verbal assessment

Many family caregivers felt they became experts in reading non-verbal behaviour indicating the patient was in pain as time elapsed (e.g. 002, 004, 009,

024). Family caregivers used many different non-verbal cues as sources of information on the patient's pain. For example, they looked at patient behaviours (*"...and every now and then you'll turn and you'll catch her crying (010: 158)"*) including facial expressions (*"You can see his facial expression: he starts grimacing (001, 35-36)"*); color (*When she's really in pain, she goes very, very white (010: 157)"*); mood (*if he gets angry at a silly thing. That seems to be very much pain related (015: 55-56)"*); body language (*"...to listen to his body expression is the most important (015: 191)"*); and/or diaphoresis (*"It shows in his face and he becomes more sweaty (024: 6)"*) to gather information about their pain. Overall, some family caregivers felt quite strongly that they could assess pain simply by "looking" at the patient (e.g. 001, 008, 012, 013).

The frequency of use of non-verbal cues to assess a patient's pain also ranged from always used, sometimes used, to rarely used. The analysis of the transcripts showed that there were several instances where the family caregiver spoke of the need to always rely on non-verbal methods in their assessment of the patient's pain. This need was explained by family caregivers as necessary in situations where the patients were in too much pain to communicate verbally (e.g. 002, 024), or if they could not articulate their pain well for other reasons (e.g. 008). Also, if the family caregivers felt the patients were trying to "hide" their pain to "protect" them or simply not say if they are in pain, they felt it was better not to ask but to use other indicators (e.g. 001, 010). One patient had early stages of dementia and at times displayed signs of mild cognitive impairment, and so his wife felt that she would get more accurate information about his pain by observing his behaviour than through verbal means (008).

One son explained his reason for always relying more on non-verbal cues as due to the patient's lack of communication skills.

"...my sister who is a RT (respiratory therapist), said...she's never seen anybody with worse communication skills. If he gets asked to rate his pain on 1 to 10, he will say 2 and five minutes later he will pass out from the pain. So he has no concept. He has a very high pain threshold but also he has no concept on how to describe his pain or how severe his pain is. [Assessment is done] more by observing him. Watching what he says, how he talks with me and interacts with

me, or the way he's doing things around the house, his impatience with things. That would let me know that he's in pain (017:60-65, 68-70)."

There were also cases where non-verbal assessment was not needed, and was therefore rarely used, because the patient was seen as a capable reporter of pain or because pain was well controlled at the time of the interview (e.g. 009, 006).

In many cases, a non-verbal assessment was sometimes used by the family caregivers to confirm a verbal assessment or vice versa. For example, family caregivers questioned the patient after observing cues of discomfort: *"Well, some cues are she just closes her eyes and lifts her backside...[then] I'm going to say: 'You're in pain', and [she says] 'Yeah' (007: 107-109)."* In those cases verbal questioning and a non-verbal assessment were used together.

In order to perform accurate pain assessments and to determine the characteristics of the pain the patient is experiencing, family caregivers used both verbal and non-verbal assessment strategies, and often needed both together to be able to ensure that the patients received appropriate interventions leading to optimal pain control. When family caregivers began to determine the characteristics of the patient's pain, they considered the quality, duration, location, frequency, and type(s) of pain. Information gathered by their verbal and non-verbal assessments helped the family caregivers put together a more comprehensive picture of the patient's pain. Once they were able to identify what they must manage, they were able to use that information to decide what could be done.

Implementing Strategies for Pain Relief

There are a range of strategies used by the family caregivers as they tried to manage the patient's pain at home that can be grouped into two major categories: 1) pharmacological strategies and 2) non-pharmacological strategies. Although either suggesting or giving medication was the predominant intervention, non-pharmacological interventions were used frequently as well. Such interventions were either used in conjunction with medications, or independently, depending on the situation and the type of pain.

Properties and Dimensions- Pharmacological strategies

There were several properties of pharmacological interventions. One was the success of pain medication as an intervention which ranged from "*it never works*" or "*sometimes it works*", to medications being "*always successful*". Another characteristic was the timing of when pain medication was given, and this ranged from unscheduled medications as a response to witnessing a pain crisis, to giving medications to prevent pain by giving them prior to pain occurring, or following a pain medication schedule.

Success of pain medication

Several family caregivers felt that giving medication was the only strategy that would be successful at pain relief (e.g. 003, 007, 024). These caregivers did discuss the fact that they had other options available to them and that they did at first try to implement a range of different interventions, but pain medication was the only thing that worked effectively and worked quickly. This then became the sole intervention they had confidence in using when they observed the patient in pain: "...*sometimes there's nothing you can do about it [the pain] except give drugs (003: 460).*" They felt that this was the one strategy that they were comfortable doing which provided the greatest amount of pain relief and were reluctant to experiment with other methods of pain relief. Similarly, when asked what he does to help manage his wife's pain, another family caregiver stated the

only thing he did was give his wife medication when she felt pain and that his involvement in her pain management was limited to that (004). This idea that medications are “*the only thing that works (024: 128)*” highlights the fact that they can be a successful strategy for pain relief almost all the time for some family caregivers.

There were also many family caregivers who felt that the pain medications they gave their family members for pain were partly successful part of the time. For example, family caregivers stated that “*the medication sometimes alleviates it [the pain] to a certain extent (012: 50-51)*” or “*it [pain] can sometimes be controlled with the right medication... (015: 55).*”

While some family caregivers felt quite strongly that medications for pain were quite successful in relieving the patient’s pain, there were also cases where the family caregivers felt that pain control was not attainable by their current pharmacological regimens. Of interest to note was that in both cases of completely unrelieved pain family caregivers were caring for patients experiencing severe neuropathic pain. In both cases, they were seeking interventions beyond medications such as “*cutting the nerve (007:129-130)*” or “*block the nerve (006: 195).*” For them, pain medication never worked, as evidenced by one patient who said “*my body is immune to painkillers (007: 149).*”

Timing of pain medication

Another characteristic was when pain medication was given. Pain medication was either scheduled or not scheduled. Some family caregivers “*gave pills immediately (023: 010)*” upon assessing the patient’s pain while others did not require their family member to be in pain in order to give pain medications. In these cases they prevented pain by giving medications prophylactically and by following scheduled times for medication (e.g. 001, 005, 019, 020).

Unscheduled medication

The first part of many of the pain management regimens was the pharmacological treatment of the patient’s pain. It was often the immediate

response once it was assessed that the patient was in pain (e.g. 009, 019). One family caregiver explained what she does for her mother: *“the first thing is give her something for the pain (019: 67-68)”* and then she tries to calm her down. In other cases, family caregivers attempted to thwart a pain episode by giving medications as a means of prevention. This behaviour can be explained by their ability to identify a pattern to the pain and the conditions that seemed to precede it. They were then in a position to medicate the patient in the hopes the pain would be avoided. One family caregiver felt that her ability to anticipate her husband’s pain was quite good in this description of what she does:

“Yes, very much, working very well. Because he has to mention it and I have to look out for it.[It’s important] to be proactive, anticipate so he doesn’t reach that point of pain because then it would take us a lot of time to restabilize, to be stable (024:71-74).”

In this case, being proactive meant giving her husband his pain medication before he was to do any physical activity. Other caregivers gave medication prior to an outing such as going out to dinner or shopping (e.g. 008,016), an activity such as gardening (e.g. 006, 013), or a dressing change (e.g. 003). One family caregiver described how preventing pain from occurring was essential to their excursions and quality of life as a couple. Her intervention was to give him his Dilaudid prior to going out, either at her own initiative or if he asks for it:

“...if we have to go somewhere that he likes, he wants to be comfortable. He’s going to say: “Give me a Dilaudid because I have pain”. So I know it’s because he wants to be comfortable where we’re going (015: 71-72).”

The above descriptions of conditions when medication was given by the family caregivers demonstrate the importance of medicating prophylactically. The family caregivers felt they were more “in control” when they were able to keep the patient comfortable during an activity that they enjoyed. Preventative action did not necessarily have to precede an activity or an event. It was also successful at times for averting pain with the use of breakthrough medications to keep the patient’s pain from reaching a point of intolerance.

Scheduled Medications

All the patients in this study were taking at least one pain medication or more, or were also on several other non-pain medications. As a result, some family caregivers were giving medications in an organized, structured manner according to a fixed schedule. In palliative care, it is common to have pain medications prescribed to ensure that the patient has around-the-clock and breakthrough (PRN or “in between”) medications. One family caregiver commented on the importance of a medication schedule:

“I’ve printed out a lot of information for her... that she should keep to a pretty regular medication schedule. That if she feels a little bit of pain, she knows it’s going to get worse so if she takes the pills right off the top, it’ll control it a little bit better (019: 78-83).”

These caregivers also highlighted their roles in helping the patients adhere to the prescribed timetables. One woman caring for her husband said *“If I’m not to be there, he wouldn’t take the pill (006: 436).”* The patient echoed this sentiment by pointing out that his wife followed the schedule for his routine medications exactly how they were ordered:

“What the doctors tell her to do, she does it punctually and exactly. And there’s no such thing that I forget to take the pill, because she’s there (006:435-435).”

The fact that many patients had routine medications to be given at fixed times dictated when the family caregivers would give medications. This emerged as an important condition under which medications were given, since even when faced with an unanticipated pain, the family caregiver still respected the scheduled medications. For example, as previously discussed, medications were given by family caregivers if the patient was in a pain crisis, was in need of breakthrough medication, or was requesting it. Even in these situations, the family caregiver still prepared and gave routine medications as per their prescribed times, as they would have been instructed by the prescribing physician:

“He’s pretty good when he has to take [it]. He’ll...say ‘Can I have my Dilaudid?’ His routine medication I prepare for him and I give to him (001: 81-83).”

In this case the family caregiver follows a routine and responds to the patient's request for medications as needed. In these cases, the importance of establishing and respecting a routine was mentioned by the family caregivers.

Overall, medications given to control pain were either planned in advance or were given spontaneously as a response to seeing the patient in obvious distress due to pain. The use of unscheduled medications was also explained by family caregivers as a means of preventing pain. In most cases, the patients had a fixed regimen for pain relief and the family caregivers gave pain medications according to the prescribed schedule.

Non-pharmacological strategies

Types of Strategies

The use of distraction (e.g. 002, 007, 008, 010, 015, 019, 020), massage (e.g. 002, 007, 012, 015, 019), being present (e.g. 008, 019, 021), positioning (e.g. 001, 010, 018), heat/cold (e.g. 003, 004, 012, 016), humour, (e.g. 007, 010), and other strategies were described by these caregivers.

Distraction was one of the most common non-pharmacological strategies for pain relief. Often this involved using conversation about something pleasant to refocus the patient. One family caregiver described her mother's pain as agony, but felt that she was able to use distraction to help her mother deal with her pain. She described how they often looked through family albums together:

"And so they were good memories and then there were family pictures in there. We were looking and we were laughing... I just try to take her mind off so she's not thinking about the pain so much and the fact that, you know, it's basically just time left (10:94-97)."

Family caregivers also tried to engage the patients in activities that would occupy them. For example, one family caregiver describes how she involved her mother in a "scrapbooking" project.

"So I've taken to bring in stuff from my place to her. Like all my old photographs that I've taken from when we were teenagers when I started taking photographs... So I've asked her to go through them and try and organize them by timeline. So that gives her something to do. And it's also something sentimental that makes her smile and remember how nice those days were or whatever you know just kind of takes her mind off what she's going through (019:179-186)."

She felt that this task not only took her mother's mind off the pain, but it also gave her mother something meaningful to do. Other distraction strategies included going out (e.g. 019, 022, 023), entertaining visitors (*"Because company makes him forget, you know, gets it out of your, not of your, it isn't that pain is less but I think you're entertained (008:42-45),"* and the simple act of putting on the television (*"and I sit with him [and watch TV], and he feels more comfortable like that... because he doesn't think as much if I distract him...(015:010-213))."*

Massage was an important non-pharmacological intervention for three reasons. Firstly, it served as an activity that distracted the patient (e.g.010). Secondly it helped with pain because of its possible beneficial physical effects (e.g. 002, 012, 015). Finally, massage was a technique that was used to provide comfort to the patient (e.g. 021). One patient said this about his wife and how she reacts to him in pain:

"...she grabs my, place where I have the pain... [and] ... massages me softly (015: 462-464)."

Family caregivers also mentioned that they felt that simply being present and involved in the patient's care was an intervention for pain control. All the family caregivers felt they were "there" for the patient and were "supportive" and "caring."

"When she has her terrible, terrible pain that makes her cry, of course I stay next to her...from the moment she has pain, I'm beside her, I don't leave her. I talk to her, I touch her...I tell her 'in a moment, it will be better' (021: 209-210, 53-57)."

Changing positions to relieve discomfort was another strategy that was part of pain management. Since most patients in this study were able to mobilize independently, the family caregivers either helped them to change position, encouraged/suggested a position change, or helped them to maintain comfort once they had already changed positions. One family caregiver mentioned how different positions helped her husband with his different types of pain. He had "stabbing" pain in his lower back and "shooting" nerve pain down his legs. She tried to relieve the pain of both using position changes.

“For the stabbing and shooting pain, it’s just usually lying still and keeping his legs elevated. We put him on an antispasmodic for the shooting pain to see if that could help. ... But mostly it’s just positioning, not moving (001: 28-31).”

For many patients, their pain was clearly positional, where being in one position for an extended period of time triggered their pain, or where an injury or wound prevented them from being in certain positions comfortably. The family caregiver helped the patients find comfortable positions when they were experiencing pain.

The use of heat and/or cold were also mentioned by family caregivers as examples of ways they tried to relieve the patient’s pain. One family caregiver used heat to manage arthritis pain, and she also used it for all the pains the patient had, including the cancer pain secondary to breast cancer which she described as pain that was: *“deeper in the chest...because it’s breast cancer...”* She said she *“just used our [heated] bean bag in an attempt at pain control (003:142).”* She also used heat for headache pain, and offered this suggestion: *“...they should wear a small [heated] towel around their neck or a warm bean bag if they have a headache... (003:157-159).”* In this case, the family caregiver drew on her own past experience with the use of heat for her own pain. Similarly, another family caregiver also mentioned heat in the form of a bath as one of her strategies for pain control. She described a variety of different strategies and then said: *“and sometimes it will be a hot bath if I get him at the bath tub (001: 30-31).”* Another family caregiver said that along with giving Tylenol, he placed cold compresses on his wife’s arms and legs for generalized pain (004: 74-77). Family caregivers were using heat or cold to provide both pain relief and comfort to patients (e.g. warm tea, 024). It was either used for a specific type of pain, or indiscriminately for all types.

All of the described non-pharmacological strategies were rarely used alone, but rather were coupled with other interventions or they were one of many strategies that the family caregivers were experimenting with.

Properties and Dimensions- Non-Pharmacological Strategies

Non-pharmacological pain relief strategies, such as those described above, were used quite frequently by the family caregivers interviewed for this study. An important property of this category is frequency. Non-pharmacological interventions were never used, sometimes used, or often used. Another property is dependency on pain intensity. The dimensions of this were that non-pharmacological strategies were used either for mild pain, moderate pain, or severe pain.

Frequency of use

There were some family caregivers who did not use any non-pharmacological strategies as part of their pain management regimen. Some family caregivers explained this by emphasizing that they felt strongly that medications were the best way to intervene for pain (e.g. 001, 004, 005, 001). The use of non-pharmacological interventions was also rare for those family caregivers who had patients whose pain was under control (e.g. 009). There were also family caregivers who stated they “sometimes” used strategies that don’t involve medications. For these family caregivers, non-pharmacological interventions were used only when their preferred intervention of giving pain medication was unsuccessful. For example, some family caregivers always started with medications as a first attempt to the patient’s pain. If that that didn’t work they tried other strategies:

“I try to convince her to take the medication. It doesn’t always work. And then I’ll offer a cup of tea and I’ll start talking about things that pick her mind. My brother has a young girl... And you bring that up and it automatically my mother like this extra boost...I just try to take her mind off so she’s not thinking about the pain so much...(010:72-75).”

Sometimes non-pharmacological strategies were seen as part of a pain management regimen that often started with medication or was added to medication (e.g. 020). It was also seen as an alternative method to relieve pain if the pain medication given was ineffective.

Non-pharmacological strategies were always used by some family caregivers because they felt that they were always successful in decreasing and controlling the patient's pain. For example, one family caregiver was bothered by the side effects of the narcotics he had to give his wife and preferred to use distraction as a way to prevent the pain from occurring:

"... distraction, it's being proactive. You distract her before the pain really starts to set in. So she doesn't think about it, she doesn't have time to think about it. (002:5-7)"

He felt this non-pharmacological strategy meant that she didn't require the medications that had detrimental side effects.

Pain Intensity

The use of non-pharmacological strategies was related to the intensity of the patient's pain. Family caregivers determined the characteristics of the patient's pain and then decided if the pain was mild, moderate, or severe. Some family caregivers selectively used non-pharmacological strategies for mild or moderate pain, but not when the pain was severe. For example, the family caregiver who preferred to use distraction before medications did note that *"distraction worked...depending on the level of pain... More severe [pain], then you knew that you couldn't do any of these [non-pharmacological] things [distraction or massage] (012:101-102)"*

The family caregivers articulated that some non-pharmacological strategies, such as distraction, were not a first choice intervention for severe pain primarily due to the fact it did not necessarily relieve pain, it only took the patient's focus away from it. The family caregiver of a patient with pain *"24 hours a day (007:14)"* felt distraction was an important intervention because *"...if you do something else you sort of like... don't forget it totally because it's still there...but it changes your mind on pain (007:457-458)."*

Distraction was used as an intervention for pain control if the pain was not too strong. Some patients felt that it did have some merit in decreasing their pain

levels because their attention was shifted elsewhere, but they stated that the pain was not relieved.

In other cases where the patient's pain was quite severe, family caregivers were more often attempting to incorporate a range of interventions as they tried to master pain control. This often meant that non-pharmacological methods were used. For example, one family caregiver, who had once seen her husband *"writhing in agony on the floor in a fetal position (012: 21-22)"* felt she had tried everything: *"Distraction, massages, you name it (012:132)."*

Physical presence was also described as a non-pharmacological intervention when the patient was assessed as being in severe pain. Physical contact and "moving closer" to the patient was almost an immediate response for the family caregivers when they saw someone they love in pain. This non-pharmacological intervention is what some family caregivers called "being present." When some family caregivers were asked if they did anything other than medications for pain relief, they responded by saying that they used physical proximity (e.g. 012, 019, 021). For example, one family caregiver said this when asked the question: *"Yeah, I go and kiss him and give him a hug or we talk and I try to remind him about past things we've gone through (008: 217-218)."* In these cases, family caregivers were intervening for severe pain by using themselves, often in addition to other strategies, as a method of pain relief.

Influencing factors: pharmacological and non-pharmacological strategies

There were many factors that influenced the use of either pharmacological methods or non-pharmacological methods, and the choices made to use them. Many of the family caregivers who had expressed concerns about detrimental effects or who held onto strong beliefs about medications used to treat cancer pain changed their opinions as time progressed. Beliefs that medication was *"poison (006: 242),"* fears that morphine means *"...the end (003:273),"* and thoughts about the patient *"losing [their] mind (010:175-176)"* are examples of initial concerns held by family caregivers in this study. As a result, medications were given inconsistently, with hesitation, or not at all. In another case, a family caregiver spoke of how at first she was *"scared and upset... [without] any kind of*

control (014:48-49)” when she assumed the responsibility of giving her mother her medications. She expressed that she had eventually developed a comfort level with her mother’s medication regimen:

“I was writing down the hours I was giving her the Dilaudid. Now I don’t even do that anymore because there are very few breakthroughs...I just know off the top of my head. I don’t write it down... (014:160-162).”

Another family caregiver said, “...as time progressed, it’s easier ... (019: 225-227).” For these caregivers, in just two weeks and three months respectively, their concerns had been alleviated and beliefs changed. In these cases, it was noted that those who overcame their initial hesitations about pain medications were those who saw evidence of pain relief.

Side effects were another influencing factor. Family caregivers described dizziness, constipation (e.g. 019), drowsiness (e.g.002, 014), nausea (e.g.), weakness (e.g. 001, 006), confusion (e.g. 008), dry mouth (e.g. 019) and a lack of appetite (e.g.003, 005). For example, one family caregiver was angry at the side effects of the narcotics prescribed:

“Sometimes I don’t think the doctors know what they’re doing...they want to keep her stoned and stupid. Stoned and stupid is what they want (002: 90-91)?”

He, like many of the family caregivers in this study, had strong negative feelings related to medications, and chose to explore other options of pain relief (e.g. 007,008, 018). The results of this analysis highlighted the fact that it is at the initial stages of their pain management responsibility that family caregivers struggle with concerns about side effects. Again, once pain relief was observed over time, family caregivers began to place more faith in the medications (e.g. 003,008, 010,019).

The analysis also showed that there were some family caregivers who used medications as their intervention of choice if attempts using other methods had been unsuccessful (e.g. 002, 006, 020).

The following example of one family caregiver who felt that medications should not be the first strategy to relieve pain illustrates this point:

“I think at the beginning when you’re dealing with somebody who’s in pain you want to get rid of it right away. So you probably say ok I have these medications,

and which one am I supposed to use and let's get on with it. But then after a period of time you realize that sometimes you don't need to medicate. You know sometimes it could be another reason that's causing the pain. And you have to give it a few minutes; you can't act on it immediately. Sometimes you have to wait and see what's causing it (012:51-52)."

She used several other strategies, such as distraction and massage. She acknowledged that these strategies did not always work, particularly when the pain was quite severe. In these cases, she felt that medication was the most effective (012).

In sum, as family caregivers became more adept at pain management over time, some expressed a change in their previously held beliefs or concerns. This was a result of an increased sense of control and confidence which affected the giving of medications. Changes over time were reflected differently across the interviews. For some, fears about narcotics were overcome with continued use and monitoring of the side effects. Beliefs were gradually changed as information was received by the family caregiver and knowledge increased. These factors had a direct impact on medication as an intervention as family caregivers were more at ease implementing this strategy. As previously mentioned though, there were still some family caregivers that maintained their initial apprehensions.

In addition to the interventions that have been discussed, there were other alternative interventions that were mentioned. Three such cases are homeopathy (002), vodka (006), and Chinese oil (018). These examples provide insight into the motivations of some family caregivers as they choose to use such interventions. Of interest to note was that in all three of these cases, the family caregivers had some reservations about the medications that their family members were taking. This may suggest that they were very interested in experimenting with alternative methods as part of their pain management regimen. The family caregiver who used Chinese oil said this about her husband's morphine:

"It just made him drugged up or whatever. To me that's not good management of pain to be always in a stupor sort of thing. You like to have pain management till you have no pain but you can still function on a day to day basis but with the morphine, it didn't seem to do anything (018: 238-242)."

In these cases, the family caregivers had strong negative beliefs about medications and were using different non-pharmacological ways to control pain.

The data analysis was also able to shed light on why, in some cases, family caregivers did not mention or use non-pharmacological interventions at all. In some cases, a lack of familiarity about non-pharmacological interventions as potential strategies was cited as a reason they were not used by a family caregiver:

“Frankly again I don’t know enough about these things [non-pharmacological interventions] ...And we got some books on it and so on. But I myself again don’t feel the least bit qualified to be able to cope with it (007: 725, 732-33).”

He felt that he was unprepared overall for the responsibility of pain management, both for giving medication and for other methods of pain relief. In other family caregivers, this lack of information was central to the idea that “trial and error” as an important way family caregivers learned about interventions (e.g. 001, 012, 018).

In other cases, non-pharmacological interventions were not considered by the family caregiver. Even though the patients had experienced pain before, medication had been used successfully without experimenting with other strategies and the need to try alternative solutions for pain management had not arisen. For example, one family caregiver mentioned how the pain was controlled with the use of medications. She said there was no need for other ways to manage the pain: *“It [the pain] seems to be well managed. The medication is working well (013:21-22).”* This was an important reason pharmacological methods were used more often by the family caregivers.

Although both the male and the female family caregivers engaged in a variety of different interventions, either involving medication or not, the data seemed to indicate that some male family caregivers preferred giving more instrumental support. For example, when asked what he did to help manage his wife’s pain, one family caregiver listed ways he helped her to manage her daily activities:

“Well, probably...assistance, more assistance in well lifting things on the car and that sort of things when she went shopping and stuff... I help her to the bathroom and I’ll bring the wheelchair and help put the jeans on (011: 101-104, 180-181).”

Another husband felt that his major contribution to his wife's pain management was that he had used his connections to help get her admitted to the hospital for symptom relief (005). There was also one family caregiver who said that he felt that his sole contribution to his wife's pain control plan was the following "*The only thing is I supply the money [for her care] (022:198-199).*" In these cases, the husbands did not see themselves directly implicated in the daily management of the patient's pain. Although they did have differing roles to play in handling and giving pain medication, these were not seen by them as concrete pain control interventions. Overall, male caregivers preferred instrumental or "hands on" interventions which can be defined as interventions that are: "*functioning or tending to produce effects*" (Webster's Online Dictionary, October 3, 2007). The male family caregivers in the study seemed to prefer more instrumental interventions, such as transportation or helping with cooking which they saw as having a direct impact on the patient's level of pain because they were preventative strategies. They also favored the giving of medications as a "fool proof" strategy with a higher likelihood of success than non-pharmacological strategies.

Overall, although the use of non-pharmacological pain management interventions was discussed by many of the family caregivers, not all of them used such strategies. Some family caregivers did use non-medicinal strategies but they experimented and learned through trial and error. Lack of information was often cited as a reason for not using non-pharmacological strategies. If pain was not an immediate concern or under control, family caregivers often felt no action (pharmacological or otherwise) was required. Finally, for some male caregivers, non-pharmacological strategies were not used simply because their vision of pain control did not include such methods.

Verifying the degree to which pain relief strategies were successful

Properties and Dimensions.

Communication

Non-verbal communication

An important property of the process of verification is verbal communication, and the dimensions are “infrequently used” or “always used.” Similar to the assessment of pain, family caregivers often relied on the non-verbal indicators expressed by the patients to evaluate pain relief. One family caregiver mentioned how she kept watching the patient’s face to see if her intervention for pain control had been effective. She felt that looking at the eyes was critical in being able to evaluate pain relief (021: 401, 403). Although there was overlap in the types of behaviours observed during assessment and during evaluation of pain relief, there were some specific to assessing pain relief. For example, sleep (e.g. 002, 005, 014, 023), eating (e.g. 001, 005, 010), smiling/laughing (e.g. 010, 019) and hugging (e.g. 008) were not mentioned by family caregivers as patient actions they look for initially to determine that the patient is in pain. They do, however, feel that if these behaviours are noticeable after an intervention for pain control, the intervention can be deemed successful. One family caregiver said that she knows the patient had less pain because “*she’s resting. And she’s sleeping. She has a better night. She rests better (003: 164-165)*”. One daughter stated that she knows a strategy may have worked for her mother if “*maybe if [she has] a little something to eat*” (010:82-83).” In some cases, a family caregiver used both sleep and the patient’s ability to eat as evaluation indicators (e.g.001). Another family caregiver said she knows her intervention (i.e. massage) has helped because: “*... she’ll [the patient] laugh. So I know like it does work to a certain point because like I get the smile... (010:163-166)*.” In another case, the family caregiver knew her strategy had been effective “*... because of the way ...he [the patient] wants to hug me (008:223)*.” The results show that non-verbal cues were used for both the assessment of pain and the evaluation of pain relief in the pain management process.

Verbal communication

Similarly, verbal questioning played as important a role in the evaluation of pain relief as it did in the assessment of pain prior to intervention. Many family

caregivers stated that they simply asked if what they did helped (005: 151, 010:73-74, 019: 37-38, 023:106). What is important to note is that most family caregivers used both direct verbal questioning and non-verbal behaviours to determine the success of their interventions, with few exceptions. For example, one family caregiver stated that she asked the patient to evaluate if something has worked, however she is careful to observe his non-verbal cues to see if the message he is conveying is consistent with what she observes.

“When he says: ‘Ah, j’suis bien [I am well]... When he tells me that in a convincing way, I can see in his face that he is ‘bien’... A non-convincing is he won’t look at me... I’m gonna ask him: ‘How are you?’ ...and he doesn’t look at me. I know that he’s faking it. (015: 237-242.)”

This is a case where observing the patient’s actions and the direct asking were both needed to give the family caregiver an accurate picture of the patient’s pain control.

Even though many caregivers used different ways to verify what effect their strategies had, there were some family caregivers who felt it was only the patient who could say conclusively if the strategies worked. When one family caregiver was asked if she felt her strategies worked for pain control, she felt it was best to ask the patient because *“he’d be able to say it more than me (008:264).”* In a similar manner, another family caregiver felt only his wife could evaluate that, and so he relies solely on her feedback. *“C’est elle qui, qui évalue sa, sa propre douleur [It’s she who, who evaluates her own pain] (004: 58).”* Overall, both verbal and non-verbal strategies were used in this part of the pain management process.

Evaluation Tools

Another important property of the process of verification is the use of pain evaluation tools, and the dimensions ranged from “never used” to “always used.” Some family caregivers always took notes or graphed the progress of pain relief in order to be able to evaluate the success of these interventions. In these cases the family caregivers tracked what they did and how well it worked. One family

caregiver was asked how he evaluated if his pain relief strategies had worked and he said:

“By graphing it down. I’ve been graphing it all along... [I can tell] if she had a good day or a bad day because I go through my graph and see. Okay, from like six in the morning to twelve she popped like eight and then in the afternoon she popped up two or three and the next day she didn’t take any. I can see if it’s coming, coming in waves... it gives a chance to say ‘That’s not working, so try this, this protocol for a certain amount of time...’ (002: 222, 15-19, 22-24).”

From the data he collected, he was able to evaluate that the current pain management regimen wasn’t working and that a change was necessary to keep the patient comfortable. Similarly, another family caregiver said that she evaluated pain control by keeping diligent notes and looked at how often she was giving medication for the pain. In her case she said *“We can see it [pain relief] by the intervals [between medications] (024: 144).”* A change in the frequency and doses of medications prescribed by the physician was a common result of a family caregiver’s evaluation if it was found that the current treatment plan was not working well.

The pain scale that had been used by caregivers for pain assessment was another tool used to verify the success of pain relief strategies. It provided a measure of the success of their pain management strategies and indicated if a change in these strategies was warranted.

“I ask him often: ‘You have pain? ... on what level do you have pain?’ Because after five it’s very hard to control...I use it [pain scale] often. If he has very little pain, I will ask him an hour after or half hour: ‘How did it get now? Is it getting worse?’ And I call him very often from work and I ask him: ‘Do you have pain?’ (015: 194-200).”

While some family caregivers did use such evaluation methods as described above, others never used them. One family caregiver who had used the pain scale in her professional life as a nurse said she “never” uses the pain scale, but uses “other things” (013) to evaluate her success at pain relief. These other things were non-verbal observations and direct questioning. She explained this by saying that her husband is always truthful in communicating his discomforts to her.

In other cases, evaluation tools or other methods are not used because there were some family caregivers who felt that they were not in a position to evaluate the patient's pain relief. This did not mean however, that an evaluation was not done (e.g. 004, 008). These patients reported whether their pain had been relieved or not.

What family caregivers assess as successful in relieving pain

Pharmacological Success

Medication was, for many of the family caregivers, the most successful strategy that led to a decrease in the patient's pain. Many family caregivers made statements that seemed to echo the following: "...*Right now...the narcotics she's on seem to be doing the trick (020: 169-170),*" or "*the moment we started the pain killer, the pain was more bearable...The pain killers evidently [make it better] ...It dulls the pain (008:68, 69-70).*" As a result, family caregivers discovered that one of the most important characteristics of the pain they were managing is that it was amenable to medication. Related to this is a change in the pain medication regimen that, when done successfully, "*reduced [the pain] dramatically (012:28).*"

Overall it was seen that across cases that medications can make the pain better. In some instances, the medications were seen as successful, despite the fact that some pain still lingered. One family caregiver said that the medication only "... *dulls the pain (008: 68)*" while another made the following comment "...*with the Dilaudid it'll start to subside...(014: 69).*" There were also examples where the pain was not relieved by pain medication. For example, one family caregiver commented that the medications were: "...*more often not working than working (007:122).*" In such cases, medications were not evaluated as successful interventions for pain relief.

Non-pharmacological Success

Many non-pharmacological strategies were evaluated as successful in decreasing or alleviating the patient's pain. Distraction, massage, humour, rest,

heat, and being present were all strategies that were used and found to have an impact on pain. The following examples demonstrate this point:

“Distraction almost always works... for a short period of time it is the distraction that will take her mind off [pain] ...sort of almost immediately (020: 214, 218).”

Almost all family caregivers brought up distraction as a method they used that worked to make the patient's pain better. Although the way in which the patient was distracted varied, the most important thing was that it “changed” the patient's thoughts and took the focus away from the pain (e.g. 003, 007). Once family caregivers were aware that they could help the patient feel less pain by helping to take their mind off it, they used distraction quite frequently.

Humour emerged as another strategy that some family caregivers felt worked quite well. One daughter offered this interesting observation: *“...and I'll try to make her laugh. I find that's a very good remedy actually...I'm such a believer in humour that I really believe it takes, it's not only good for their pain but it's good for your pain (010:35-36, 272-273).”* Other family caregivers also mention the importance of maintaining a sense of humour when taking on the responsibility of pain management, for both the family caregiver and the patient (e.g. 003, 007, 010). Clearly, in some cases the family caregivers feel that humour changes the intensity of the pain experienced by the patients.

Some of the non-pharmacological strategies proved ineffective for some family caregivers. For example, when asked if massage worked, one responded *“...not really... (012:134)”* and another said *“I don't think it helps (015: 145).”* The strategy of changing positions, while effective for some, *“doesn't always work (020: 213-214)”* for others.

In many instances, verifying the success of pain control strategies involved family caregivers making comparisons between different strategies they were using. This was done to determine which strategies, if more than one was used, were most effective. For example, one family caregiver distinguished between three different strategies used for her mother's back pain:

“Changing positions doesn't always work. Distraction almost always works...Medication usually works but not always in the same way. So the one that

almost always works for a short period of time is the distraction [that] will take her mind off [the pain]. Something sort of almost immediately (020: 213-218)."

Family caregivers then, were able to verify if certain interventions had been effective by comparing them to other interventions that had also been used.

In sum, the analysis showed that finding out what made the patient's pain better was an important part of the pain management process for family caregivers. There were many examples that showed that with the passage of time, constant monitoring, and increasing familiarity with the pain management regimen used for the patient, the family caregivers felt better able to determine what worked for the patient and what was less successful: "*...pain is something that can be controlled with the right medication but it has to be constantly followed every day (015: 55-56).*"

These family caregivers became more confident over time in their pain management responsibilities. They felt that their evaluations were correct and that their selected interventions would be successful. In the 7 interviews where patients were included, they were asked about the accuracy of both the assessment and the evaluation of the success of the interventions used. In most cases, they felt that their family members were able to accurately determine the nature of the pain and the degree of pain relief that they were experiencing (001,007, 013).

Reaction to Unsuccessful Strategies

An important part of this piece of the pain management process was determining what to do if the implemented intervention was not effective enough, meaning that the patient was still in more pain than he/she found tolerable. Some family caregivers retried the strategy they had already used, some modified the strategy, while others decided to try another one.

In an example provided earlier, the family caregiver who suggested vodka for her husband's neuropathic pain felt it was an intervention that warranted repeating despite the detrimental effects it had on him after the first attempt. "*He tried yesterday, the day before yesterday it didn't help (006: 159-160).*" Since she called his pills "*little poison (006: 242)*", it can be speculated that this played some role in her determination to attempt other strategies.

In another case, once the family caregiver evaluated her intervention of giving pain medication as unsuccessful, she changed the intervention a little bit. She first describes how she noted that the patient's pain was not being controlled:

"I can tell by the intervals between pain medications how well it's working. If...I see that an hour later or two hours later I have to re-medicate, and an hour later I have to re-medicate, then I know it's not working (012: 134-139)."

As a result, she changed the dosage and frequency of his medications and said that over time this process of assessing the pain, acting on it, and verifying the success of her interventions had become easier for her. In another case, the family caregiver felt *"frustration (005: 119)"* when *"nothing helped (005: 121)"* and then arranged for his wife's admission to *"...a very good palliative care program"* through a physician *"who was in charge there and on [the caregiver's] request, admitted her (005: 80-82)."* He describes his evaluation of the success of this intervention by saying: *"Now I'd say she's almost 90% well (005: 82-87)."* For this family caregiver, giving his wife medications at home was evaluated as ineffective. He felt helpless and frustrated, so he changed his intervention strategy to pushing to have his wife admitted for pain control.

In sum, some family caregivers retried unsuccessful interventions to avoid those they had little confidence in or were apprehensive about (e.g. narcotics), or modified strategies secondary to a pattern of relief emerging, or they tried other ones when they became frustrated with the failure of the attempt they had made. Overall, all the family caregivers in this study at some point returned to the process of *"determining the characteristics of pain"* and fitted this puzzle piece with *"implementing a strategy for pain relief"* and then returned to *"verifying the success of pain relief strategies."* The "striving to respond to pain" process puzzle piece requires that all three of these sub-process pieces are joined.

Assembling the Pain Management Puzzle

The assembly of the puzzle is an independent and a personal process that each family caregiver engaged in. Across cases, while it was seen that all family caregivers had each of the process pieces as part of their pain management

experience, the composition of each piece, the time invested in each piece, and the order in which the pieces were assembled differed from case to case. Examples will be provided to illustrate the individual nature of the pain management process for family caregivers.

The pain management puzzle is formed and considered complete when the process pieces “strategizing a game plan” and “striving to respond to pain” are joined together by the family caregiver. As previously discussed, the analysis showed each of these processes is composed of smaller process pieces that are necessary for each process to occur. The assembly or “fitting together” of these pieces will be presented in this section of the results.

The sub-processes of “accepting responsibility,” “developing a pain management relationship,” and “seeking information” are the process pieces that comprise ““strategizing a game plan”. While accepting responsibility for the management of the patient’s pain was a necessary first step before any of the other processes could occur, there was no particular order in which the next piece would be fit. Family caregivers could either be in the process of developing their relationships with the patient and/or the healthcare team or collecting information separately or at the same time.

The sub-processes of “determining the characteristics of pain,” “implementing a pain relief strategy” and “verifying if pain relief strategies were successful” are the process pieces that need to fit together to form the process of “striving to respond to pain.” In this case, either the assessing of pain or the evaluation of pain relief can precede intervention by the family caregiver. While the processes of “determining the characteristics of pain” and “verifying if pain relief strategies were successful” overlap at times, they are two separate processes occurring at specific times in relation to the intervention. It is the strategies used to either assess or evaluate the patient’s pain before and after the intervention that were at times similar.

The “strategizing a game plan” puzzle piece may not necessarily be completed prior to the assembly of the “striving to respond to pain” piece. Each process piece can be pieced together at the same time as the other. The

“strategizing a game plan” piece often gets elaborated over time with experience, and secondary to changes in the characteristics of pain.

“Gauging the best fit”: The Assembly Process

What Assembly Entails and the Role of Decision-Making

Three family caregiver “pain management puzzles” will be presented to clarify the complex process of fitting the process puzzle pieces together.

“*Gauging the best fit*” is a critical decision-making process that the assembly of the puzzle relies on. This will also be described.

Properties and Dimensions

Family caregivers are constantly making decisions in the pain management process. The decisions that they make are the critical links that enable them to join the process pieces of the puzzle together. The interviews showed that there were several properties determining when and how the family caregivers in this study decided to attach the puzzle pieces together. One property of “*gauging the best fit*” is satisfaction with the previously assembled puzzle piece. The dimensions ranged from “*highly satisfied*” to “*not satisfied at all.*” Another property is readiness to join two pieces together. The dimensions for this property range from “*very ready*” to “*not ready at all.*”

Satisfaction with Assembled Pieces

The satisfaction family caregivers feel about the way they have constructed a puzzle piece determines how they will fit other puzzle pieces together. For example, one family caregiver was highly satisfied with her process piece of “accepting responsibility for pain management.” She accepts that “[she’s] *not coming up with any miracle cure... (010: 293-294)* and is satisfied with “[*making*] *the best of what [they] have... (010: 294-295.)*” She is satisfied with it because her decision to accept the responsibility was an informed one, and because she recognized the limitations to her capabilities, and finally because she accepted that she must make the best of the present situation. Given this, she fit the process piece of “accepting responsibility for pain management” with the

process piece of “seeking information on pain and pain management.” She acknowledged that part of accepting the responsibility for pain management involved collecting information on pain control. She collected information about the pain from the NOVA nurses and from “... *just...studying and researching cancer and the special type she has (010: 119-121).*” In this case, in “*gauging the best fit*” she decided to fit the process pieces of “accepting the responsibility of pain management” and “collecting information about pain management” together. This was done so she “*[felt] safe when [she] [made] decisions (010: 236)*” (e.g. about selection and timing of medications). Her satisfaction with “accepting the responsibility” was also critical in her joining this piece with the process piece of “establishing a pain management relationship.” In light of the fact that she chose the responsibility she said:

“It’s not a sense of duty. I don’t think that would be the right way to put it. It’s just something that it seems to be filling something inside of me (010: 220-222).”

As a result, the pain management relationship she developed with the patient was one where she could freely articulate her choice:

“Like if she’s being moody and she’s being uncooperative, I’ll say like: “I don’t have to do this job, you know, I can quit anytime”. And she’ll just look at me and she’ll start to laugh (010: 288-291).”

In this case, humour was described as an important part of their pain management relationship.

In another case, the family caregiver had accepted the responsibility of managing the patient’s pain but stated that it was like being in “*prison*” or a “*locked room*” (003, 025, 362). While she chose the responsibility (“*I made a promise*” (003:35)), she was not as satisfied with her choice as the previously presented caregiver because she felt she “*needed to [always] be there in case of a pain crisis (003: 369).*” She decided to fit the “accepting the responsibility” puzzle piece with the “establishing a pain management relationship” with the healthcare team piece to fulfill her promise of keeping the patient at home. Although initially she said the following:

“I don’t like strangers in my house. If I can’t get a family to come in and sit with her, then I will stay home... I’m very skeptical...I know there are resources out there somewhere (003: 228, 231, 232-233).”

Despite these initial thoughts, she made the decision to establish a relationship with the health care team and eventually *“becomes friends (003: 204)”* with the nurses and calls the doctor when the patient is in severe pain to respect the fact that she accepted the responsibility for managing the patient’s pain at home to avoid hospitalization (003: 400). As a result, the decision had to be made to join the process pieces of “accepting the responsibility for pain management” and “developing a pain management relationship,” in this case, with the healthcare professionals responsible for the patient’s pain management.

Readiness to Fit the Pieces Together

“Gauging the best fit” for two puzzle pieces to join is also contingent on whether the family caregiver feels ready to join them. For example, in one case, while the family caregiver accepts the responsibility of his wife’s pain management, he is at first hesitant to establish a relationship with the healthcare team responsible for pain management. He felt his physician could at times be “mean,” and could not care for the patient as he could. He was not ready to establish a relationship with any healthcare professionals initially. The decision to form a pain management relationship was triggered by a pain crisis, in which case he decided he needed to establish a relationship with them. Even as he did so, he was not completely reassured by the physician’s attitude, and felt *“indifferent”* about the relationship (004:273). In this case, while the puzzle pieces of “accepting responsibility for pain management” and “establishing a pain management relationship” with healthcare professionals were fitted together, the decision to do so was made tentatively. As a result, the composition of the “establishing a pain management relationship” process piece differed from others in that the relationship was not described as a strong one by the family caregiver. There were also other caregivers who were not immediately ready to fit the pain management process pieces together. One caregiver felt that he did not have enough information to engage in the “striving to respond to pain” process because

collecting information about his wife's pain, and her medication had been "*frustrating*" (002:20"). Despite feeling that his "*hands [were] tied*" and that he was "*helpless* (002: 31)" he still took on the responsibility of her pain management and felt he was doing well, but still "*wanted to improve* (002: 218)." Another family caregiver felt he was not ready to join "determining the characteristics of pain" to "implementing a strategy for pain relief," but did so tentatively, while others also expressed feelings of not being ready, but still joined them together based on a decision made to attempt to control the patient's pain (e.g. 004, 005, 006, 022).

There were also family caregivers who rushed to join process pieces together in an effort to help manage the patient's pain at home. The following example illustrates how, after accepting the responsibility of managing his wife's pain, the family caregiver immediately joined the pieces of "collecting information about pain management" and "establishing a pain management relationship" with healthcare professionals. He stated that his readiness to join the puzzle pieces together immediately was based on the following sentiment:

"... if a person is a caregiver who is willing to undertake a certain responsibility ... You don't allow [them] to do anything today without training. And there isn't anything that's more technical, complex than [being] a caregiver to a very sick person (005:767-771)."

As a result, he built relationship with his wife's professional caregivers. He described the reciprocal nature he had with the nurse caring for his wife:

"... I frankly gave her [the nurse] as much information [on the patient's pain] as she gave me because, at one point... I was able to report back to her on what I experienced on a 24-hour basis, over two days. So that was very useful for them too (005:669)."

In this case, he decided it was urgent to assemble the "strategizing a game plan" pieces as quickly as possible because he wanted to be "*functioning with knowledge rather than with ignorance* (005: 718-719)."

Some family caregivers were quickly ready to join the puzzle pieces together for the process of "striving to respond to pain". For example, readiness to assemble this part of the puzzle was based on decisions that family caregivers

needed to be “very hands-on” (e.g. 012, 018), or they needed to react immediately (e.g. 001, 019, 021). In one case, a family caregiver quickly joined the pieces of “accepting responsibility for pain management” with “determining the characteristics of pain” and “verifying the degree to which pain relief strategies are successful” based on a decision that she wanted to prevent her husband from undue suffering (001: 30), while another joined them together quickly so she could feel like she is doing everything in her power to achieve pain control for the patient (021: 71-72).

The following case examples illustrate the processes of “the puzzle of pain management,” where “gauging the best fit” can be seen as a key process in fitting the puzzle pieces together. Each family caregiver engages in the processes that comprise “the puzzle of pain management,” yet each of the puzzles remains unique to each family caregiver. The field notes were particularly useful in the provision of details for the case examples. Diagrams of these three cases can be found in Appendix VIII.

The Pain Management Process: Examples of Assembled Puzzles

Pain Management Puzzle: Family Caregiver 001-Mrs. G

Mr. and Mrs. G had been married 45 years. Mrs. G was a nurse at a Geriatric facility, and her husband was involved in the construction business. They had just bought a new condominium and had moved in a few months prior to his diagnosis of prostate cancer. Mrs. G. was on a sick leave from her work because of a mild stroke that she had suffered about 6 months prior to our first meeting. She stated that as his wife, and a professional at caring for people, she had immediately assumed “*responsibility for everything*” related to her husband’s care (001: 46). She displayed readiness to join the puzzle process pieces together and decided she was comfortable to proceed with the assembly of the pain management puzzle. Although she was prepared in terms of knowledge and experience to manage his care, including the pain management aspects, she was often weak, and fatigued quite easily, and stated that she soon realized she needed help to fulfill these responsibilities. For example, helping her husband change

positions for pain relief took a lot of energy on her part, and she stated that always having to monitor and “do” was exhausting for her as she was trying to recover from her stroke. In this case, the processes of “developing a pain management relationship,” and “collecting information” occurred simultaneously. Mrs. G expressed a lot of frustration as she discussed her attempts at obtaining supportive services from the community. She described how she tried to establish a relationship with some external community resources, and was told they “*wouldn’t come in*” (001: 148).

She had spoken about her mother’s illness, and how difficult it had been to watch her suffer and eventually die of cancer while experiencing a lot of pain. As a result of being the primary family caregiver in that situation as well, she had experienced personal angst from being so emotionally and instrumentally involved. She described how she was deliberately developing a very different pain management relationship with her husband. While she was quite successful at developing a pain management relationship with him in which she managed his pain, she kept an emotional distance by being “*professional*” in her relationship with him (001: 165). She often described several processes she was engaged in as occurring simultaneously. For example, she was also collecting information from the physicians caring for husband as part of the hospital’s Supportive Care Team. As a nurse, she had worked for many years assessing, intervening, and evaluating pain for patients with many different illnesses. As a result, most of her information was from her past professional experiences. Despite this, she described how she gathered additional information about her husband’s pain and treatment as she developed a relationship with the physician. In this case example, each process piece fits together because the family caregiver felt confident and competent and sought the other puzzle pieces in a desire to “complete the puzzle.” She then decided what to do. “Gauging the best fit” was the key to the puzzle assembly. For example, Mrs. G decided it was best to fit “developing a pain management relationship” (by more aggressively pursuing a relationship with the healthcare professionals) with “seeking information” (by getting more information about her husband and appropriate treatment). This was because she

was frustrated with the care her husband was getting when she brought him to the hospital for symptom management:

"I said 'You know what? I'm going to see Dr W'. And I went to the office and, right away, he admitted him (001:196-197)."

Mrs. G also described how she assessed her husband's pain using both verbal and non-verbal methods, and then selected an intervention based on the type of pain he had. Her descriptions of his "shooting pain" being relieved by position changes, his "nerve pain" being relieved by medications, and his "swelling pain" being relieved by elevating his legs provided insight into her ability to differentiate between the types of pain her husband had, and match interventions to them successfully. Given this information, we can examine how she pieced together the "striving to respond to pain" process pieces. She assessed her husband's pain using both verbal and non-verbal methods, and then selected an intervention based on the type of pain he had. The process pieces fit together based on the decision of selecting an intervention. Again, these processes were framed by her past experiences as a nurse and from having cared for her mother in the past. Similar to the nursing process, "verifying if pain relief strategies have worked" followed intervention and was based on a comparison to his pain prior to her intervening (001: 101-103).

In putting together the pieces of "striving to respond to pain," again, decision-making by "gauging the best fit" was an important part of when and how to fit each piece together. She talked about making educated decisions and thinking things through before she did anything to help with his pain control. Her past experiences, comfort level, and confidence were key factors in her "satisfaction" with previously assembled pieces and helped her "gauge the best fit" to move on to make decisions about joining subsequent puzzle pieces. She also stated she "*decides*" (001: 93) what medication to use based on his pain, and thus fits the "determining the characteristics of pain" and "implementing a strategy for pain relief" process pieces together. At times, if she evaluated that none of pain relief strategies had been successful, she returned to the intervention process, thus fitting the "verifying if pain relief strategies were successful" and

“implementing a strategy for pain relief” pieces together. The following statement shows at what point she decided that the best strategy for pain control was to call the physician, and why:

“So, when I, when I think the pain is getting really out of control or there’s something else going on then I call the doctors and, you know, we try to get down to the bottom (001: 206-208).”

As demonstrated above, this family caregiver completed both the “strategizing a game plan” and “striving to respond to pain” process pieces. She was able to join them because she decided to be *“totally involved in [her husband’s] care (001: 166).”* While she acknowledged that *“...it’s a hard decision to put somebody’s life in your hands (001: 116)”* she made the decision to care for him, and as a result was responsible for his pain management. Her past experiences contributed to the strong sense of self-confidence she demonstrated in her care and in the decisions she had to make. Overall, it was quite clear in both interviews that she felt *“prepared,”* and this was key to putting the “strategizing a game plan” process piece together with the “striving to respond to pain.” She made a decision to strive to respond the patient’s pain and said the following: *“I have to stay home and, and look after him. But it’s a very hard decision (001: 121).”* Once she made that decision, she assembled the pain management puzzle.

Pain Management Puzzle: Family Caregiver 008-Mrs. L

Mrs. L talked about having married her best friend, and having made a promise that she would stand by him, no matter what. Despite this, she was not completely prepared for what her promise would actually entail. Her husband, although present physically for the interviews, was not a participant as his ability to understand and to process information was limited. He was able to communicate verbally, but was not always coherent. It was clear that caring for him and managing his pain were tasks that required patience, and perhaps even creativity. Her husband had been diagnosed with a melanoma 1 year earlier that had already spread, and his physician had initially suspected brain metastases. However, his confusion and other neurological symptoms had another reason, and Mr. L was diagnosed with an early onset of dementia. Mrs. L stated that when

she accepted the responsibility of pain control for her husband with early signs of dementia, she realized she had to develop a “*complete new way of living... (008: 145-146)*” and that accepting this responsibility meant she had “*taken most of the burden (008: 298).*” After this decision, she then developed “pain management relationships” with the healthcare team and her husband. She said the following when asked to explain how pain and pain management influenced the relationship with the patient:

“I think if you care a lot for a person, you find ways as you go along... I think I’ve lost something...his support... it’s related to the sickness and the pain. (008: 304, 98-9, 103).”

The pain management relationship that she described with her husband was one in which he was quite dependent on her. She explained that this meant that she needed both resources and information to assume the responsibility she had accepted. She engaged in the process of developing of a pain management relationship with the nurses caring for her husband and this led to her ability to engage in the next process piece that she needed (“seeking information”). She requested information and asked questions and felt comfortable doing so because of the relationship she had with them. They “*give [me] books...and are involved with what [I] read (008: 73-75).*” This is how she collected her information about her husband’s illness and his pain.

Mrs. L determined the characteristics of her husband’s pain using both verbal and non-verbal methods, but often relied more on his face for an assessment of pain and pain intensity since she was not always certain if her pain assessments were impacted by her husband’s decreased ability to communicate. After her assessments, she decided that she “*...feels that [she has] to do something to make him better (008: 107).*” She gauged the best fit by relying on a “feeling” she had as to what her course of action should be. She then engaged in the process of “implementing a strategy for pain relief.” It was this decision-making that fit the two process pieces together. After intervening for pain control she would ask him how he felt and if he was still in pain after she had done

something in an attempt to relieve his pain (008: 271). This fit all three pieces together to complete the part of the puzzle related to “striving to respond to pain.”

In her case, the framework of drawing on past pain and pain management experiences was of great importance to the assembly of her pain management puzzle. Mrs. L had talked extensively and passionately about experiences with other family members who had died of cancer and admitted that these experiences colored the way she engaged in the “striving to respond to pain” process. She felt strongly that *“too much medication...diminishes [the patient] (008: 312-313).”* This coupled with a previous negative experience her husband had with morphine made her hesitant, so when she intervened for pain control she would *“tend to give him less [medication] (008: 99).”* This continued until her engagement in the “developing a pain management relationship with the healthcare team” and “seeking information” processes led to an alteration in her giving of pain medication and the process of “implementing a strategy for pain relief.” She explained that once the physician had explained things to her she felt *“prepared”* after receiving reassuring information (008: 119). This was one example of her “readiness to fit the pieces together.” She was also very “satisfied” with the process pieces of “seeking information” and “establishing a pain management relationship” with the health care team because she stated she saw that her husband really did look so much more comfortable after she gave him medications for his pain. This led to her decision to *“...give him [the medication] rather than have him in pain...(008: 111)”* and her feelings of preparedness were critical in helping her fit the process pieces of “strategizing a game plan” and “striving to respond to pain” together.

Pain Management Puzzle: Family Caregiver 017-Mr.D

Mr. D was the 45 year old son of a man with colon cancer that had metastasized to his lung and liver. This family caregiver was a teacher from Halifax, and shared caregiver responsibilities with two other siblings who were also from out of town. It was his turn in the rotation to be in Montreal and be the primary caregiver for his father for four months. His is a case where the family caregiver had completed the “striving to respond to pain” piece and the

“strategizing a game plan” piece, with the composition of the individual sub-process pieces being composed slightly differently than the previous examples. Mr. D’s past experiences provided the frame that bordered the pain management puzzle in this case. When asked what influenced how he managed his father’s pain at present he said: *“past experience with a family member taking prescription pills and abusing them severely (017: 223).”* This was seen to affect his decisions related to pain management, and his “readiness to fit the pieces together.”

In “strategizing a game plan” for his father, “accepting responsibility” for being involved in his father’s pain management was once again the first process piece of the pain management puzzle. Mr. D accepted responsibility, but not as fully as the caregivers in the previous examples. He lived at a distance, and had been the main family caregiver for about 3 weeks. Given the fact that he alternated the caregiving responsibility with his 2 siblings and that his father insisted on being responsible for his own pain medications, his level of responsibility was much lower than the family caregivers from the previous examples.

Unlike the previous examples, while he did accept responsibility for his father’s care, and to a certain degree, his pain management, he also stated that he *“[didn’t] make that [his] full reason for existence (017: 242).”* This showed that the composition of his process piece “accepting responsibility for pain management” is different from the previous examples where both wives had invested themselves fully in their pain management duties by accepting complete responsibility for their family member. Although he was “ready” to proceed to join the other process pieces together, he was not ready to assume complete engagement in the processes as the other family caregivers had.

Mr. D then made the decision that he was comfortable with this responsibility and with the change in the relationship he would experience as a result of this. This decision fit together the two process pieces of “accepting responsibility for pain management” and “establishing a pain management relationship.” Despite the fact his father was an independent man, he still required

care, but his son said *“I don’t consider it to be a burden. I don’t find it frustrating that I need to be there to do things. I’m ok with that (017: 179-181).”* He accepted that his father would be more dependent on him in this new pain management relationship. When asked to describe the relationship he has with his father as a result of the pain management responsibility, Mr. D became quite emotional and began to cry as he tried to explain the impact of the cancer on the both of them. He said they now *“talked a lot more frankly about [their] emotions... and that’s brought [them] a lot closer together (017: 153, 157).”*

In comparison to the other family caregiver examples, he was more invested in developing a pain management relationship with his father than in developing one with the healthcare team. He decided to leave the latter up to his sister because he felt she was better qualified for that, being herself in a health-related field (017: 194). His “satisfaction with the previously assembled puzzle piece” of “establishing a pain management relationship” with his father was instrumental in his decision to proceed and engage in other processes as part of the pain management puzzle. The realization that he would have to manage some aspects of his father’s pain at some point was quite intimidating for him. Nonetheless, he did develop a tentative relationship with the community resources but it was not as developed as perhaps the relationships described in the previous caregiver examples since he seemed less comfortable in this relationship when he said: *“...you don’t want to call and waste somebody’s time (017: 188).”*

He also did not invest much time in seeking information about his father’s medication or about pain, and admitted the following:

“How much do I know about the meds? Not that much. Like I know Dilaudid’s a much heavier duty pain reliever than the Tylenol and the ibuprofen. That’s about it (017: 195-197).”

Despite this, he still had the process piece of “seeking information about pain management” as a part of the pain management process he was engaged in because he got information from his sister. He described one example of how this piece was joined to the “developing a pain management relationship” process piece as a result of the decision to collect information on emergency contacts. As

he spoke about his relationship with his father, it was clear that communication about pain was not a common topic for discussion. Mr. D was very worried about missing cues about a pain crisis. He expressed fear that he would not be able to help his father if the pain became unbearable and difficult to control. This meant that he had to “fit” his relationship process piece and his “accepting responsibility” piece with that of “seeking information about pain management” in order to be prepared. He collected information about emergency contacts in case of such a crisis. Both pieces of the puzzle were necessary to ensure he was completely prepared to manage his father’s pain.

Overall, he felt that *“he [was] fine (017: 200)”* with having the amount of information he had and that he was sufficiently prepared to manage his father’s care, and perhaps his pain. He fit the processes of “strategizing a game plan” with “striving to respond to pain” together despite his concerns about pain medications. He did this because he decided that he felt sufficiently prepared and knew *“that [he] can make the call [for help] anytime (017: 187).”*

As part of the process of “striving to respond to pain,” the family caregiver felt that most of his efforts were concentrated on his pain assessments. He decided his methods of assessment based on the relationship he had with his father who was very independent:

“I won’t ask directly: ‘Are you in pain?’. I’ll say: ‘How are you doing?’... And if he sort of goes (mumbling) ‘yeah, yeah’...that kind of thing, that’ll be my clue. Yeah, he’s in pain. (017: 73-75).”

When he did feel that his father needed an intervention to relieve his pain, he decided not to actually give medication. His intervention or course of action was to suggest that his father take something himself to relieve the pain. This links with the established relationship he had developed with his father related to pain management, where his father maintained control over what he chose to. This decision also fit the pieces of “determining the characteristics of pain” with “implementing a strategy for pain relief” together because while he may not have intervened directly, he still intervened by suggesting an intervention: *“I’ll say:*

'Well, you know, you're not looking too good dad, why don't you take something?' (017: 75-77)."

Mr. D was greatly influenced by the past abuse of pain medications by other members of his family (i.e. two cousins). These memories influenced his beliefs and created a certain fear in him when it came to giving pain medications and/or monitoring their effects. He stated that his decision to constantly monitor his father for pain was based on some "uncertainties" and the fact that "*...it really scares [him] that the pain medication is unlimited (017: 212-213).*" This explained why and how he fit the intervention process piece of "implementing a strategy for pain relief" with "verifying the success of pain relief strategies." He said that he played a "*huge (017: 272)*" role in assessment and in evaluating comfort level after his father took his medication, but was less involved with actual concrete pain relief strategies. Again, the composition of the process pieces in his pain management puzzle differed from the previous caregivers in that his involvement in actual pain control intervention was limited. This was related to several factors, including his father's desire for independence, his temporary family caregiver status, and his concerns related to pain medication. Despite this, he still engaged in the process of "striving to respond to pain" because he suggested that the patient take his medications to control pain, and was actively involved in assessment and the evaluation of pain relief.

Across Case Comparisons

If we begin by looking at the first necessary process puzzle piece of "accepting responsibility," we see that while Mrs. G and Mrs. L accepted full responsibility for pain management, Mr. D was more hesitant and selective in what he chose to be responsible for. There are three main reasons that can explain this variation in acceptance. The first is the type of the relationship the family caregivers had with the patient. Throughout the study, those caregivers who were spouses were almost always completely invested and involved in various aspects of the pain management process. The nature of the marital relationship was seen as "for better or for worse" (e.g. 011, 017), and the choice to become the one responsible for pain control was almost predetermined, although, as evidenced in

the case studies, we saw that these caregivers still had to go through an acceptance process. Unlike in the case of Mr. D, daughter/niece patient dyads discussed “role reversal” and talked about their accepting responsibility being akin to their parent having previously taken care of them. Another reason Mr. D accepted partial responsibilities was because he did not live in Montreal, and was sharing family caregiving and pain management responsibilities with his siblings.

Finally, as always, the context of past experiences accounted for the differences in how they accepted responsibility for pain management. Past experiences also impacted differences in comfort level giving pain medications. For example, Mr. D had previous negative experiences with pain medications with other family members, Mrs. L, however, was able to overcome this and give medications because she saw the relief they provided. Her continual seeking of information and a strong pain management relationship with the homecare nurses provided her with information and support leading to a change in her beliefs and subsequently in her pain management behaviours. Mrs. G accepted the responsibility for pain management given both her background as a nurse and as a previous family caregiver. Her past experiences accounted for the difference in her comfort level giving medications. It also explained her ability to articulate what the medications were for, and her decisions about when to change their doses and frequencies.

The pain management relationships each of these caregivers had with the patients also differed. Mrs. G talked about how she maintained an “emotional distance” from her husband, while Mrs. L talked about how she had lost the “emotional” connection with her husband secondary to his early dementia. Mr. D described how he “got closer” to his father. Again, the nature of the relationships can help explain the variability. Mr. D had discussed how his father’s illness had brought him back to Montreal so that he could spend time with him. He did not have a pre-existing close or strong relationship with the patient, as the family caregivers who were spouses often described. The past experience Mrs. G had caring for her mother who died of cancer while experiencing a lot of pain was the

important factor in determining her relationship with her husband, where she kept her distance to protect herself.

Another difference noted across these cases was in the process piece of “developing a pain management relationship” with the healthcare team. The variability in these cases was related to the level of commitment and responsibility that was part of the “accepting responsibility” process piece. Mr. D reported he was not fully engaged in this process, whereas the other caregivers who were responsible for the patient’s pain control required, and sought out, support. They were much more invested in developing relationships with the physicians (Mrs. G) or nurses (Mrs. L).

There were also observable differences in how much information was needed by the family caregivers. Once again, the frame of past experiences explains the differences in how they were engaging in the processes. As a nurse, Mrs. G required less information, while Mrs. L required more, and therefore sought it out from the nurses and by reading. In contrast, Mr. D had negative experiences with pain medications and did not seek information about them or how to give them. In fact he was comfortable with his limited knowledge, stating he had all the information he felt was needed. Again, closely tied to this was the fact his responsibility to manage his father’s pain was mainly around assessment, and not intervention.

In sum, the above three case examples demonstrate that while all family caregivers engage in similar processes, the composition of the process pieces may differ. The entire pain management experience, or puzzle, is very dependent on the past experiences that the family caregivers have had in their lives related to cancer, pain, pain management, and medications used to control pain. These past experiences explained much of the variability across the cases, as was demonstrated by the examples of family caregivers Mrs. G, Mrs. L, and Mr. D. “Gauging the best fit” was a decision-making process that emerged as the important link that enabled and was necessary for the joining together of the process pieces. The process of “accepting responsibility for pain management” came first for “strategizing a game plan” at home. This process was critical to

understanding how they made many of their decisions. For example, it impacted how they engaged in developing relationships with the patients and with the healthcare team members. The more invested they were, and the higher their level of responsibility for pain control, the more importance they placed on seeking information and developing and maintaining relationships with healthcare professionals. This also meant that their involvement in the “striving to respond to pain” process was influenced by how much responsibility they accepted, and how committed and comfortable they were.

After this piece of “accepting responsibility”, the order in which the other puzzle pieces were assembled was not critical in the process, and the family caregiver often seemed to be engaged in each process simultaneously. The joining of the “strategizing a game plan” process with the “striving to respond to pain” process was based on the decision that family caregivers felt they were ready to proceed with the actual care involved in managing the patient’s pain at home. Once fit together, these two processes together formed the pain management process for family caregivers. Puzzle pieces became clearer over time, as confidence grew in the decisions related to pain management. Each puzzle was slightly different, as explained by the case examples. The commonalities were that the processes and sub-processes were all engaged in with the intent to “chase the pain” from the patient. Furthermore, the sub-processes of “drawing on past experiences” and “accepting responsibility” often explained much of the variability between cases and also influenced how decisions were made as caregivers were “gauging the best fit.” The puzzle of pain management was completed by all family caregivers in the study, and the assembly of this puzzle was based on several critical processes and sub-processes that have been presented in this chapter.

DISCUSSION

In this section of the thesis, the study questions are revisited, with an emphasis on the implications of the theoretical model that was derived from the study findings. I will also examine how these findings relate to the existing literature. The “puzzle of pain management” and its processes are compared to a coping model, a decision-making model, a problem-solving model and other family caregiving models. These are examined and compared to the pain management process discovered here and similarities and differences are highlighted. The theoretical contributions and related clinical implications are presented. The previously identified gaps from the literature review section are discussed to examine if the results from this study were able to provide information towards filling any of those gaps. Implications of such new information will be discussed. The limitations of this study are discussed. Finally, the important role this grounded theory study has for future research and its potential influence on policy concludes this discussion section.

Revisiting the Study Questions

This study focused on the following question: What is the process used by family caregivers at home to manage the pain of palliative cancer patients? Secondary questions were related to the types of pain family caregivers of palliative cancer patients were managing at home and the interventions that family caregivers were performing at home.

What is the process used by family caregivers at home to manage the pain of palliative cancer patients?

The “puzzle of pain management” describes the process of pain management used by family caregivers at home to manage the pain of palliative cancer patients. Each of the puzzle pieces represents an important process that, once fitted with the other pieces of the puzzle, explains how they view their pain management process. Previous work outlines processes that are consistent with

the “striving to respond to pain” process. For example, Yates et al. (2004) observed that both pharmacological and non-pharmacological strategies involve “assessment, planning, intervention, and evaluation” (p.288). This was similar to “striving to respond to pain”. While this study found similar the results, it was also indicated that there was another process occurring as family caregivers took on the responsibility of managing pain for a family member at home, the other being “strategizing a game plan” that needs to be fit with “striving to respond to pain.” Although the creation and the execution of them were at times quite different for some family caregivers, these two processes were central to establishing their pain management regimens at home. All the family caregivers assembled their pain management puzzle by attaching “*strategizing a game plan*” and “*striving to respond to pain*” using a decision-making process. Family caregivers often moved frequently between the two processes, and may have been engaged in different activities or sub-processes from either or both at any given time. The emergence of these two processes and the sub-processes provide, in essence, the answer to the main research question proposed at the beginning of this study.

To date, there has been no study or description of exactly what activities family caregivers are engaging in for pain management, or how they are making decisions related to pain control when caring for patients in pain in their homes. Family caregiving processes have been studied, and pain management is often mentioned as a part of the process. Models such as “The labor of caregiving: a theoretical model of caregiving during potentially fatal illness” (Steltz & Brown, 1999); “A transactional model of cancer family caregiving skill” (Schumacher, Biedler, Beeber, & Gambino, 2006); and “Caregiving and the stress process model” (Pearlin Mullan, Semple, & Skaff, 1990) all describe processes of family caregiving, but none focus specifically on pain management. Since an important part of grounded theory is to compare the theory with other models in the literature to determine if similarities exist in explaining the phenomena under study (Munhall, 2007), it was proposed in the background section of this thesis that the findings of this study be compared with the existing frameworks of

coping, problem-solving, and decision-making to see if the pain management process at home has overlapping features that may be explained in part by any or all of them. Since these models form some part of some of the family caregiving models mentioned above, these models will also be included in the following discussion.

“The labor of caregiving: a theoretical model of caregiving during potentially fatal illness”

Steltz & Brown (1999) looked at the family caregiver process of delivering care to patients with the life-threatening illnesses of cancer and AIDS (Brown & Stetz, 1999). Similar to this study, the patients were at the end of their illness trajectory. In contrast, they looked at family caregiving over time (10 weeks) and described sequential phases with specific tasks for family caregivers to accomplish. They described four phases of the caregiving process: “becoming a caregiver,” “taking care,” “midwifing the death,” and “taking the next step”. While they do not discuss pain management explicitly, it can be seen as part of the processes described. For example, during the phase of “becoming a caregiver” (sub-categories “choosing to care”, “developing competency”, and “looking to the future”) they must learn and develop new skills, one of which is often pain management. Furthermore, “choosing to care” can be paralleled to “accepting the responsibility” in this grounded theory study. Choosing to care was a comfortable decision made by the family caregiver given the nature of the relationship they had with the patient (Steltz & Brown, 1999). In this study, accepting the responsibility for the patient’s pain control was often done freely and because of the relationship as well. However, an additional important finding was that some caregivers felt trapped after having assumed the responsibility for pain management, but still did not regret their decision to do so. “Developing competency” which is similar to “collecting information about pain management,” involved family caregivers collecting information from various sources in order to have a better understanding of the illness and to gain some control over their situations. As in this study, it seems implied that “preparing” for the responsibility of caregiving in their model (e.g. choosing to care, developing

competency, collecting information) may occur at the same time as the actual caregiving and continues throughout the patient's illness as they must constantly "refine their skills" (Stelz & Brown, 1999, p. 191).

During the phase "taking care" (subtheme: providing comfort and support) they describe as part of their model an example of pain management. "Taking care" meant "doing" to meet the patient's needs. The present study looked at one aspect of "taking care" of the patient, and examined it in depth. It studied the family caregiving tasks of providing comfort and support (e.g. pain management) as an independent process, recognizing that it is enmeshed in the larger process of caregiving, but requiring study as an independent and vital process on its own because it involves more than just "taking care." The results of this study suggest that it also involves preparing to provide the care, and evaluating the success of that care (e.g. with pain management). Furthermore, the family caregiving model described by Steltz & Brown (1999) includes the bereavement phase, or "taking the next step." The puzzle of pain management did not and cannot include such processes since the responsibility and process of pain management the family caregivers were engaged in ended once the patient died.

"A transactional model of cancer family caregiving skill"

"A transactional model of cancer family caregiving skill" (Schumacher, Biedler, Beeber, & Gambino, 2006) was developed focusing on the skill acquisition process for family caregivers. In this study, family caregivers were looking after cancer patients who were receiving active treatment, with the treatment goals being cure, control, or palliative care. They also included some patients in their study, but with limited success due to recruitment issues. Despite the different patient population, the results from their study are of interest as they describe a model of caregiving skill, and pain management can be considered one of the important skills people have to learn and then use in their role of family caregivers. Their model depicts "*caregiver processes*" at the center (including such processes as monitoring, interpreting, making decisions, taking action, making adjustments, accessing resources, providing hands on care, working together with the ill person, and navigating the health care system (p. 276-277)).

Each of these processes has several sub-processes that capture specific aspects of caregiving that caregivers might use to respond to the *demands of the illness situation* and to the dyad's *pattern of care*. The model includes an extensive list of possible demands of the illness: symptom management; nutrition support; modification of usual activities for the illness situation; interpersonal care; implementation of a treatment regimen; management of acute illness episodes; use of community resources; and navigation of the health care system. Patterns of care referred to: the shared involvement where both patient and caregivers shared responsibilities; when the patient used self-caregiving; or to a family caregiving pattern after a decline in the patient's health. The authors also stress the importance of context in the model, noting that "whether caregivers used or did not use a particular skill had little meaning independent of context" (Schumacher, Biedler, Beeber, & Gambino, 2006, p. 275).

Several aspects of the "puzzle of pain management" appear to fit into different parts of the "transactional model of cancer family caregiving skill." Given the definition of caregiving skill they used, where family caregiving skill is "the ability to respond effectively and smoothly to the demands of the illness and the pattern of care using the above mentioned processes" (Schumacher, Biedler, Beeber, & Gambino, 2006, p. 283), pain management can be viewed as a family caregiving skill that is acquired using their proposed model. The patient's pain is the "demand of the illness situation" and falls under their category of symptom management. The assembly of the "pain management puzzle" can be seen as part of family caregiver processes used in response to pain, incorporating several of their suggested processes which in this study emerged as the process puzzle pieces. For example, the authors used an example where pain management used the processes of monitoring ("determining the characteristics of pain"), interpreting ("determining the characteristics of pain and "decision-making"), making decisions ("decision-making"), taking action ("implementing a strategy for pain relief"), making adjustments ("verifying the success of pain relief strategies" and then "implementing a strategy for pain relief"), and navigating the healthcare system ("developing a relationship with the healthcare team" and

“seeking information”). These processes were part of a family caregiver response influenced strongly by context, in particular, previous experiences, as was seen in this grounded theory study.

While there is some overlap between the “transactional model of cancer family caregiving skill,” and the theory proposed in the present study, the latter explores the process of pain management in more depth by selecting one of the demands of the patient’s illness, and examining the family caregiver response to it. Furthermore, it manages to tease out two major processes, “strategizing a game plan” and “striving to respond to pain” which underscores and recognizes that both may be occurring simultaneously and that they must fit together before optimal pain management can occur.

In the “transactional model of cancer family caregiving skill,” Schumacher, Beidler, Beeber, & Gambino (2006) further mention that decision-making was an important process for family caregivers, and was comprised of the following sub-processes: 1) taking into account multiple cancer-related care issues when deciding what to do; 2) taking into account care demands related to illnesses other than cancer; 3) weighing competing illness care demands; 4) weighing advantages and disadvantages of alternative strategies; 5) attending to multiple care issues at once; 6) thinking ahead about possible consequences of a given action; 7) planning ahead about needed care; and 8) acknowledging limits of own abilities. Similar to this study, they found that family caregivers engaged in this process in varying degrees. Although not specific to the skill of pain management, some of the sub-processes in the Transactional model may certainly be applicable to pain management at home for palliative cancer patients. For example, we can reformulate them slightly to get: 1) taking into account multiple cancer-related care symptoms when deciding what to do; 2) taking into account care demands for pains other than cancer; 3) weighing competing pain demands; 4) weighing advantages and disadvantages of alternative pain-relief strategies; 5) attending to multiple pains at once; 6) thinking ahead about possible consequences of a given action, or pain relief strategy; 7) planning ahead about pain patterns; and 8) acknowledging limits of own abilities. Although some of

what is described above resonates with “gauging the best fit” as part of the “striving to respond to pain” puzzle piece, the results of this study shows that the decision-making processes are also important in the “strategizing a game plan” process that does not seem to be reflected in the above description of decision-making. Given the importance of decision-making in this model, and in the “puzzle of pain management,” a discussion on decision-making will follow.

Decision-making

Studies of family caregivers and decision-making at the end of life has focused on treatment options (Holley, 2007), life sustaining treatments (Hansen et al., 2005), placement/institutionalization (Elliot, Gessert, Pedin-McAlpine, 1997), and pain management (Taylor, Ferrell, Grant, & Cheyney, 1993). Decision-making emerged as a critical process as family caregivers “gauged the best fit” between puzzle pieces within the larger process of pain management. The results of this study validate Ferrell & Dean’s (1994) statement that family caregivers who are responsible for pain management have the implicit role of decision-maker in support of the patient in pain, and Sims, Boland, & O’Neill’s (1992) findings that a family caregiver’s previous experiences, values, and emotions substantially shaped their decisions regarding care in the home. For example, the frame for the “puzzle of pain management” is made of the family caregivers’ previous experiences with pain and pain management and encompasses their pain management process because they “draw on” these past experiences as they both “strategize a game plan” and “strive to respond to pain”

Family caregivers engaged in a decision-making process before attaching any of the sub-process pieces together, and before “strategizing a game plan” and “striving to respond to pain” were joined to complete “the puzzle of pain management.” Decisions made in this study were very specific to pain management, and occurred depending on the readiness of the family to fit the process pieces together.

Decision-making is also an important part of the problem solving framework (see next section) and “involves evaluating the available solution

possibilities and selecting the most effective alternatives for implementation” (Houts et al, 1996, p. 68). This definition was based on the assumption that family caregivers were given expert information. In this study, this was reflected in the decision-making process that occurred as family caregivers attached the “determining characteristics of pain” to “implementing a strategy for pain relief.” Unlike a previous study that found that family caregivers reported little involvement in making decisions related to interventions (e.g. the giving of medications) (Yates et al., 2004), this study showed that family caregivers did indeed make decisions on how and when to intervene. These decisions were often based more on a variety of factors, including pain intensity, family caregiver feelings and intuition, and communication patterns, instead of on expert information.

In this grounded theory study, the decision to join two process pieces together was prompted both by the satisfaction the caregiver felt with a puzzle piece and with their feelings of readiness to join another piece to the puzzle they were creating. This information brings forth new information on the process of decision-making, unlike previous studies that focused on the “content” of decision-making (Taylor, Ferrell, Grant, & Cheyney, 1993) or view decision-making as a discrete event instead of an “aspect of ongoing caregiving by families” (Hansen et al, 2005p. 33-34). Critical to the process of decision-making for the “puzzle of pain management” in this study was: the severity of the pain, the type of pain, communication patterns between the patient and the family caregiver, a “feeling” caregivers had that they must intervene, their desire to prevent the pain and the availability of other caregivers. These factors were all framed by the family caregivers’ past experiences and existing knowledge base. Pain intensity was the single most important factor in deciding when to intervene.

The results of this study underscore the importance of the statement “inherent to managing pain at home is decision-making” (Taylor et al., 1993). They also show that while information was an important factor in decision-making, past experiences had a large role too. This was particularly relevant in this study as many caregivers reported the lack of information related to pain

management. In earlier work, Sims, Boland, & O'Neill (1992) also found that the process by which a person "frames" a problem is essential in understanding decision-making. In this study, the "problem" was the management of the patient's pain.

Taylor, Ferrell, Grant, & Cheyney (1993) found that family caregivers were typically making decisions related to assessment using type, location, and intensity of the pain to decide how they should intervene. They also made critical decisions about "choosing the right medication" (i.e. intervention) and "whether it worked or not" (p. 923). The results from this study validate these earlier findings (e.g. family caregivers "determine the characteristics of pain" then decide when and how to "implement a strategy for pain relief" and "verifying the degree to which pain relief strategies are successful" and adds to them by recognizing that they also make decisions about: accepting the responsibility for pain management, developing relationships with the patient and the healthcare team, and collecting information. Overall, it puts forth the idea that pain management involves the two processes of "strategizing a game plan" and "striving to respond to pain" and that decisions made are not limited to assessment, intervention, and evaluation (i.e. limited to "striving to respond to pain").

This information is valuable to nurses because the provision of expert information necessary to make key decisions, as suggested by Houts et al. (1996), must be included in any planned intervention for family caregivers managing pain at home. Of equal importance is the knowledge that there are multiple influencing factors that either facilitate or inhibit family caregiver decision-making. Nurses should recognize and explore these in order to be in a position to support effective decision-making or encourage family caregivers who may be struggling with the decision-making process. Finally, it should also be recognized that decision-making processes are an important component of problem-solving processes. This is discussed next.

Problem-solving

Family caregiver problem-solving, specific to an advanced cancer population at home, has been defined by Houts et al. (1996) as the rational and

systematic construction of a solution through the use of specific problem-solving processes: (1) problem orientation, (2) problem definition and formulation, (3) generation of alternatives, (4) decision-making, and (5) solution implementation and verification. They also believe that this process is the same for family caregivers and for health professionals. In examining the results of the present study, while the “puzzle of pain management” does contain several elements that can be paralleled to the problem-solving process, it involves a combination of many sub-processes and is, overall, a far more complex process. Furthermore, the processes described by some family caregivers in this study were not always “rational and systematic,” at times being based on intuition or engaged in as part of a developed, comfortable routine. Another point of interest is that while problem-solving may indeed appear to be similar for both health professionals and family caregivers as suggested by Houts et al. (1996), the past experiences of family members were not all professional by nature, and the relationships they had with the patients they cared for were far more involved and intense than any relationship healthcare professionals had with the patients. As a result, family caregiver problem-solving may share some aspects similar to the process used by healthcare professionals, but their decisions and their problem orientation, definition, and formulation were most certainly influenced by different factors.

The elements of problem-solving described above can be viewed as parts of several process puzzle pieces that make up the “puzzle of pain management.” They can be discussed as similar to the puzzle pieces of “striving to respond to pain” where problem definition and formulation is “determining the characteristics of pain”; generation of alternatives and decision-making are part of deciding a course of action; solution implementation is “implementing a strategy for pain relief”; and verification is “verifying the degree to which pain relief strategies are successful.” For example, many family caregivers defined the problem as pain, generated pain relief options and selected a course of action, chose interventions, and then evaluated the results. Therefore, problem-solving can be seen as a possible explanatory piece for the process “implementing a pain relief strategy.” However, when and how the family caregivers chose to engage in

each step was different, resulting in very different pain management processes. In addition, the “strategizing a game plan” and “drawing on past experiences” processes are missing from the problem-solving framework. Perhaps this may explain why standardized problem-solving training using a COPE (Creativity, Optimism, Planning, and Expert information) intervention for family caregivers to improve symptoms of hospice home care patients failed to diminish the actual intensity of the pain for the patients (McMillan & Small, 2007).

Houts et al. (1996) stressed the importance of expert information for problem-solving to be successful, however, many family caregivers in this study expressed the lack of such information. This made it difficult, if not impossible for them to engage in optimal and successful problem-solving. This fact strengthens the proposal made by Houts et al. (1996) that these problem-solving steps need to be taught to family caregivers of cancer patients at home. They suggest basing educational materials (problem-solving manuals) for family caregivers on a COPE model, including information and coping strategies, and suggest means to communicate with healthcare professionals. COPE interventions have had previous success with caregivers of advanced cancer patients (Cameron, Shin, Williams, & Stewart, 2004; McMillan & Small, 2007). While the creation of such manuals is certainly an important teaching intervention and a much needed resource for family caregivers, it was clear from this present study that family caregivers needed a much more individualized and broader approach. None of their pain management puzzles were found to be identical.

For example, the following were identified as the types of information that needed to be included in the educational manuals: 1) general information about the problem, including its causes and consequences as well as reasonable goals for family caregiving efforts; 2) when and how to get help from health professionals, as well as facts they should have ready when they call; 3) what family caregivers can do on their own to deal with or prevent the problem; 4) obstacles that interfere with carrying out a plan and how to deal with them; and 5) how to develop an orderly plan, how to monitor its effects and how to make appropriate adjustments (Houts et al., 1996, p. 70-71). While these were also

identified as important by the family caregivers in this study (with the majority of information needed relating to pain and pain management), it was also found in this study that information needs differed from caregiver to caregiver, and that their reasons for collecting information were varied. This underlines the need to evaluate and understand individual family caregiver information needs, the way they process their information, the manner in which they feel comfortable collecting information, and their comfort level in using the information. Above all, their individual past experiences, thoughts and feelings related to pain management need to be part of a baseline assessment to collect critical information that must be addressed. This may be overlooked in the standardization of teaching materials, especially if they are only focused on the more narrow theory of problem-solving proposed by Houts et al. (2006).

Overall, problem-solving bears semblance to the process puzzle piece of “striving to respond to pain.” It also contains elements of “seeking information about pain and pain management,” a crucial part of the process of “strategizing a game plan” (e.g. problem definition and formulation involves seeking all available facts and information). It further involves decision-making, which was seen as a critical process that attached the process puzzle pieces together, and will be discussed below. Therefore, problem-solving can be seen as a part of the process of pain management at home, but the complete pain management process involves several more processes that are not included in a problem-solving framework, such as drawing on past experiences and establishing relationships with the patient and/or healthcare team.

“Caregiving and the stress process model”

Several studies in palliative care have used the stress process model to examine family caregiver experience (Hauser & Kramer, 2004; Kinsella, Cooper, Picton, & Murtagh, 1994; Waldrop, Kramer, Sketny, Milch, & Finn, 2005). The “caregiving and the stress process model” was first proposed by Pearlin, Mullan, Semple, & Skaff (1990) and is a theoretical framework that is used to understand

the variability in the well-being of caregivers. It has more recently become a useful model to understand family caregiver experiences as they care for patients at the end of life (Hauser & Kramer, 2004). Since the stress process model incorporates coping theory, coping theory will be presented here, followed by a discussion on the stress process model. A comparison of these will be made to the “puzzle of pain management.”

Coping Theory

Lazarus & Folkman (1984) define coping as behaviours and thoughts that are used to meet the demands of a stressful situation. While some family caregivers were indeed reacting to the patient’s pain as a stressor, others did not necessarily describe the patient’s pain as stressful. In fact, many family caregivers managed the patient’s pain well, having established a routine or a pattern. Family caregivers did discuss the patient’s pain as a concern for them and acknowledged that the pain was a trigger for them requiring a response, however, it was not always a stressful stimulus if they felt it could be well managed. Furthermore, the coping framework requires a trigger or primary stressor, initiating a coping response. There were some family caregivers who were starting their assembly of the “pain management puzzle” with the “implementing a pain relief strategy” process piece. As a result, the family caregiver did not always assess for the trigger of pain before initiating their pain control responses. This was evident in the cases where they were giving medications as a preventive measure or if they were following a prescribed schedule of medication. In these cases, the family caregiver “response” or action was to intervene for pain relief, but did not have the requisite stressor that the coping theory requires. It is important to note that pain may have initially been a trigger for a stress response and had ceased to be one as a result of the passage of time and experience of good pain management when they were being interviewed for this study.

In comparing Lazarus & Folkman’s (1984) coping theory with the pain management process of family caregivers at home, some parallels can be drawn. They describe problem-focused processes aimed at managing the problem, and emotion-focused processes to control emotions of distress evoked by the initially

stressful situation. If the patient's pain can be labeled the "problem", there was evidence that family caregivers used problem-focused strategies to manage it. The tracking and recording of pain and pain interventions done by some family caregivers was one example of this. When trying to compare emotion-focused processes to the reactions of family caregivers managing advanced cancer pain at home, it was seen that they did use some of the emotion focused coping behaviours described by Folkman & Lazarus (1980) (e.g. distracting activities). These family caregivers did not use these strategies as a coping response for themselves, rather they encouraged the use of such strategies to help the patients cope with their stressor of pain. Furthermore, family caregivers did not seem to engage in emotion-focused processes to cope with their roles as family caregivers necessarily specific to pain management. They did however engage in problem-focused behaviours such as seeking external support or information. Emotion-focused strategies were not explored in depth for this study, and were an interesting finding that needs to be explored more directly in future studies.

The Stress Process Model

The stress process model for family caregivers identifies four major components in the family caregiver's experience (Pearlin, Mullan, Semple, & Skaff, 1990). The first is the background and context of the situation (e.g. demographic characteristics and the illness trajectory such as the onset of symptoms and diagnosis). As previously mentioned, the model incorporates elements from coping theory when they mention their primary and secondary stressors. Primary stressors include caregiving tasks through the continuum of care (e.g. hands on personal care, instrumental tasks and managing change) and unique to end-stage caregiving (e.g. near acute care, executive functioning and final decision-making). Secondary stressors include family/role conflict, work conflict, and financial strain. A third component is family caregiver outcomes (e.g. negative and positive indicators) and the fourth is the resources (intrinsic and extrinsic) available to moderate stress and therefore potentially improve

outcomes. Although appropriate to look at many family caregiving experiences, this model does not appear to fully capture the pain management experience. Using this model, pain may be viewed as a primary stressor for the family caregiver, resulting in a range of family caregiving tasks related to pain management. Unrelieved or poorly managed pain may result in secondary stressors. Examples may be feelings of helplessness or strained relationships with the patient. The resources in this case may be the healthcare team or family members. The context of the family caregiver situation, as in the “puzzle of pain management,” has an influence on the overall experience for the family caregiver. The results of this grounded theory show that not all family caregivers viewed pain as a stressor, which would render the stress process model as an inappropriate model to use to interpret the pain management process for them.

Overall, neither the coping framework or the stress process model seem to adequately explain or capture fully the pain management processes that family caregivers engage in to manage pain at home. The question of whether this pain management process can be viewed as a problem-focused process to manage the “problem” of the patient’s pain can be answered as follows. The family caregivers were responding to the patient’s pain, but did not necessarily appraise it as a stressor at the present time. Pain management was, at times, a regulated routine where the family caregiver responded to a schedule instead of a trigger. Their behaviours and engagement in the two pain management processes of “strategizing a game plan” and “striving to respond to pain” were aimed at facilitating the patient’s pain relief. The stress process and coping theories make the suggestion that an individual’s coping skills are key to their ability to successfully adapt to a stressful situation.

Furthermore, the stress process model fails to capture the processes leading to the family caregiver’s ability and comfort level with their caregiving tasks done in response to the primary stressors. This is how the “strategizing a game plan” part of the “puzzle of pain management” differs from the stress process model. It provides a more in depth description of the overall complex processes involved with pain management. As mentioned by Schumacher,

Biedler, Beeber, & Gambino (2006), the stress process model does not focus on caregiver skill. Pain management is a critical family caregiver skill, particularly for those caregivers managing pain for palliative cancer patients in their home. It is for this reason that the process of pain management that they engage in can best be understood using the “puzzle of pain management” which was developed with a focus on pain management and is grounded in the experiences of family caregivers engaged in such pain management processes.

Implications of the Theory- “The Puzzle of Pain Management”

Theoretical Implications

The development of a theory specific to family caregivers who are managing pain for palliative cancer patients at home has several important implications. The first critical theoretical contribution the “puzzle of pain management” makes is that it is the first, to my knowledge, caregiving theory that focuses exclusively on the process of pain management as experienced by family caregivers of people with cancer providing care at home with the responsibility of pain control. Although it has elements similar to the previously published processes or models above, it has the unique focus of pain management in the context of the home environment. Secondly, the theory prompts the realization that the actual pain management process for family caregivers begins before they actually have to start “doing.” In fact, it begins from the moment they need to decide to accept at least some responsibility for pain management and includes the time they must spend preparing for it. This “becoming a caregiver phase” with all the new knowledge and skill required by the family caregiver been shown to have a significant impact on them since it is an extremely emotional time for them as they deal with the diagnosis and progression of the patient’s illness (Steltz & Brown, 1999). Furthermore, although there has been little evidence in previous family caregiver literature that actually supports a link between assessment and management of advanced cancer symptoms, including pain (McMillan & Small, 2007), the results of this grounded theory suggest that family caregivers are making such links. For example, the theory put forth as the “puzzle of pain

management” describes the family caregivers’ process of joining the process puzzle pieces of “determining the characteristics of pain” and “implementing a strategy for pain relief” by “gauging the best fit” between the processes. It has been shown that family caregivers are able to use the information from pain assessment to create and implement pain management plans.

A further critical implication of this theory is related to the fact that both the process puzzle pieces of “strategizing a game plan” and “striving to respond to pain” can be simultaneously assembled. This theory indicates that family caregivers are starting to “implement” strategies for pain relief without fully feeling or being prepared. For example, family caregivers in this study often stated they did not have enough information or the right information required for pain control at home. Others lamented the fact they were unable to establish relationships with the healthcare team, resulting in feelings of isolation, frustration, helplessness, and overall lack of support. Unsuccessful or unsafe interventions can be an expected outcome of this, as was seen in a few examples in this study. The information from this study adds to previous work done that shows that consequences of this are a poorly assembled pain management puzzle resulting in inadequate pain control for the patient, and a feeling of helplessness (Mehta and Ezer, 2003) and increased stress for the family caregivers. Increased family caregiver stress results in increased depression (Doorenbos et al., 2007; Hayley et al., 2003), increased mortality (Schultz & Beach, 1999), decreased self-efficacy (Hayley & Baliey, 1999; Keefe et al., 2005), less satisfaction with caregiving (Oberst, Gass, & Ward, 1989), and little meaning in their roles as caregivers (Folkman & Moskowitz, 2000). Managing cancer pain also places extreme physical stress on family caregivers (Clark et al., 2006; Mazanec & Bartel, 2002) and impacts their quality of life (Clark et al., 2006). As a result of the information describing the processes family caregivers engage in at home for pain management, the clinical implications are clear: nurses must ensure that caregivers are prepared to manage their family member’s pain at home, to optimize pain control, and to prevent detrimental secondary effects on these caregivers. Also noted by this work, and that of Steltz & Brown (1999), support

of family caregivers is critical at the beginning, as they engage in the “accepting the responsibility” process.

Overall, a nursing theory is intended to provide nurses with the framework and goals for assessment, diagnosis, and intervention (Meleis, 2007). The “puzzle of pain management” contributes a new theory that makes us aware that family caregivers are engaging in several processes, often simultaneously. Nursing interventions to help them require assessment of how they are engaging in these processes, and what support may be indicated and at what point of their pain management responsibility. The theory also contributes knowledge towards clinical interventions. This is presented in the next section.

Clinical Implications

Given the above description of the important theoretical contributions of this theory, it can be said that nurses need to be aware of the composition of a final assembled pain management puzzle (i.e. the theory), and what each of the process pieces looks like. They need to assess if family caregivers have each of the pieces necessary, and what the composition of each piece is for a particular family caregiver. They can also help with “gauging the best fit” between puzzle pieces by helping family caregivers make informed decisions and can help foster successful relationships with the healthcare team. This allows nursing interventions to be tailored to the family caregivers’ individual needs in supporting their pain management processes (e.g. see discussion below “Types of pain and intervention selection”). The knowledge that family caregivers assemble their “puzzle of pain management” within the context of their past experiences emphasizes the importance of an assessment of these experiences. Nurses can then intervene in ways that help them overcome past negative experiences (e.g. alleviating previous negative experiences with medications with teaching and support) or that help incorporate other experiences (e.g. encouraging family caregivers with previous pain management experience in using existing successful skills).

Nurses are also in a position to help family caregivers “assemble” their puzzle in the most efficient and effective manner possible by providing them with information, teaching them the skills, or setting up resources to ensure the optimal composition of each sub-process puzzle piece. For example, with the knowledge that the first piece of the puzzle is “accepting responsibility for pain management,” nurses can assess the family caregiver’s comfort, confidence, and commitment to the responsibility of pain management. The results of the study indicated that family caregivers must engage in this process piece prior to being able to assemble the rest of the “puzzle.” If nurses do not assess this piece, and incorrectly assume the family caregiver has accepted the responsibility for pain management at home, assembling the rest of the “pain management puzzle” will be challenging, resulting in poorly managed pain and possible family caregiver distress. Furthermore, nurses might be able to give family caregivers necessary skills and tools that allow them to successfully manage new pains that arise and ones that may change. Together they can build a plan to deal with changes in pain as soon as they arise, allowing them to feel less helpless and potentially get the pain under control sooner.

The above discussion relates to the first research question: “what is the process used by family caregivers at home to manage the pain of palliative cancer patients at home? The following sections discuss the secondary research questions.

What are the types of pain family caregivers of palliative cancer patients are managing at home?

There was only one family caregiver in this study who mentioned “emotional pain” referring to the psychological distress experienced by the cancer diagnosis. She did not mention how she specifically managed this type of pain. This finding might benefit from more exploration as we focused only how caregivers spontaneously described pain and did not probe further to see if they also understood pain to have an emotional component or not. In fact, it is not uncommon for palliative cancer patients to experience other types of pain such as

emotional, social, or spiritual (Mehta & Chan, 2008). Perhaps these types of pain would also warrant different interventions.

The finding in this study that cancer patients had many types of pain in differing sites was consistent with previous work done (Lema, 2001; Portenoy, 1989; Twycross, Harcourt, & Bergl, 1996). Additionally, these results showed that related to this finding was the fact that family caregivers were the ones managing these different types of pain which meant that pain management was often a complex process, ideally requiring separate assessments, interventions and follow-up for each type of pain. These pains were, at times, occurring at the same time, requiring family caregivers to evaluate several types of pain and to plan for appropriate actions simultaneously. Overall, it proved interesting to have explored whether family caregivers were managing more than one type of pain, as the results showed that they were managing them in different ways. For example, the results showed that not all family caregivers matched specific pain relief interventions to specific types of pain. Some family caregivers used the same strategy regardless of what type of pain the patient had. Others felt comfortable assessing for types of pain, and then selected their interventions accordingly. This was an important finding because, at times, this made the difference between controlled pain versus uncontrolled pain. It was found that the assessment of the types of pain family caregivers had to manage was an important part of the process “determining the characteristics of pain.”

An important implication of this finding is that pain control interventions were then selected based on this information, joining the puzzle pieces of “determining the characteristics of pain” and “implementing a strategy for pain relief”. This highlights an important link between the secondary research questions, (the other question being “*what types of interventions are family caregivers performing at home?*”), as the types of pain often had an influence on the types of interventions that family caregivers were selecting at home.

What types of interventions are family caregivers performing at home?

Pain medication and non-pharmacological strategies such as distraction were used quite often, in this study. This was an interesting finding since findings from other studies have shown that non-pharmacological strategies were sometimes underutilized by family caregivers caring for cancer patients in pain (Yates et al., 2004). Consistent with previous findings is that distraction was one of the most common non-pharmacological strategies used for pain relief, and it was described by the family caregivers as one of the most effective ones (Rhiner, Ferrell, Ferrell, & Grant, 1993; Tasso & Behar-Horenstein, 2004). When asked, family caregivers reported that they had not been informed of or taught such strategies. In fact, many family caregivers felt that when they were using non-pharmacological strategies, it was at their own initiative, and often interventions of their own invention. This validates the fact that family caregivers are still learning about such interventions through trial and error (Given, Given, & Kozachik, 2001; Marzanec & Bartel, 2002). There are few studies that examine the family caregiver's knowledge and use of non-pharmacological interventions for pain relief. An important implication of this study is that it provides us with information that such studies are needed, particularly given that the combination of pharmacological and non-pharmacological pain interventions ensures optimal pain relief for cancer patients (Ardery, Herr, Titler, Sorofman, & Schmitt, 2003; McCaffery, 1990; Mobily, 1994; Mobily, Herr, & Kelley, 1993; World Health Organization (WHO), 1990).

Strategies such as Chinese oil or vodka for pain relief highlight family caregiver creativity, however, this finding also stresses the need for nurses and other healthcare professionals to be assessing family caregiver knowledge of interventions. This is because in some cases, family caregiver thought processes related to intervention selection may result in harmful ones being employed (e.g. burning the palate with vodka) and nurses may be able to prevent further pain for the patient and suggest other pain relief strategies. In other cases, nurses can support those interventions that are successful (e.g. Chinese oil for muscle pain relief). Successful interventions may also provide new information for nurses, who can share the benefits of such interventions with other family caregivers

caring for patients with similar pains. While not guaranteed to work, the possibility does exist that what works for one patient may work for another.

The male family caregivers in the study seemed to prefer more instrumental interventions, such as transportation or helping with cooking, which they saw as having a direct impact on the patient's level of pain because they were preventative strategies. They also saw the giving of medications as a "fool proof" strategy with a higher likelihood of success than non-pharmacological strategies. This finding differs from previous findings which show that male family caregivers had greater concerns giving medications than female caregivers (Letizia et al., 2004). Evidence does exist that pain management, and the views taken toward it, do indeed differ for male and female family caregivers (Kim, Loscalzo, Wellisch, & Spillers, 2006; Kristensson, Hallberg, & Jakobsson, 2007; Letizia et al., 2004). Gender differences in pain management practices were not explored in depth in this study, but the findings lead to the hypothesis that there are gender differences in how family caregivers manage pain, and warrant further exploration in order to build interventions that will meet the needs of both men and women who are family caregivers.

Implications

Types of Pain and Intervention Selection

Different types of cancer pain are best managed differently. It has already been noted that "central to the management process is recognition of different types of cancer pain, which have their own individual management emphasis" (Kenner, 1994, p. 1272). For example different medications are used to treat different types of pain (e.g. gabapentin for neuropathic pain) (Keshkinbora, Pekel, & Aydinli, 2007). Another example is nociceptive pain that can be targeted with different combined treatments such as opioids, electrical modalities (Seaman & Cleveland, 1999) or other medications. Other non-pharmacological interventions are also useful for pain, but there is limited literature as to what interventions work best with specific cancer pains. There does appear to be some evidence that the type of pain should dictate the type of treatment. For example, therapies such

as music therapy and massage have shown to be successful at treating chronic cancer pain (Mansky, Wallerstedt, & Dawn, 2006). Overall, the type of pain experienced by the patient is of prime consideration in the determination of the management of the pain.

The fact that most patients felt that their caregivers accurately assessed their types of pain and intervened appropriately was an interesting finding for future use of the theory. It was important to be able to conclude this study with suggestions for nursing interventions, and the fact that the processes of pain management as they emerged from this study were ones that patients felt comfortable and secure with. This meant that interventions based on the results of this study can be developed with some confidence that successful pain management is an achievable outcome.

Nurses involved with palliative patients with advanced cancer and their family caregivers need to be aware of all types of pain experienced by the patient, and how the family caregivers are managing them. This will permit insight into whether the family caregivers are recognizing the different causes of pain, are treating all the pains experienced, and if they are treating them appropriately. The nurse's involvement in this must be ongoing to keep abreast of any new pain that may present itself, and to monitor the success of the family caregiver's pain relief strategies and any new strategies they may try or want to try. Furthermore, much of the teaching presently done by healthcare professionals centers around the management of the cancer pain, and not necessarily on other pre-existing pain that caregivers have been managing and will continue to manage as they take on new pain management responsibilities. The results from this study show that the types of pain patients experience may not all be related to the cancer or to some other underlying cause, but may be related to the treatment of cancer, or completely unrelated. At times, the most devastating pain is not the cancer pain.

Nurses need to be aware that some family caregivers with previous experiences with pain differentiated between the different types of pain the patients had, and were therefore able to make more informed decisions about appropriate interventions. Nurses should routinely ask family caregivers what

their previous experience with pain and pain management has been and can build on strengths caregivers have. They should also assess for those family caregivers who have no such previous experience since it was seen that these caregivers did not describe themselves as well informed or as active in the pain management regimen. Ongoing provision of information, support, and monitoring of these caregivers is critical to ensure that each type of pain the patient experiences is assessed, addressed, and evaluated regularly for optimal pain control.

The type of pain should influence intervention selection. If family caregivers are not selecting interventions based on the type of pain, it may not be the most appropriate intervention. This study validates a finding from a previous study that found that family caregivers were selecting interventions (non-pharmacological) that were not optimum for the types of pain experienced (Rhiner, Ferrell, Ferrell, & Grant, 1993). The undesired consequence of this is that some interventions may also be unsafe and unsuccessful. Inappropriate or detrimental interventions can also be discovered prior to the patient being harmed, and the simultaneous control of all types of pain can lead to successful overall pain control. Recall the example of the wife who gave her husband vodka for neuropathic pain resulting in the burning of his palate. In this case the family caregiver felt medications were poison and since they were deemed harmful, she felt she would try this intervention because she had heard that “alcohol helps things.” This is a case where an assessment of the family caregiver’s beliefs and where they come from can prove beneficial. For example, if negative perceptions stem from inaccurate information then accurate information can help clarify misconceptions and influence existing beliefs. On the other hand, if these beliefs originated from a previous negative experience involving friends or family, then reassurances can be made to the family caregiver that efforts will be made to avoid a repetition of that experience by working closely with them, and monitoring the effects of the medications closely for effectiveness and side effects. Overall, information on the type of pain her husband had (e.g. neuropathic) as well as an explanation of underlying causes, coupled with the most effective treatment for it might have been helpful for her. Furthermore, a

review of her understanding of treatment options for pain, and an ongoing monitoring of how she was treating or planning to treat the patient's pain may have prevented the unnecessary additional discomfort created by the vodka intervention.

The finding that it was those family caregivers who were more experienced (e.g. as a result of caring for their family members over time) who were better able to differentiate types of pain, and select interventions specific to each type, highlights the need for nursing support and teaching at the immediate onset of the family caregiver's "accepting the responsibility for pain management." The fact that more information was needed earlier on in their pain management experiences was a concern voiced by several family caregivers, who felt that collecting (accurate) information was often a challenge. Nurses are in a prime position to assess the types of pain the patient at home has, and to include the family caregiver in such assessments. Nurses can also consult with members of other disciplines to ensure that all types of pain are addressed (e.g. physiotherapist for musculoskeletal pain or a physician if radiation therapy seems indicated). This would prepare the family caregivers from the onset to accurately assess all sources of the patient's pain, and provide them with the information and the support available on how to manage each of them. The simple fact of knowing that it is not just the cancer pain that they may be dealing with primes them for the potential challenges they may otherwise be unprepared to manage.

Lack of information and experience and patient's and family caregiver's beliefs and knowledge about pain medications were all explanations given by caregivers in this study for the selection and use of the same intervention for each type of pain. With this knowledge, nurses can tailor their information and interventions to address these areas. This translates into individualized pain management care plans that incorporate the specific pain control needs of the patients and outline the most appropriate pain relief methods. These care plans also need to take into account the family caregiver's knowledge of the type(s) of pain the patient has, and their current treatment plan. Modifications to existing strategies and/or additions to them can be made accordingly.

Furthermore, the knowledge that family caregiver intervention selection is influenced by several factors is critical for nurses who are attempting to teach them pain control strategies. Their past experiences may color their belief in the strategies taught, and impact their comfort level and the frequency of the use of the intervention. The results of this study underscore the need to explore what family caregivers are already doing, and where the support or information is needed, before trying to teach them what to do. For example, some family caregivers were giving pain medications as an intervention, and their learning need was not necessarily about the intervention itself, but rather on how to go about implementing it. The simple suggestion of a dosette box rendered this pain relief strategy so much easier for caregivers to administer. Their ability to organize the patient's medications was very important in determining when, how and whether medications would be given.

The fact that family caregivers felt they had not been given enough information on non-pharmacological strategies means that nurses should explore their openness, their knowledge, and their desire to try such strategies. An important implication in this case is that nurses then need to be informed of such strategies. It has been found that one area of pain management where nurses know the least is that of the usefulness of non-pharmacological methods of pain relief (McMillan, Tittle, Hagan, Laughlin, & Tabler, 2000). The findings in this study reinforces previous work showing that nurses and other healthcare professionals should be aware and knowledgeable about different pain relief interventions, including non-pharmacological ones, to help patients (and their family caregivers): obtain accurate information, understand their options, and administer these interventions safely and effectively (Snyder & Wieland, 2003; Tasso & Behar-Horenstein, 2004; Rhiner et al., 1993; Zaza, Sellick, Willan, Reyno, & Browman, 1998).

Overall, the intent of this grounded theory was to answer the questions posed at the beginning of this study. The preceding discussion highlights and discusses what was found. A further purpose was to see if new knowledge would be obtained to fill in gaps that were found in the literature. The next section

examines what new information the theory “the puzzle of pain management” adds to the existing literature.

Return to the Identified Gaps

The literature review had revealed the following gaps in order to successfully create pain management interventions to support family caregivers. There was a need for more information in the following areas: 1) the actual involvement of family caregivers in pain management at home; 2) the types of pain patients experienced and intervention selection related to these types of pain; 3) the knowledge, the skills, and the resources that a family caregiver requires to be successful at pain management at home; 4) how family caregivers intervene; 5) factors that may influence the pain-management process at home; and 6) the interaction between the patient and the family caregiver as pain is being managed at home.

The identification of the processes of “strategizing a game plan” and “striving to respond to pain” and the sub-processes that compose the process of pain management showed that family caregiver involvement in pain management is complex and ongoing, extending beyond just “doing.” In fact, the puzzle of pain management is actually how family caregivers are involved in pain management and describes the processes of pain management grounded from the data they provided for this study. The information obtained to address the gap related to the types of pain and intervention selection, as well as how they intervene for pain relief have already been discussed in the sections above addressing the secondary research questions. The knowledge and skills that family caregivers require to be successful at pain management at home are discussed above in the section where the puzzle of pain management is compared to “a transactional model of cancer family caregiving skill” (Schumacher, Biedler, Beeber, & Gambino, 2006). This study further showed that the information required for family caregivers was specific to pain, pain intervention, and resources available for them and was required sooner rather than later as they accepted and assumed the responsibility for pain management.

The fact that the family caregivers engaged in a process of “drawing on past experiences” provides some information to address the gap related to additional factors that may influence the pain-management process at home. It was quite clear that past professional and personal experiences as well as family caregiver beliefs were just some additional factors that proved to be an important part of the pain management process. Finally, the interaction between the patient and the family caregiver was captured in the sub-process of “developing a pain management relationship” with the patient and thus provides some information to address this identified gap. In contrast to a previous study (Hauser et al, 2006), the results showed that all patients interviewed felt that their family caregivers were successful at their assessments of pain as part of these pain management relationships.

Study Limitations

Although valuable information was obtained from this study about the pain management experience for family caregivers of palliative cancer patients in the home environment, it is understood that the results only reflect the experience of a limited portion of this population. These results therefore cannot be assumed to be reflective of other family caregivers caring for different patient populations in different contexts than this one, such as with different health care services available.

Grounded theory requires that the data collection occurs in an environment that is jointly created by the researcher and the participants (Harley et al., 2007). It is very possible that the same study conducted by different researchers and interviewing different participants would yield somewhat different results. As with any type of research, the researcher’s personal values and beliefs may have colored the selection, prioritization, and interpretation of the data. For this study, every attempt was made to absorb the information in an unbiased manner, however to “clear...one’s perceptual field” completely is impossible since as humans we possess our own values, biases, and preconceptions (Brink & Wood, 1998). In grounded theory, it is also an advantage that the researcher brings to the

study and the analysis of the data his/her own sensitivities as a result of his/her preexisting knowledge and familiarity with information and theories, particularly from their own field of expertise (Wuest, 2007).

Another limiting factor related to this study is the study population. This is a noted concern in qualitative research and is known as the “elite bias” (Sandelowski, 1986, 32). The family caregivers who agreed to participate in this research project may have been somehow different than those who chose not to. For example, they may have been the most accessible and articulate of the families being cared for by NOVA and the SCT, which referred them to the study. It may also be possible that those who did agree to participate had more concerns related to pain, poor pain management, and uncontrolled pain, despite the fact the inclusion criteria stated that pain did not have to be an issue at the time of the interview. On the other hand, those family caregivers caring for patients with severe pain requiring more care may have refused to participate in the study based on their lack of time and ability to participate. This would mean the theory of “the puzzle of pain management” may not adequately address the process experienced by all family caregivers who are trying to manage cancer pain at home. Finally, those family caregivers who were interviewed with the patients present may not have been as forthcoming with information, or honest about their experiences of pain management. However, no systematic difference was noted between family caregiver data based on the presence or absence of the patient during the interview.

Furthermore, although not required to the development of this grounded theory, patients were sought as participants for this study. They were included to gather information about their experiences with pain management in order to gather preliminary information that would help develop an intervention. Through the course of this study, it was recognized that a grounded theory developed to answer the research question posed initially had to be grounded in the data of the family caregivers themselves since it was the processes that they were engaging in for pain management that were the focus. It is for this reason that the patient interviews were not used in the development of the theory “the puzzle of pain

management.” Important information was obtained, however, on the success of the strategies that were being used by the family caregivers, lending some support to the idea that the family caregiver processes engaged in were appropriate and often successful.

Finally, although a theory developed using grounded theory does have “explanatory power” (Strauss & Corbin, 1994, p. 267), it must be recognized that the “puzzle of pain management” is grounded in the data that was collected in this study pertaining only to the family caregivers. Given the complexity of pain management for the advanced cancer population, a broader context which includes the perception of the patients, other family members, and health care professionals would certainly provide details that were unattainable in this study. Such details would contribute to a broader understanding of the process of pain management and could support, modify, and further develop this theory. This would enhance the explanatory power of the theory.

Because of these limitations, the context within which the grounded theory has been developed may not be replicated (Greenwood & Levin, 2005). As a result, this qualitative study does not permit any causal conclusions or any generalizations beyond the scope of the present study. Nonetheless, it does provide us with much needed information on which to base future interventions. It is only through studies such as this one that the groundwork can be put in place for intervention development and testing, to either validate or refute the theory developed from this study.

Contributions

Theory

Glaser (1978) stated that grounded theory results in the development of a middle-range theory at substantive or formal level. Since a formal middle-range theory normally refers to a more developed theory than a general one and often reflects a wide variety of nursing care situations from multiple studies, the puzzle of pain management is a substantive grounded theory (Meleis, 2007; Reed, Shearer & Nicholl, 2004; Strauss & Corbin, 1994). This study resulted in a theory

that was developed and grounded in the data yielded from the interviews conducted with 24 family caregivers and 8 of the patients for whom they were managing pain. Consistent with grounded theory methodology, this theory “evolved during actual research” as data collection and analysis occurred concurrently (Straus & Corbin, 1994, p. 273). A more formal theory would be one that is less specific to a particular population or setting, and that can be applied to a “wider range of disciplinary concerns and problems” (Strauss & Corbin, 1998, p. 23). Although a higher level “general” theory can be developed by grounded theory methodology, it is both desirable and necessary to first begin with the development and creation of a substantive one (Strauss & Corbin, 1994). Furthermore, this study evolved from the study of pain management processes in the specific situational context of the home, unlike formal theories which pertain to a conceptual area examined under several different types of situations or contexts (Eaves, 2001).

Strauss & Corbin (1994) define theory as a set of plausible relationships among concepts and sets of concepts (p. 278). Concepts were defined in this study as processes that family caregivers were engaging in, and their relationships to one another described as part of the puzzle of pain management. The goal of grounded theory is to discover processes and to describe the conceptual relationships between them (Strauss & Corbin, 1994). Overall Strauss and Corbin (1994) describe grounded theories as “systematic statements of plausible relationships” (p. 279). In this study, this was evidenced by the fitting together of processes as puzzle pieces creating relationships between them.

Substantive theory is grounded in research in one substantive area and may apply only to that specific area (Straus & Corbin, 1994, p. 281). As with most grounded theory studies a substantive theory was developed to capture the process under study: pain management at home for family caregivers of palliative cancer patients at home (a specific population and setting). Key to the results of a grounded theory is that the theory developed provides an explanation.

Theory and Practice

The identification of key explanatory concepts and the relationships among them is an important outcome (Wuest, 2007). The puzzle of pain management explains the processes family caregivers engage in from their point of view, showing that they are often “strategizing” how to manage pain at the same time they are “striving to respond to it”. The puzzle of pain management explains the feelings of frustration, helplessness, and often poor pain management for patients as family caregivers manage pain at home. The composition of the puzzle process pieces explains what pain management for individual caregivers will look like. For example, the lack of information, difficulties developing relationships with the healthcare team, and limited intervention choices often explains why pain control can be a challenge for family caregivers and less than optimal pain control achieved for the patient. “Gauging the best fit” is the process that explained when and how family caregivers fit the pieces of the puzzle together, and the context of their past experiences explained much of their knowledge, beliefs, actions, and comfort levels related to pain management. The fact that the two processes of “strategizing a game plan” and “striving to respond to pain” must join together to complete the puzzle of pain management explained how good pain management may be difficult to achieve if pieces are missing, or have insufficient substance to their composition.

Meleis (2007) states that one of the primary uses of theory is to provide insights about nursing practice situations and that through interaction with practice, theory is shaped and guidelines for practice evolve. In this study, the experiences of family caregivers caring for patients in pain at home provided data that gave rise to a theory about the process of pain management for family caregivers: the puzzle of pain management. Implications for nursing practice were clear as the theory was developing. For example, creating and maintaining relationships with patients and their family caregivers is an important task for nurses as this was key to the family caregivers’ ability to manage pain, and to feel supported doing so. Another example of an important practice implication for nurses is the critical role they could play in the provision of information about

pain and pain management, as many family caregivers felt this was a challenging process. Furthermore, as family caregivers “strive to respond to pain,” their assessment, intervention, and evaluation skills related to pain management differ. To respond to this, nurses must include an assessment of the caregivers’ past experiences, the types of pain they are managing, their current pain control practices, and the need for information they articulate as important to them. With an established baseline, nurses can tailor their teaching of interventions to the specific needs identified for the family caregivers, instead of proceeding with a predetermined, standardized plan that may not be suitable for a particular family caregiving situation. The consequences of not doing this are often poor pain control, feelings of helplessness and frustration by the family caregiver, and a strained relationship with the healthcare team. These implications stem directly from the theory of the puzzle of pain management. In this way, such a theory can guide practice until empirical validation, modification, and support are completed for this theory in the form of additional studies. It can certainly be given support through clinical practice and validation, and can therefore be permitted to give a tentative direction to practice at present (Meleis, 2007, p. 46).

Understanding and being able to teach or support interventions related to pain control is critical for nurses, as they can then offer support to family caregivers. This can only be done if the nurse understands the process used by the family caregiver to select their interventions. An understanding of the environment and circumstances (e.g. beliefs; resources) in which nursing interventions take place is necessary in order to design them to be most effective. Knowledge of what barriers or existing strengths are present is critical prior to proceeding to the creation of interventions. A better understanding of the caregivers’ experience allows for health professionals to better support these family caregivers. This support given by health professionals will enable the family caregivers to feel some control in the patient’s care, and help them implement these interventions independently at home. The ultimate goal is improved pain control for the patients and a decrease in distress for both the family caregivers and the patients.

While it has been recognized that it is important to “improve home care pain management processes,” much of what has been written has been from the perspective of clarifying this complex issue for nurses’ own direct management of patient pain (Goodman, Hiniker, & Paley, 2003, p. 325). This study highlights the fact that pain management processes done by family caregivers also need to be assessed and supported. There is a report in the literature of one hospital that did realize the need to “develop individualized pain management strategies, thereby empowering the patient, family and caregiver” (Goodman, Hiniker, & Paley, 2003, p.327), as the results of this present study suggest is required. While this was part of their mission statement to improve patient pain management at home, the focus was on staff development with no information on how the interventions were individualized and what the content of the interventions/information was. This present study provides us with necessary information on which to base nursing interventions needed for family caregivers. For example, the assessment of past pain experiences to either clarify misconceptions or incorrect/unsafe practices, the inclusion of what they already know or are doing, the assessment of the types of pain and appropriate interventions specific to them, and non-pharmacological pain relief strategies are all important components of the pain management process and must be incorporated into planning and teaching interventions to family caregivers.

Theory and Research

Theories developed using grounded theory may be “elaborated” and modified subsequent to their initial development (Glaser, 1978; Straus & Corbin, 1994, p. 273). I hope that new studies will be conducted and new results reported. New data can be compared, incorporated, and even change existing theory. The puzzle of pain management can be adapted by further studies, and strengthened by additional information. Additional puzzle pieces may emerge as relevant, and the ones described in this study may not resound with another family caregiver sample studied. It is important to note that successive research can validate, refute, and/ or modify this theory as well as generate new theories related to the

process of pain management at home (Meleis, 2007). The process of pain management would be interesting to study in more depth with different family caregiver populations managing pain at home (e.g. AIDS patients), at different points of the cancer trajectory, or with different family caregivers (e.g. more male family caregivers) to observe if the puzzle of pain management resonates with them, or needs modifications or more elaborate adjustments.

Furthermore, nursing theories stimulate nurse scientists to explore significant responses (e.g. to pain monitoring) in the field of nursing (Meleiss, 2007). In doing so, the potential for the development of knowledge that informs daily activities of patients, families, and nurses increases (Meleis, 2007, p. 46). To date, few studies have examined family caregiver management of cancer pain during the end of life phase (Redinbaugh et al., 2002), meaning that further studies are warranted to add to information obtained from this study. For example, although this grounded theory serves a vital role in contributing knowledge on the types of pain that family caregivers are managing at home, on how they assess the patient's pain (e.g. cues they use), on the processes that they use to select a strategy/intervention, and on the way they evaluate pain relief in light of the pain management process, additional work remains to be done to build on these findings.

As researchers move to the next generation of intervention studies and seek to develop the content of pain management interventions, knowledge about family caregivers' experiences with pain management, such as those articulated in this study, is essential (Schumacher et al., 2002). This study was a necessary first step before appropriate pain management interventions can be developed to help family caregivers. The inclusion of family caregiver knowledge and experience of pain interventions in the home will provide valuable information required to design interventions to help family caregivers manage pain. The development and teaching of interventions then creates a whole new area in which research can be pursued. Their effectiveness, both to control patient pain and to reduce the distress unrelieved patient pain causes family caregivers, family caregiver comfort levels, and knowledge are a few areas where data collected can yield valuable

information on whether the puzzle of pain management and the described processes are indeed the most appropriate ones on which to base pain control interventions directed at family caregivers.

Policy

The results of this study clearly point out the great demands pain control places on family caregivers. Many caregivers talked about the physical, emotional, and psychological impact this had on them. Comparing their responsibility of pain management to “being in prison” and talking about their “hands being tied” highlight that they are not adequately prepared and do not have the support they require to function optimally in their new roles. This suggests structural and policy changes may be needed at the hospital and government level to meet the family caregiver needs so that they, in turn, can meet the needs of the patients.

Brown & Stetz (1999) suggest that structural changes to health care systems are an immediate requirement and must be initiated by policies that dictate that families, not just the patient, be the recipient of care. They further state that such a healthcare system does not exist and family caregivers are still not included throughout the illness experience. The family caregivers in this study did not feel that they were not implicated in the care, but rather that they were not implicated in the right way and with the right information. This is unfortunate as the World Health Organization had clearly identified the family as the unit of care for palliative care services (WHO, 2007). Suggestions for policy change within the healthcare institution must be targeted at creating, enforcing, and evaluating guidelines that focus on preparing family caregivers to care for patients with pain at home. Furthermore, the current structure is not conducive to treating and alleviating the ever present pain that exists for some patients. The perception of one family caregiver was that despite services being available, she still felt unsupported. She stated: “pain is not 9-5, so why are the resources for pain only available then (012)”? It is also critical to strengthen the links between hospitals and the community resources to monitor family caregiver knowledge, skill, and

coping patterns in a consistent and communicable manner. For example, if a patient is hospitalized, and nurses in the hospital teach the family caregiver about pain and pain interventions, then the nurses in the community can build on and follow-up on this if they are aware of what preparation the family caregivers have already received. In this way, ideal care can be provided by both community services and hospital-based ones working together.

Brown & Stetz (1999) also noted that policies that existed when they wrote their paper do not support family members who commit to being caregivers. The family caregivers in this study talked about the time commitment pain management required, stating that they sometimes “put their lives on hold.” For example, in Quebec, governmental community health services are increased only when the patients are deemed to have 3 months left to live (Agence de la Santé et des Services Sociaux de Montréal. 2006), however, the need for family caregiver support much earlier on was highlighted in this study, as pain was often ongoing and persistent. Furthermore, there are also implications for health service organization (e.g. at the level between individual nurses and the government) since healthcare professionals delivering homecare to the palliative population need more time when they first begin to care for a family with a terminally ill member to proactively support them. This can perhaps avert a crisis that may cause needless suffering also resulting in potential extra costs to the healthcare system if a pain crisis results in the patient going to the emergency room and/or being admitted to hospital for pain control.

In this data collected in 2004-2006, caregivers still felt they could have benefited from external resources as they struggled with pain control at home. Furthermore, in Canada, as of January 2004, the government introduced *the Employment Insurance Compassionate Family Care Benefit*, which allows for a 6 week paid leave for a gravely ill, or dying family member, (Service Canada, 2008). This benefit recognizes the overwhelming nature of family caregiving and the financial consequences it may have. It is a crucial first step towards acknowledging their efforts, however, it is not without room for improvement. For example, it does not recognize the time commitment required to manage pain.

For many family caregivers, such as those in this study, the time, skill, and commitment they invest far exceeds a 6 week period. Pain fluctuated for many patients, with unpredictable patterns. It can also be present at the onset of the illness, and occur as a result of treatments, and can augment for many reasons. Pain management, therefore, is a responsibility that must be fulfilled along the entire illness trajectory. There is no defined time period for how long pain can/will last, and 6 weeks is an insufficient time frame for which to offer compensation for pain management alone, even if there were not many other roles and duties for family caregivers. Other concerns such as the 2 week unpaid period prior to the first payment, problems with awareness and access to information, and the actual application process all point to room for further refinement to the benefit (Williams et al., 2006). The results from this study validate this recommendation and provide valuable information that can help influence policy change.

Finally, nurses can play a vital role in advocating for policies that will support family caregivers managing pain at home. Having first hand exposure to their experiences, and insight into the challenges they face, nurses are in a prime position to put forth policy suggestions and fight to see them into creation and implementation. Participation in groups, advocating for changes to existing legislature, and working within professional organizations to initiate legislation that supports family caregivers are all suggestions that have been previously made (Brown & Stetz, 1999), and are applicable to nurses supporting caregivers through their pain management experiences.

Education

At present, nursing theory and theory development are considered crucial within most doctoral nursing programs (Meleis, 2007). The active involvement in the conducting of a grounded theory study permitted this researcher to obtain an education in the process of theory development. Secondly, it allowed for pursuit into an area that resonates personally and professionally and thus provided much needed knowledge and answered questions that had been the initial stimulus for

this study. This knowledge however, extends beyond the work of the individual researcher and becomes imperative to include in the education and professional development of new nurses and other healthcare professionals implicated in the care of palliative cancer patients and their family caregivers. Although student nurses who take courses in end-of-life care are taught about symptomatology, they also need to be aware of the implications for the family members of the patients, and their involvement in symptom management. The puzzle of pain management should be a vital part of the training received by both hospital-based and community nurses who are working with palliative cancer patients with pain at home and their family members. Nurses in hospital settings who are preparing to send patients home with their families can play integral roles in the preparation of the family caregivers by providing information, encouraging relationships with the healthcare teams, and helping to establish links to key resources, as all these were identified as important components of the puzzle. Nurses working in the community settings can reinforce the “strategizing a game plan” process and provide support as family caregivers prepare for their pain management responsibility. They are also in prime positions to teach, monitor, encourage, and correct assessment, intervention, and evaluation skills as family caregivers “strive to respond to pain.”

It is important that efforts are made to improve the education of nurses and healthcare professionals about the process of pain management as their comfort level and knowledge have an impact on their ability to successfully teach and implement pain management strategies (Rhiner, Ferrell, Ferrell, & Grant, 1993; ZaZa et al., 1998). In order to assess the content of the intervention, nurses must take into account family caregiver past experiences (Rhiner, Ferrell, Ferrell, & Grant, 1993), baseline knowledge, their commitment and comfort with the pain management responsibility, types of pain they are managing, their existing resources, and those they feel are needed. This assessment permits the nurses to select appropriate information and interventions specific to each case.

Furthermore, an important part of teaching pain management interventions to family caregivers was seen in some of the comments the caregivers made in

this study. For example, one family caregiver suggested a six week educational workshop for family caregivers (005), while others preferred a simple “sit down” session (e.g.003, 012). This shows that caregivers have different learning patterns and preferences. Finally, the results show that a one-time intervention and evaluation is not sufficient for family caregivers managing cancer pain at home. The pain often fluctuated, new pains emerged, and some interventions became ineffective over time. This highlights the need for ongoing assessment, teaching, and follow-up with the family caregivers to monitor how they are assembling their pain management puzzles. The following section describes how the results of this grounded theory will serve to educate and inform others about the puzzle of pain management.

Dissemination of Results

Of utmost importance after the completion of any research is the dissemination of the results. Sharing the results of grounded theories contribute to the transformation of practice and social processes (Charmaz, 2006). This researcher recognizes that without accepting the responsibility of sharing the processes involved in the puzzle of pain management with those who are implicated with care of the palliative care population, “no professional body of knowledge can be accumulated, nor can its implications for practice and theory be usefully developed” (Strauss & Corbin, 1998, p. 247). The results of this study will be shared with those who were instrumental in the recruitment process of this study (i.e. NOVA and the Supportive Care Team of the S.M.B.D. Jewish General Hospital) in meetings such as patient rounds; with other healthcare professionals in the hospital and community settings (e.g. Grand Rounds); with attendees at professional conferences as oral presentations and workshops (e.g. 90 minute workshop at the 17th International Congress on Palliative Care, accepted); and in the form of publications in high impact journals with multi-disciplinary audiences. Although this is only one study in the area of the pain management process at home for family caregivers, the best way to disseminate the results to those who play a role in the education of nurses will also be explored to ensure

that nurses who care for patients in pain at the end of life will be prepared to work with both patients and their families.

CONCLUSION

Understanding the puzzle of pain management allows health professionals to gain insight into the processes involved as family caregivers manage pain at home for palliative cancer patients. Support, information, and resources can and should be provided to enable these caregivers to successfully engage in these process pieces in order to successfully complete the pain management puzzle, for the sake of their own health and that of the patients. The assembly of this puzzle is instrumental for pain control to be effective and for patients to be cared for by confident, informed, and supported family members. Finally, the realization and recognition that family caregivers are assembling a puzzle of processes in order to optimize pain control at home for patients indicates that there are many factors that nurses need to be aware of prior to the creating, teaching, and/or implementing any interventions for pain management.

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APPENDIX I: DEMOGRAPHIC INFORMATION COLLECTED

Demographic Data Interview Guide

- Demographic information for both patient and family caregiver (age and sex of patient and family caregiver, diagnosis of patient, how long since diagnosis, relationship of caregiver to patient, work status, education, ethnicity, SES, family structure)
- How is the patient involved in managing his/her pain?
- What is the present pain regimen (medications etc...)
- Resources available to them (Homecare team, financial support...)
- Description of the physical environment
- Perception of relationship to the patient (cooperation)
- Description of types of pain the patient has
- How long has the family caregiver been managing the patient's pain?
- History of pain: Other types of non-cancer related pains experienced by the patient. Is this pain different? How does managing this pain compare to managing other pain?
- Extent of previous experience as a caregiver
- Description of the patient's co-morbid conditions

The questions were adapted and not necessarily followed verbatim. They were constantly validated and further ones were added as new questions emerged from the data analysis. The data was collected by the researcher at the initial meeting.

APPENDIX II: FAMILY CAREGIVER QUESTIONS

Family Caregiver Questions

Tell me about a specific time you thought your family member was in pain. Tell me about that experience.

PROBES:

- What did you feel and what do you think when you observe that your family member was in pain?
- How did you know he/she was in pain? How did you judge how bad the pain was?
- What made the pain worse? What made the pain better? Does the patient agree?

Tell me about how you help to do something to help him/her when you feel they are in pain. How do you feel when you do an intervention (for each intervention)?

PROBES:

- Tell me about how you decided how to help him/her. (Does it change depending on the kind of pain and where it is?) How was the intervention selected?
- Tell me about how you know if it has worked. (for each type of pain).
- Tell me about any uncertainties you have when trying to help.

Tell me about how you got information about pain and pain management. Where did you get information about some of the strategies that you use? How did you get this information? From whom and from where?

PROBES:

- How was this information helpful? How was this information not helpful?
- Tell me about resources are you using and which ones are you lacking?
- What has been most helpful in managing the pain? Does the patient agree?
- What has not been helpful in managing the pain? Does the patient agree?
- What else would have been of use? Does the patient agree?

APPENDIX III: PATIENT QUESTIONS

Patient Questions

Tell me about a specific time you were in pain. Tell me about that experience and what you were thinking and feeling (For each type of pain).

PROBES:

- Tell me about the type of pain you have. Can you describe it?
- How do you think the pain affects your family members?
- Tell me how you judge how bad the pain is?
- Tell me how you decide what to do to decrease the pain. (Does it depend on the kind of pain?)
- What does the pain management look like to you? Do you take your medications as prescribed?
- Do you ask for help when you are in pain? -Who do you tell? How do you communicate that you are in pain?

Who helps you manage the pain?

PROBES:

- How do you think (your family caregiver) knows you are in pain and can you describe what (your family caregiver) does when you are in pain?
- What kinds of cues do you give (your family caregiver) that you are in pain?
- Tell me about the strategies that work best when (your family member) helps you with the pain? And how do you know it has worked? (for each type of pain)

PROBES:

- Where did you get information about some of the strategies that you and/or your family member use? How did you get this information? From whom and from where?
- How was this information helpful? How was this information not helpful?
- What resources are you using and which ones are you lacking?
- What has been most helpful in managing the pain? Does your family caregiver agree?
- What has not been helpful in managing the pain? Does your family caregiver agree?
- What else would have been of use? Does your family caregiver agree?

APPENDIX IV: FIELD NOTE GUIDE

Field Note Guide
Adapted from Polit & Beck (2004)

The physical setting:

- A description of the main features noted (e.g. has the home been adapted for the patient?)
- A description of the context within which the interview takes place (For example, description of the room, the furniture, who is sitting where...)
- Note the types of behaviours and characteristics that are either promoted or constrained by the physical environment
- Note how the environment contributes to what is happening

The participants:

- A description of the characteristics of the people being observed (the family caregivers, the patients, other members present at the time of the interview)
- Note the number of people, what their roles are observed to be
- Note who has access to the setting (at home)
- Observe what draws, keeps these people together

Activities and interactions:

- A description of what is going on in terms of what people are saying and doing, behaving
- Note how people are interacting with each other
- A description of communication patterns (frequency, tone, emotion)
- A description of the connectedness to each other or to activities observed

Other relevant information:

- If possible, note what did not happen (something missing from the event or interaction)
- Note if verbal and non-verbal information is consistent (touching of patient, facial expressions while caring for patient, “fussing” or doing for patient)
- Note what types of things were disruptive to the activity or the situation
- If the patient experienced pain during the interview, and the family caregiver intervened to control it

APPENDIX V: OPEN CODES

Open Codes

NVivo revision 2.0.163 Licensee: Anita

Project: FCGs and pain management 666 2 User: Administrator Date: 5/3/2008 - 11:40:45 AM

NODE LISTING

Nodes in Set: All Free Nodes		29	bean bag and heat relieve back pain
Created: 3/28/2007 - 11:34:57 AM		30	bed makes pain worse
Modified: 3/28/2007 - 11:34:57 AM		31	bedsore pain
Number of Nodes: 752		32	bedsores
1	~bloating~ pain	33	behaviour change
2	~bottom~ pain	34	being present best intervention
3	~butt pain~	35	better communication among hcp
4	~don't want to know future~	36	block nerve for pain relief
5	~pain pain~		
6	a ~pain patch~	85	color change means pain
7	abdominal pain	86	communication better
8	achey pain	87	communication between 2 caregivers
9	acid reflux pain	88	communication btwn pt and FCG
10	acupuncture	89	communication important
11	acute pain	90	communication is good pt and FCG
12	Advil	91	comparing with others in pain
13	affection as intervention	92	concern about giving pain meds
14	agitated if pain not relieved	93	confusion
15	alcohol and qtips did not relieve pain	94	confusion hard than for fcg
16	alcohol for neuropathic pain	95	constant aching or pain
17	always the same pain	96	constipation pain
18	and I've got wide shoulders~	97	cream to prevent scarring
19	ankle pain	98	crying means pain
20	arm and leg pain	99	cushions as intervention
21	arthritis pain	100	cut nerve for neuropathic pain
22	ask for help if you have a problem	101	dampness makes pain worse
23	assessment by looking	102	deal with pain as it happens
24	avoids certain foods	103	Decadron
25	back pain	104	decide to call doctor
26	bad pains	105	decrease energy with pain
27	be proactive	106	dementia or confusion
28	be there for the person you're caring	107	Demerol
for			

108	Demerol better than Tylenol	153	family support perceived by patient
109	depression	154	fatigue
110	diaphoresis means pain	155	fatigue makes pain worse
111	diet	156	FCG ~feels~ responsibility
112	different if caring for spouse	157	FCG ~hurts~ too
113	difficult for rest of family	158	FCG accepting of death
114	dignity	159	FCG accuracy of assessment
115	Dilaudid	160	FCG advice to patient
116	distraction	161	FCG and assessment
117	distraction worked	162	FCG and patient partnership
118	dizzy means pain	163	FCG and patient remember differently
119	do not be afraid to ask	164	FCG and pt don't ask a lot of questions
120	do not be afraid to disagree	165	FCG and sense of inadequacy
121	do not be afraid to make phone calls	166	FCG asks if patient is in pain
122	don't give meds too quickly	167	FCG asks patient to evaluate relief
123	dosette box for meds	168	FCG asks pt how to intervene
124	dressing change causes pain	169	FCG asks to get information
125	dull pain	170	FCG belief about medications
126	ear burns	171	FCG belief in God~thoughts religion
127	ear pain	172	FCG believes moral important for
128	eat or drink means he's more	health	
comfortable		173	FCG can feel depressed
129	eating makes pain worse	174	FCG challenges
130	elbow pain	175	FCG characteristics
131	electric bed	176	FCG checks others give meds right
132	electric shock for pain relief	177	FCG cries~
133	elevate feet for swelling	178	FCG decision-making
134	emotional pain	179	FCG depressed
135	enjoy the small things	180	FCG describes pain for patient
136	evaluation of homeopathic methods	181	FCG doesn't feel giving meds is
137	evaluation of pain intensity	intervention	
138	every day is a pain crisis for her~	182	FCG doesn't want pt to suffer
139	excruciating pain	183	FCG empathizes
140	exercise	184	FCG evaluation of self in management
141	exercise makes pt tired, but not much	185	FCG exhausted
142	experimental trial	186	FCG experiments with interventions
143	external support should start earlier	187	FCG explains pain to pt
144	extra pill for worse pain	188	FCG fears
145	eyes to evaluate relief	189	FCG feel not enough information
146	face for non-verbal assessment	190	FCG feel she can't feel pt's pain
147	face for pain intensity	191	FCG feeling frustration
148	facial expression to evaluate relief	192	FCG feels anger
149	family Caregiver feelings	193	FCG feels concerned
150	family caregiver thoughts	194	FCG feels diet nutrition important
151	family support for FCG	195	FCG feels he can't evaluate pts pain
152	family support missing for FCG	196	FCG feels he is weak
		197	FCG feels health professional not there
		198	FCG feels helpless
		199	FCG feels he's not doing much

200	FCG feels hopeless	235	FCG in control
201	FCG feels it is not just pt dealing	236	FCG is child dealing alone
202	FCG feels lambs being led to slaughter	237	FCG is or was~wanted to be nurse
203	FCG feels like exploding	238	FCG keeps log or journal or notes
204	FCG feels overwhelmed	239	FCG learned from past caregiving exp.
205	FCG feels pain is not a shared experience	240	FCG learns over time
206	FCG feels pain medication is not always solution	241	FCG more assertive giving meds than
207	FCG feels patient depends on her	242	FCG needs support
208	FCG feels pt is not palliative	243	FCG not happy or unsure of diagnosis
209	FCG feels Pt more comfortable at home	244	FCG not in control
210	FCG feels pt presently comfortable	245	FCG not ready for pt to die
211	FCG feels pt should fight pain	246	FCG not sure if enough info future
212	FCG feels pt should smile	247	FCG opinion MD~medical community
213	FCG feels sad	248	FCG organized
214	FCG feels she is ~tannante~	249	FCG prepared for what is to come
215	FCG feels they need 24 hour support	250	FCG realizes pain may never go away
216	FCG feels US system better	251	FCG reassures pt that pain can be co
217	FCG feels when pt dies he will too	252	FCG recommends outside help
218	FCG felt not enough information	253	FCG recommends training session for pain management
219	FCG felt not prepared	254	FCG relationship with nurses & MDs
220	FCG felt prepared	255	FCG relationship with patient
221	FCG follows a ~protocol~	256	FCG relies more on own judgement
222	FCG getting different info from diff. people	257	FCG responsibilities
223	FCG gives injection	258	FCG scared and upset
224	FCG gives pt information on pain	259	FCG success in being able to intervene
225	FCG goals	260	FCG suggests DIFFERENT intervention
226	FCG graphs pain	261	FCG suggests medication
227	FCG has health concerns	262	FCG takes initiative
228	FCG has past experience	263	FCG talks to others in similar situation
229	FCG has supportive boyfriend	264	FCG tells patient not to suffer
230	FCG has therapy	265	FCG thinks death may be better
231	FCG helps pt to bathroom	266	FCG thought pain was something else
232	FCG helps pt to dress	267	FCG thoughts on death
233	FCG helps with lifting things	268	FCG thoughts on palliative care
234	FCG idea of good pain management	269	FCG thoughts or expectations of this
		270	FCG tries different things
		271	FCG tries to convince pt to take pain meds

272	FCG uncomfortable leaving pt alone	303	groin pain
273	FCG unsure what to do at first	304	gut feeling or intuition
274	FCG unsure what to do if pt has A	305	handkerchief to protect the area fro
LOT of pain		306	hands are tied
275	FCG want pt to ask for meds	307	Hard for FCG to see pt suffer
276	FCG want second opinion	308	hard pain
277	FCG wants information on how to	309	hard to always have as smile on
help		310	have to be assertive
278	FCG wants to do more	311	have to love~care about pt to care
279	FCG wondering if no pain =	312	have visitors often
remission		313	He was certainly hurt to see me hurt
280	FCG wonders if pain relief is ~real~	314	headache pain
281	FCG won't ask directly if pt in pain	315	health of FCG a concern
282	FCG worried patient may harm self	316	Health professional should follow FCG
283	FCGing is fulfilling	advice	
284	FCGing is full time work or job	317	health professionals should support
285	FCGing not a burden	318	Heat
286	FCGing shared responsibility	319	heat for arthritis pain
287	FCG's description of pt in pain	320	heat releasing pad-Ben Gay
288	FCGs father overwhelmed	321	heating pad
289	FCG's input valued	322	heating pad did not help hip pain
290	fear of death and unknown	323	heel pain
291	fear of falling	324	her pain is driving me bananas
292	fears morphine more than cancer	325	he's not dead yet
293	Fentanyl patch	326	hesitant to know the future
294	finances as intervention support	327	Highest Pain
295	find the beauty in every day	328	hip pain
296	foot pain	329	holding his back means pain
297	friends not sure how to react	330	homeopathy
298	gas pain	331	hospice a possibility
299	general pain	332	hospital care
300	gives meds as prescribed	333	hospitalized for pain control
301	good diet to prevent cancer	334	hot bath works
302	grin and bear it	335	hugs me means pain relieved
		336	humidity makes pain worse
		337	humour as intervention
		338	humour is important
		339	humour not used as pain intervention
		340	humour works for pain relief
		341	hurts to watch someone you love suffer

342	I can do nothing apart from just leave	375	jaw and lip pain
it be		376	jiggles means in pain
343	I feel like my body is immune	377	joking around more means med
344	I watch him from a distance	worked	
345	I wouldn't send her to the hospital~	378	keep a log
346	I'd like to take some of the pain aw	379	keep positive
347	I've had all the nurses and doctors	380	knee pain
available		381	knowing stronger meds available
348	ice as intervention	reassures	
349	If I can take the pain away from her	382	laid there like dead dog
350	If pain controlled, energy used for	383	laughter makes pain better
other things		384	learn how to assess properly
351	I'm flying blind	385	learn how to cook
352	impatience means pain	386	learn to circumvent system
353	Important to show ~proof~ to MDs	387	learn to minimize pain
354	incision pain	388	leg pain
355	increase in meds	389	legs up means pain
356	individualize the pt's care	390	length of time FCG involved
357	inform yourself of the illness	391	length~frequency of pain
358	Information FCG would have liked	392	lifts behind means pain
359	information overload	393	like a headache in your leg
360	information received	394	limping means pain
361	Information received is enough	395	listen to body language
362	information session on meds would	396	live the best we can with what we have
be		397	liver pain
363	information was helpful	398	location of pain jumps around
364	injection to freeze area	399	logical to keep notes
365	Intervention based on duration of	400	look at it as a privilege
pain		401	look in her eye for assessment
366	intervention based on intensity of	402	loss of spouse vs parent
pain		403	loss of weight
367	intervention dependent on time of	404	lying down makes pain better
day		405	Maintain pt independence
368	intervention dependent on type of	406	make sure your schedule breaks
pain		407	make the best of what you have
369	intervention not dependent on type of	408	massage
pain		409	massage doesn't work
370	interventions for leg pain	410	massage for back pain
371	Interventions tried	411	massage makes pain better
372	intuition determines intervention	412	massages or rubs leg means pain
373	intuition or sensing them as	413	MD exploring different options
assessment		414	MD hesitant to prescribe meds
374	It's very hard to live with myself~	415	MDs advice changes pt's mind about m
		416	MDs didn't know what pain was
		initially	
		417	medical attention did not relieve pain

418	medical mistakes	463	neurontin
419	medicates before ~activity~	464	neuropathic~nerve pain
420	medication and human touch	465	Nobody discussed anything with me
421	medication as intervention for pain	466	noises mean she's in pain
422	Medication confusing for FCG	467	not comfortable with different people
423	medication dictates schedule	468	not sure if meds work
424	medication doesn't remove all pain	469	notes help evaluate success of meds
425	medication for back pain	470	Nothing helped
426	medication is only intervention	471	nothing worked for severe pain
427	medication is poison	472	nursing experience helps
428	medication is shared responsibility	473	oncology clinic
429	medication only thing that works	474	one day at a time
430	medication takes time to work	475	One day or thing at a time~
431	medication working	476	one resource person would be better
432	medication works in different ways	477	oxycocet
433	Meds give FCG some control	478	oxygen for comfort
434	meds knock her out	479	pain & sickness change life~routine
435	meds not effective	480	pain affects mobility
436	Meds not for pain	481	pain affects sleep
437	methadone	482	Pain and death
438	migraine pain	483	Pain and death NOT neccessarily
439	mild pain	related	
440	mobility makes pain worse	484	pain and depression
441	money would help	485	pain and meds
442	monitoring as intervention	486	pain and pt's moral
443	moody means pain	487	pain assessment needs patience
444	moral support	488	pain associated with cancer disturbing
445	more information means more	489	pain chart doesn't work
comfortable		490	pain comes and goes
446	more medical support would have	491	pain descriptor for leg pain
been		492	pain intensity assessment
447	morphine	493	pain is agony
448	morphine and concerns	494	pain is tolerable
449	morphine and fear	495	pain limits pt's independence
450	morphine contin	496	pain makes patient cry
451	morphine not working	497	pain management has changed over
452	morphine working	time	
453	muscle atrophy	498	pain management is teamwork
454	muscle mass loss	499	pain means disease advancing
455	nausea	500	pain moves
456	neck pain	501	pain prevents mobilty
457	need family help to be a caregiver	502	pain qualifier
458	need health professionals to come ho	503	pain relieved if she's happier
459	need to be flexible	504	pain scale
460	need to know cause of pain for	505	pain secondary to a fall
assessment		506	pain severe without meds
461	negotiation	507	pain uncontrollable
462	nervous means pain coming	508	pain unpredictable
		509	pain when pt won't go out
		510	pain when touched

511	pain when urinates	550	patient has a lot of pain
512	painful to see pt in pain	551	patient has emotional changes
513	parking at hosp a concern	552	patient has high pain tolerance
514	past experience with communication	553	patient has routine
515	past negative experience with medication	554	patient has trouble bending over
516	patience important	555	patient has weight loss
517	patient ~fakes~ feeling better	556	patient in coma because over meds
518	patient accepting of death	557	patient intervention
519	patient advice	558	patient involvement in pain management
520	patient afraid	559	Patient is own advocate
521	patient agrees with FCG about pain	560	Patient lets FCG know if he intervene
522	patient and adjustment	561	patient loss of appetite
523	patient and control	562	patient may not always communicate pain
524	patient and death	563	patient needs FCG to be present
525	Patient and past experience with cancer	564	patient not comfortable with ~outside
526	Patient asks for help	565	patient not fighting meds anymore
527	patient can read FCG	566	Patient NOT presently in pain
528	patient can't get comfortable	567	patient not ready to die
529	Patient characteristics	568	patient pain behaviours
530	patient choosing to NOT take meds	569	patient questions
531	patient communicates intervention to	570	Patient say she breaks down and cried
532	Patient communicates pain	571	patient sleeps a lot
533	patient complains means pain	572	patient sugars high
534	patient couldn't breath	573	patient supervises cooking
535	patient cries when upset	574	Patient symptoms
536	patient depressed	575	patient takes own meds
537	patient description of effect on family	576	patient thought pain was arthritic
538	Patient doesn't show pain	577	patient thoughts
539	Patient doesn't want to complain~	578	patient tired of suffering
540	patient fears addiction	579	patient took meds herself-coma
541	Patient feel distraction doesn't worry	580	Patient tries to understand pain
542	Patient feel supported by FCG	581	patient unsure of what would help
543	patient feeling helpless	582	Patient waits to take meds
544	patient feels FCG can't help~ no point	583	patient wants to be ~old self~
545	patient feels she's fighting pain	584	patient wants to die at home
546	patient fell	585	patient was active covers pain
547	Patient felt not enough information	586	patient's daughter has cancer
548	Patient fights taking meds	587	patient's description of what FCG did
549	patient finds FCGs mood hard sometimes	588	patient's first experience with pain
		589	patient's pain is 10 on 10
		590	pharmacist helpful
		591	physician intervention
		592	pill for scratching pain
		593	position makes pain worse
		594	positional changes for back pain
		595	positioning as intervention
		596	positioning makes pain better

597	positive reinforcement for FCG	639	Role change
important		640	saliva and cancer
598	positive talking	641	same experience with father and
599	pre medicate before activity	brother	
600	prepared for emergencies	642	same position means pain not relieved
601	pressure pain	643	scalp bleeds
602	prevention	644	scalp pain
603	private resources	645	scratching makes pain worse
604	proximity or presence as intervention	646	scratching type of pain
605	psychological support a must	647	Screaming means pain
606	Pt belief in God	648	SCT helpful or supportive
607	pt cries when in pain	649	season effects pain
608	pt doesn't believe in alternative	650	second cancer
therapy		651	sedation is option
609	pt doesn't express herself	652	sharp needle pain
610	pt feels hard to help with mobility	653	She feels the pain with me
611	pt functions well despite cancer	654	She prays to die
612	pt has difficulty communicating pain	655	she won't ask
613	pt holds head	656	shifts position means pain
614	PT unsure why he has this pain	657	shooting pains
615	pt worries about FCG after her death	658	shoulder pain
616	pts are not commodities, they're	659	side effects of pain meds
people		660	side effects other meds
617	Quality of life	661	side effects to pain treatment
618	quiet means pain	662	sitting makes pain worse
619	radiation relieved pain	663	sitting quietly means pain
620	radiation therapy	664	sleep is a concern
621	reassess things at beginning	665	sleeping = no pain to deal with
622	rectal pain	666	slumped in chair
623	recurrence difficult	667	smiling means pain relieved
624	relationship changed by cancer	668	soaking feet in hot water
625	relationship getting stronger	669	soaking in water
626	relationship not affected	670	Something keeps her going
627	remember marriage vows	671	sore feet
628	remind pt about the past	672	spasm type pain
629	rent equipment	673	stabbing pain
630	resources	674	stiffens up means pain
631	respect pt's wishes	675	stomach pain
632	respite care important	676	Stoned and stupid
633	rest helps meds work	677	strange things upset patient
634	rest makes pain better	678	stress or agitation makes pain worse
635	rest or sleep means pain is less	679	stressors other than pain
636	rib pain	680	suggests health professionals show
637	right arm pain	empathy	
638	rock sitting in her stomach	681	surgical complications
		682	swelling and pain
		683	take pt where he has to go
		684	take time for yourself
		685	talk about pleasant things

686	talking her down	731	way she acts for non-verbal assessment
687	talking makes pain worse	732	we manage together
688	Talking means pain relieved	733	weakness
689	talking pt to sleep	734	weakness and pain
690	tell pt you love her	735	what ELSE could be helpful
691	terrible pain	736	what FCG knows about meds
692	The caregiver is stuck in the house,	737	what has been helpful for pt and fcg
693	There's nothing I can do~	738	what has not been helpful
694	there's no end to anyone	739	what information is important
695	thigh pain	740	When it's family, it hurts~
696	throbbing pain	741	when you know someone you know
697	tingle is beginning of pain	they'	
698	tingly and twinges	742	Where information came from
699	too bad wasn't diagnosed earlier	743	white complexion means pain
700	too late for treatment	744	whole body part in middle
701	touching shoulder means pain	745	wife is not nurse when a FCG
702	treat bedsores as intervention	746	wipe her face as intervention
703	treatment for neuropathic pain	747	wont eat means pain
704	treatment for skin cancer	748	worsens pain
705	trial and error	749	wrapping legs eases the pain
706	Tried different interventions	750	you want to fix it, but can't
707	Tries to calm her down	751	You're standing there like a fool an
708	Tylenol	752	zero tolerance to pain now
709	type of information		
710	unbearable pain		
711	uncertainties		
712	uncertainties about death		
713	uncertainty about meds		
714	understand the medications		
715	unsuccessful attempt at pain relief		
716	unwanted information		
717	use your resources		
718	vacation would help morale		
719	verbal assessment not reliable		
720	verbal confirms non verbal		
721	visual imagery		
722	voice for pain assessment		
723	VON		
724	waist pain		
725	waist up		
726	waiting makes pain worse		
727	warm socks		
728	warmth or heat for back pain		
729	warmth makes pain better		
730	way he moves tells type of pain		

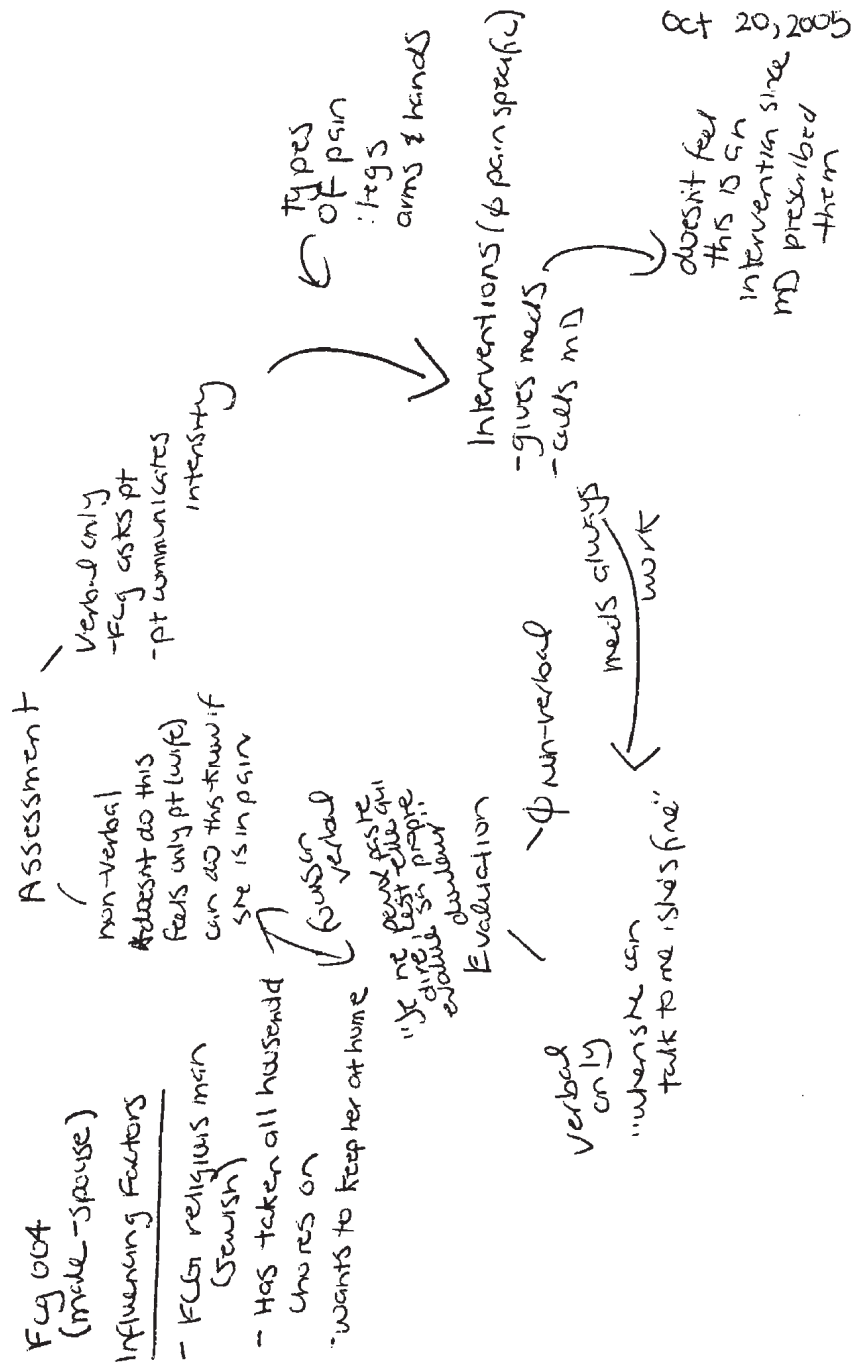
APPENDIX VI: CATEGORIES/NVIVO SETS

Categories/NVIVO Sets

1. Communication
2. Death
3. Decision-making
4. Depression
5. Descriptors of pain
6. External resources
7. Family caregiver advice
8. Family caregiver assessment
9. Family caregiver beliefs
10. Family caregiver challenges
11. Family caregiver intuition
12. Family caregiver interventions
13. Family caregiver evaluation
14. Family caregiver feelings
15. Family caregiver support
16. Family caregiver thoughts
17. Information
18. Makes pain better
19. Makes pain worse
20. Medication
21. Mobility
22. Other stressors
23. Pain and loss of appetite
24. Pain and sleep
25. Pain controlled
26. Pain NOT controlled
27. Patient beliefs
28. Patient weakness
29. Prepared or not prepared
30. Patient advice
31. Patient support
32. Relationships
33. Types of pain

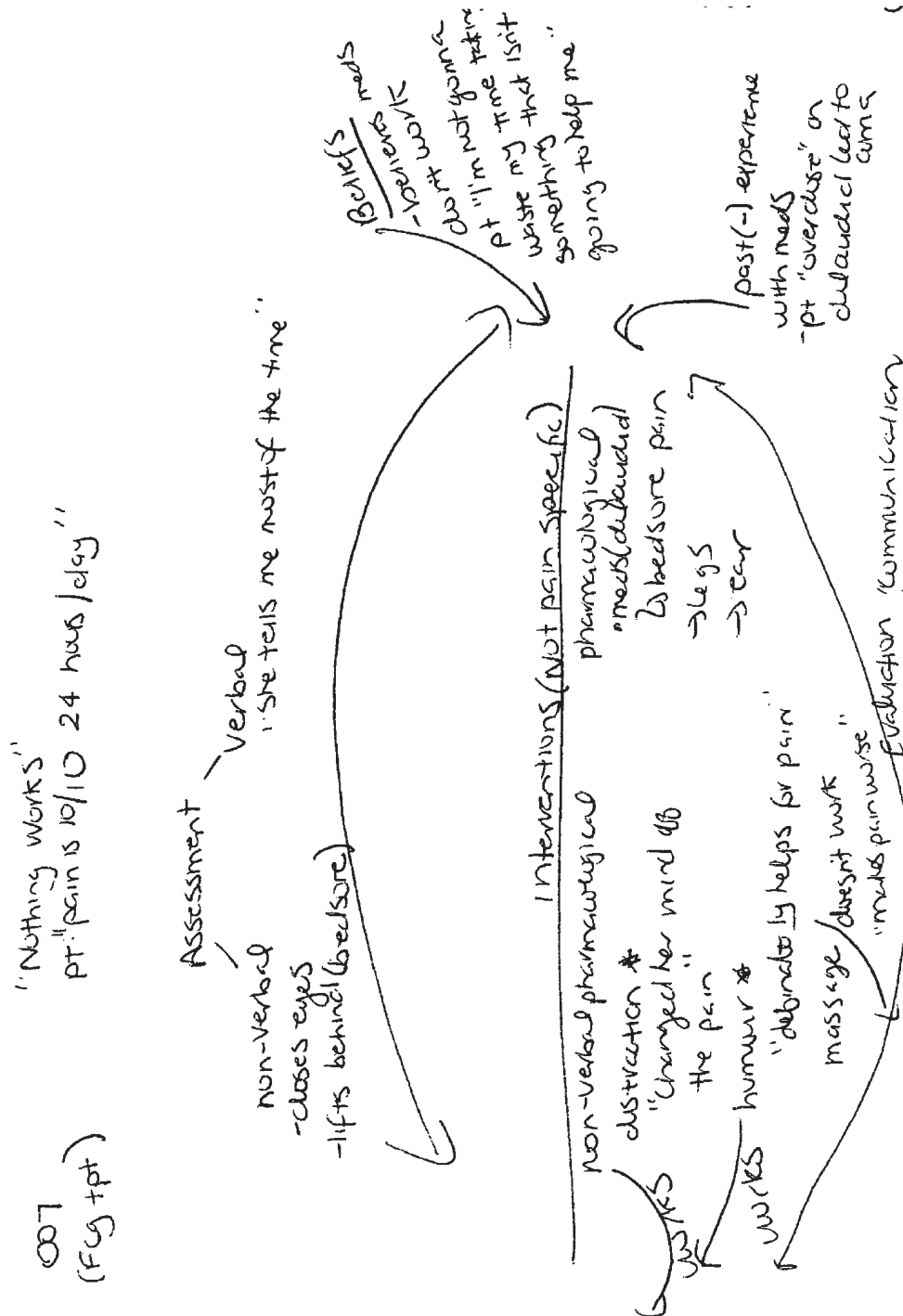
APPENDIX VII: DIAGRAMS

Oct 20, 2005



Early diagrams show thoughts about influencing factors and relationships after each family caregiver interview.

Nov 10, 2005



Early diagrams show thoughts about influencing factors and relationships after each family caregiver interview.

Fig #20 Daughter

Influencing factors:

- Travelling from mtl to Ottawa regularly
- feels unsupported alone because other siblings are not supportive of her
- Father at home, feeling overwhelmed
- pt's Δ of mood - personality
- Fig planning her own daughters wedding
- pt has high tolerance to pain
- Fig (and father) keep notes and shares with health care team.

Assessment

Verbal
"weasle her 20 times a day"
- "if she mentions it it must be intense pain"

non-verbal
behavior will change
- facial expressions
- strain on her face
- shifting positions

Evaluation

non-verbal
"if she gives you to sleep you know she is comfortable"

verbal
too reliable

Interventions

pharmacological
- narcotics
- also checks her father when he gives meds to pt

positioning
doesn't help

distraction
better than meds

Based on types of pain
eg headwre dying
other pain \rightarrow distraction

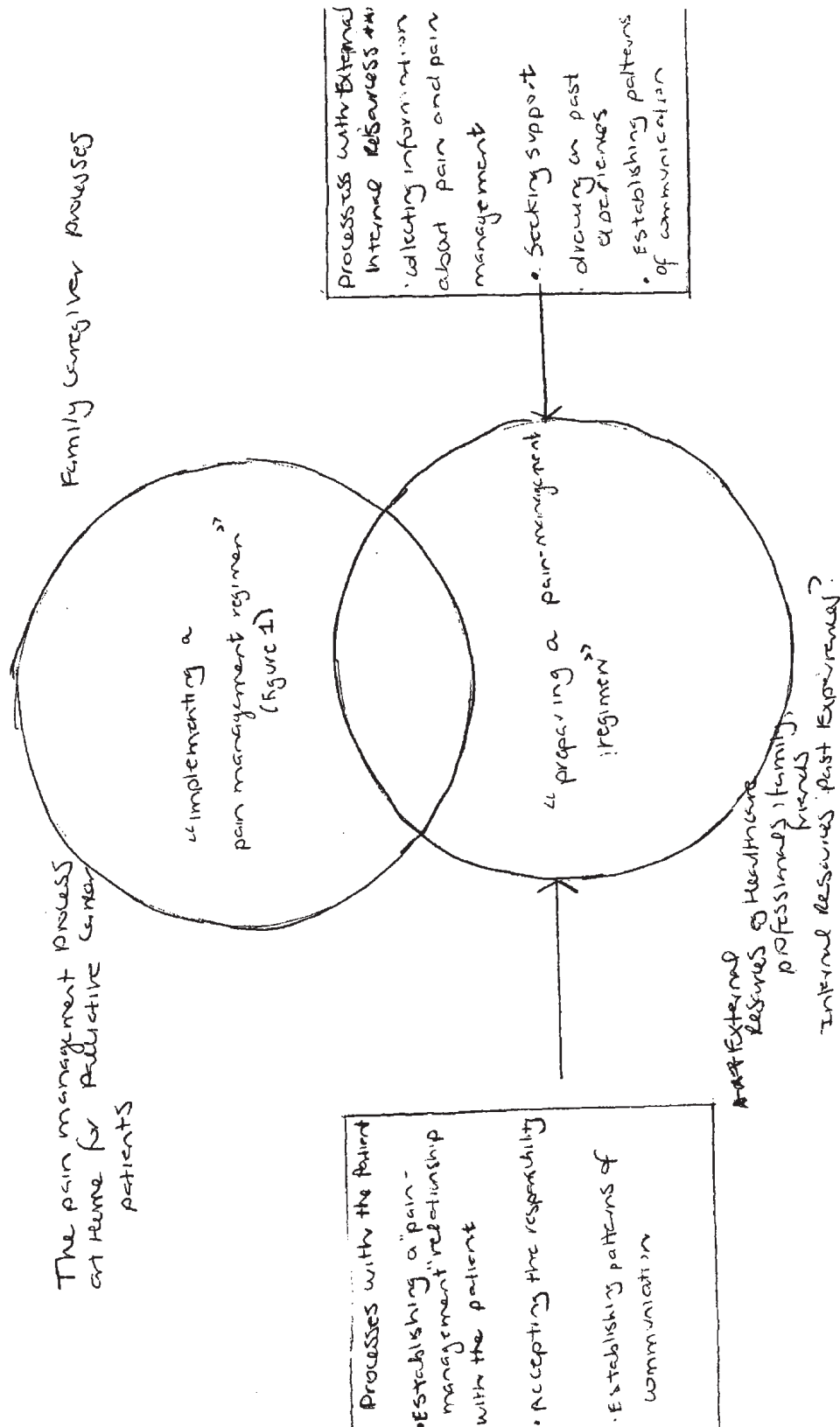
types

00 pain
leg/bank
20 not
"other
cancer
pain
things
collar
bone
neck
bedding
hip

positions
- Δ
positions
Bigger in time
day

218

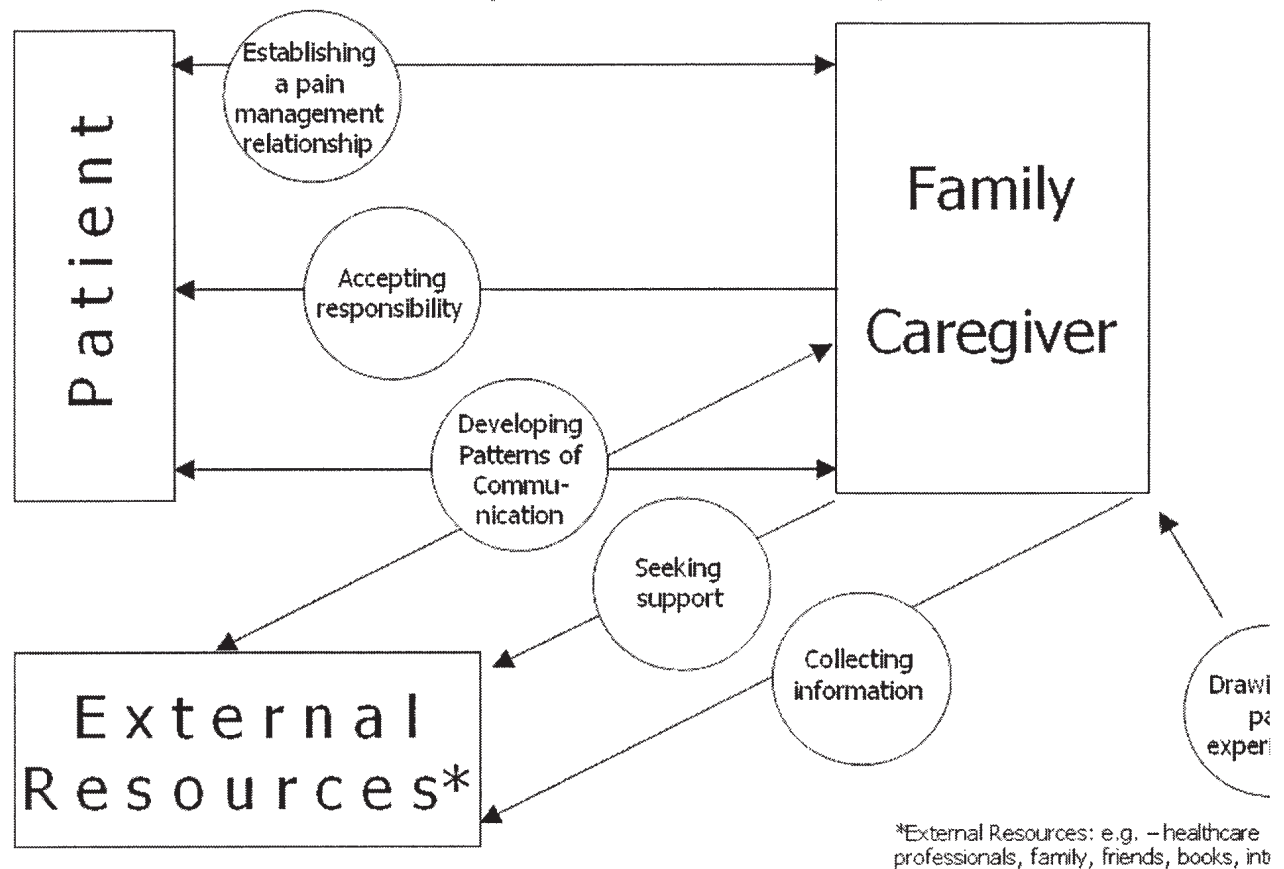
June 26, 2007



Identification of two main processes, and trying to determine how they relate

November, 2007

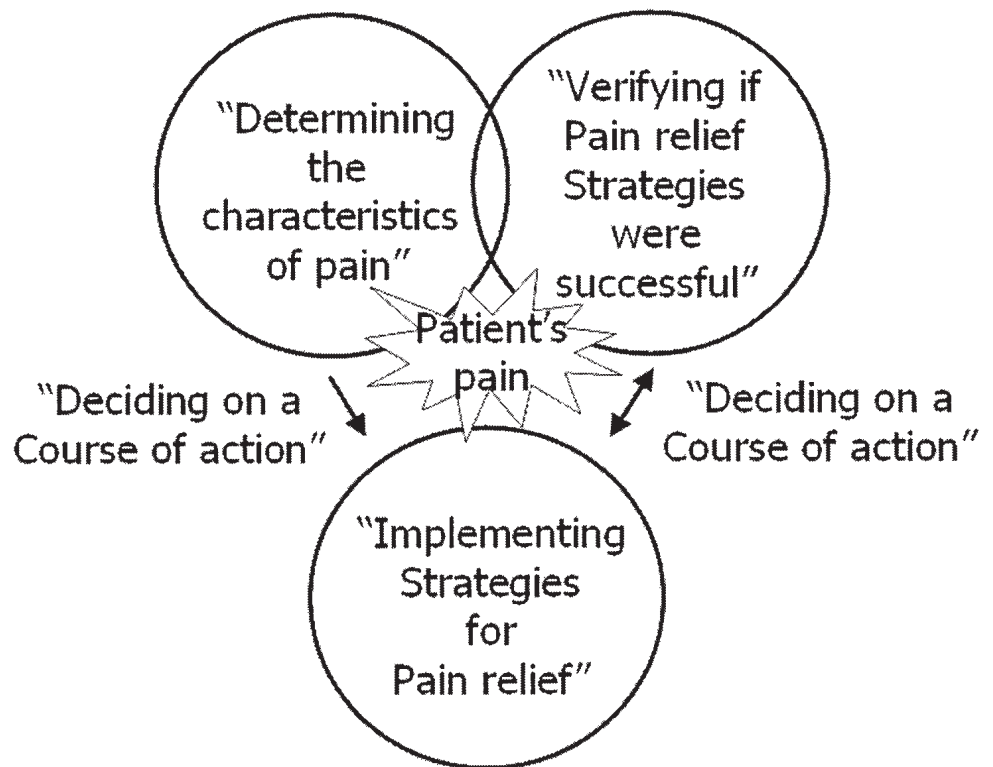
Preparing a pain management regimen



This is how I originally perceived the “process of pain management” and what I had initially called “Preparing a Pain Management Regimen”

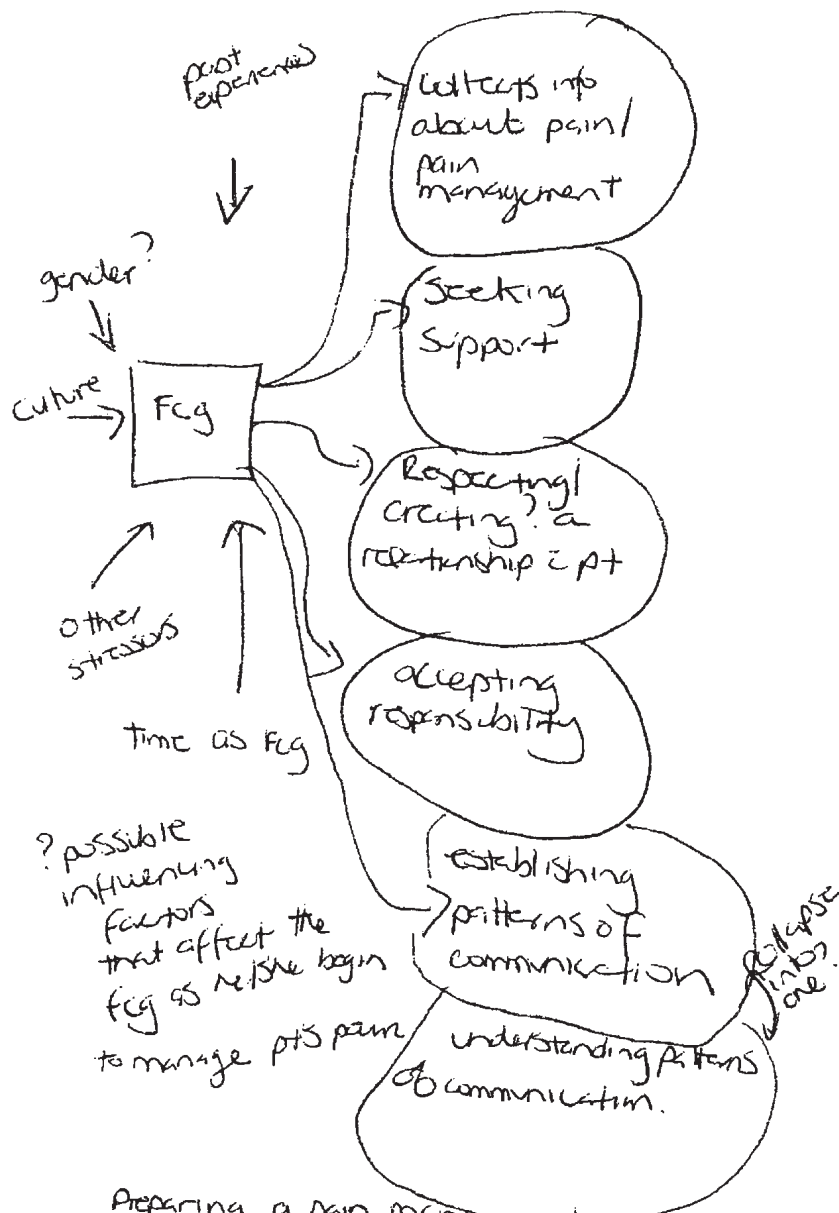
November, 2007

Implementing a pain management regimen



I struggled when trying to conceptualize this part of the process...the “doing” and the “deciding” and how they related was a challenge to understand at first.

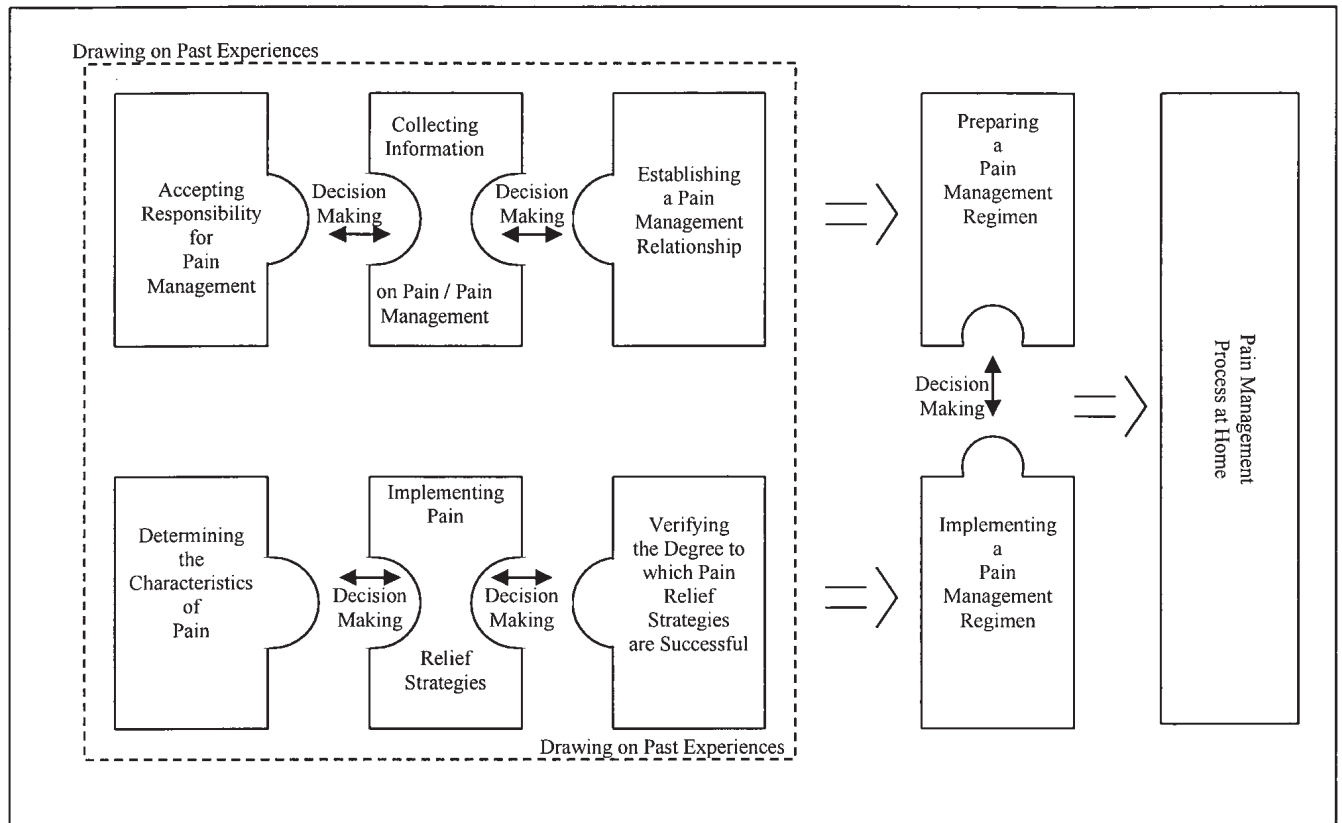
Dec 9, 2007



Preparing a pain management regimen. Seems to be a step they may/may not proceed actual doing or managing the pt's pain. Fcg goes through a few non sequential steps. They ~~also~~ do this to some degree. They start by gathering info. seek support family/hcp? when I say 'respecting relationship' I mean Fcg communicates & care develops their role in collaboration w/ pt. Can be in charge of: minimally/slightly involved & pain management. MUST ACCEPT responsibility/commitment (degree varies!). Pain management regimen is to establish how they will be assessing/evaluating pt/pain and effectiveness.

Trying to look at influencing factors on different pain management processes related to "preparing" or "strategizing a game plan".

January 2008



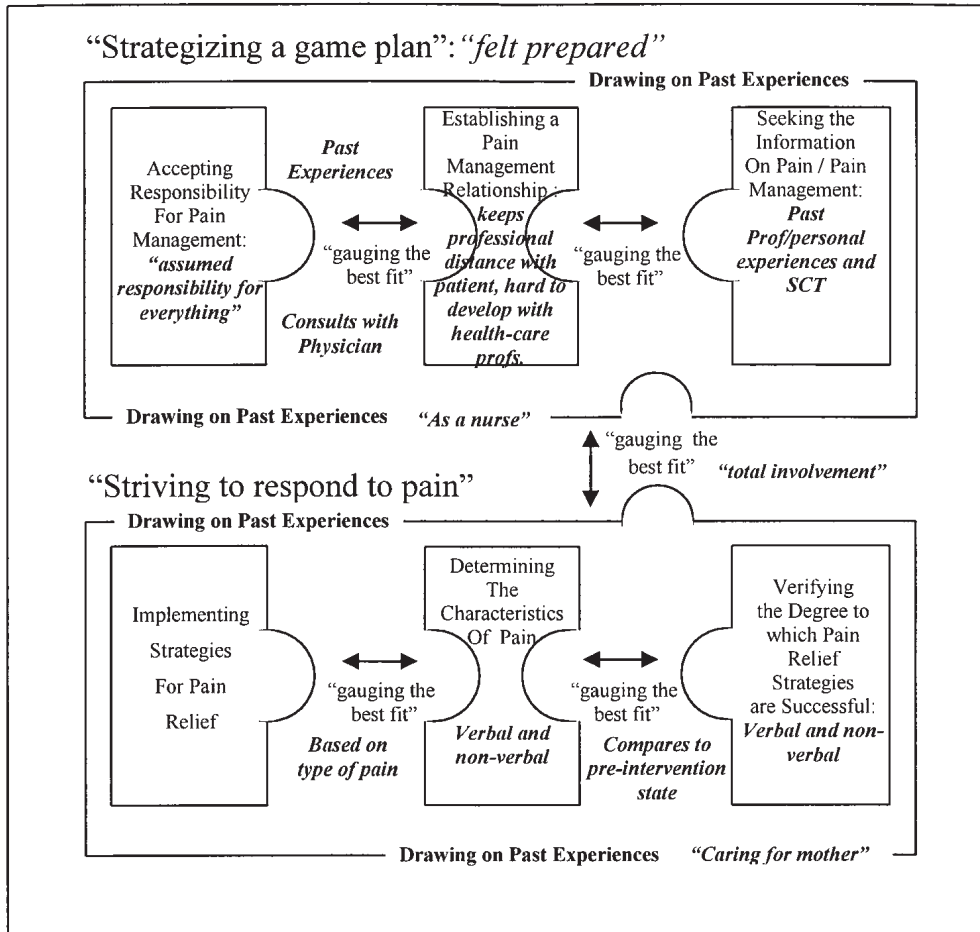
Getting very close to the final conceptualization of the “puzzle”

APPENDIX VIII:

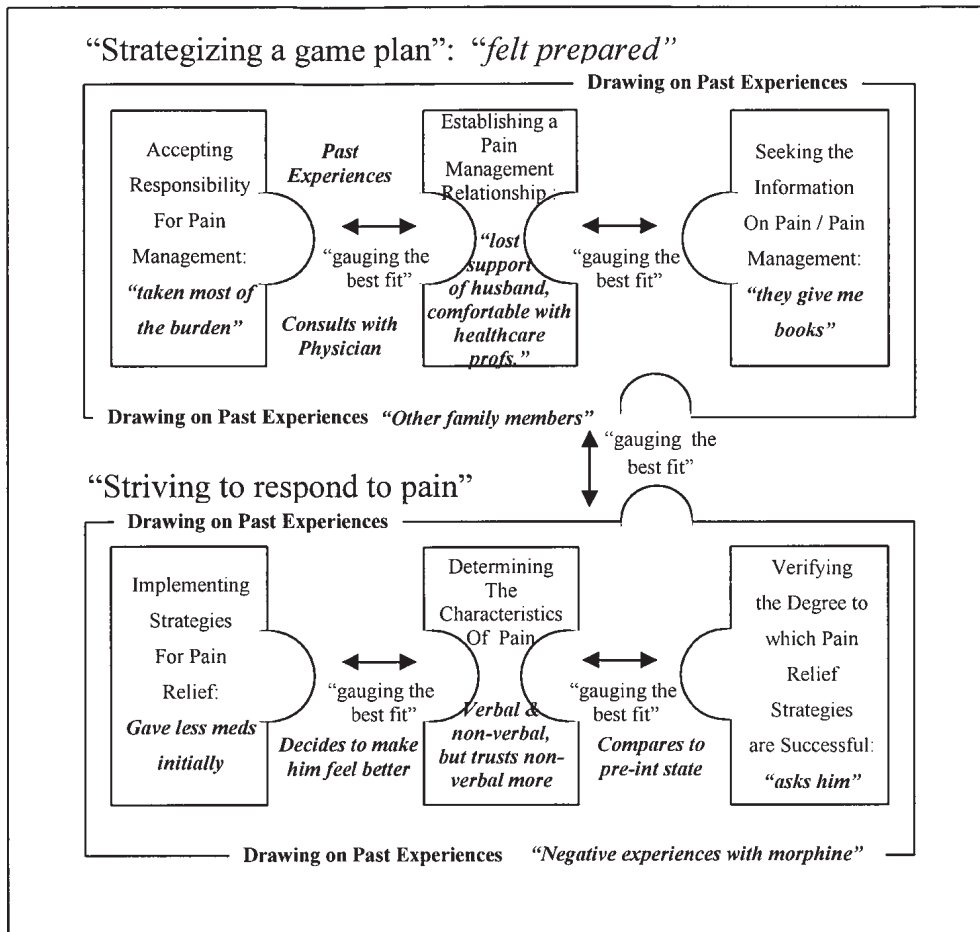
PAIN MANAGEMENT PUZZLES:

**Case Examples (Mrs. G) 001, (Mrs. L) 008, (Mr. D)
017**

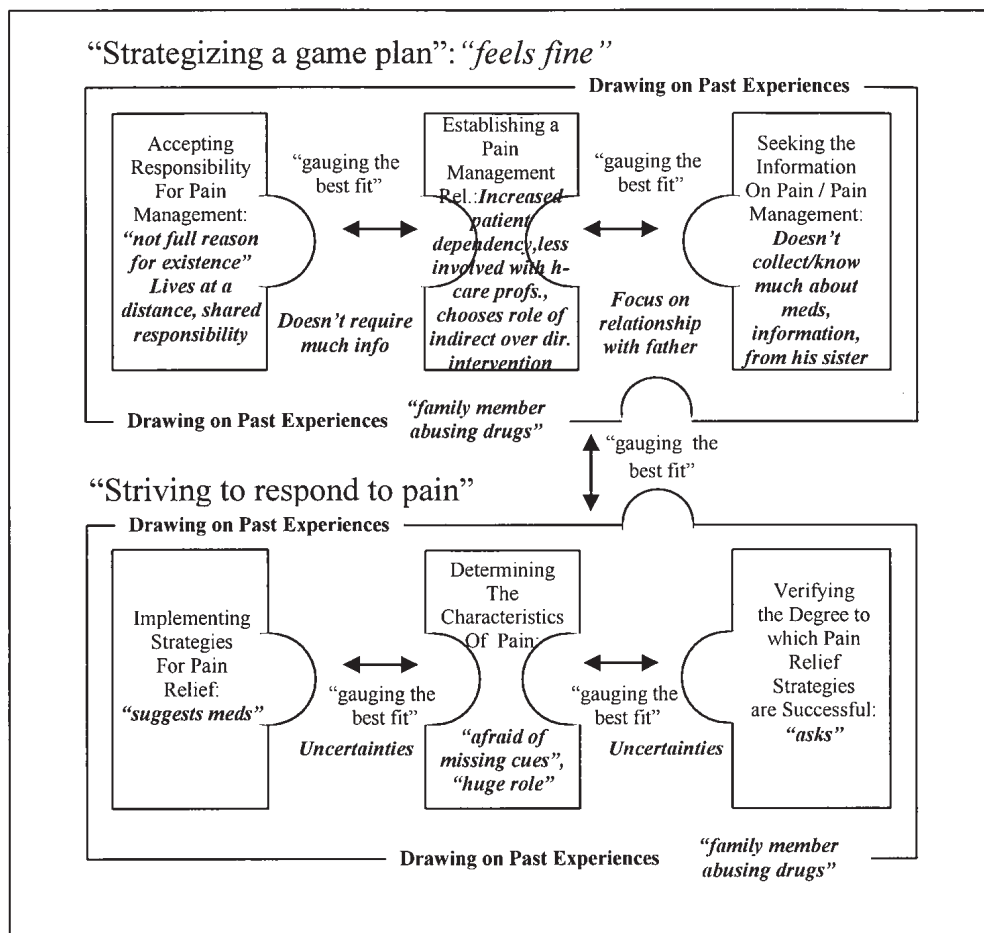
Pain Management Puzzle: Family Caregiver 001-Mrs. G



Pain Management Puzzle: Family Caregiver 008-Mrs. L



Pain Management Puzzle: Family Caregiver 017-Mr. D



APPENDIX IX: CERTIFICATES OF ETHICS APPROVAL



HÔPITAL GÉNÉRAL JUIF
SIR MORTIMER B. DAVIS
JEWISH GENERAL HOSPITAL

HÔPITAL D'ENSEIGNEMENT DE L'UNIVERSITÉ MCGILL
A MCGILL UNIVERSITY TEACHING HOSPITAL



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May 8, 2007

Dr. Robin Cohen
Departments of Oncology
SMBD – Jewish General Hospital

SUBJECT: Protocol #05-062 entitled “Family Caregivers of Palliative Cancer Patients at Home: The Pain-Management Process”

Dear Dr. Cohen,

Thank you for submitting the following documents pertaining to the above-mentioned protocol to the Research Ethics Office for review of your Continuing Review Application:

- Protocol (May 24, 2005)
- English and French Patient consent form (dated June 20, 2005)
- English and French Family Caregivers consent form (dated June 20, 2005)

The Research Ethics Committee of the SMBD-Jewish General Hospital (Federalwide Assurance Number: 0796) is designated by the province (MSSS) and follows the published guidelines of the Tri-Council Policy Statement, 1998 (with 2000, 2002 updates), in compliance with the “Plan d'action ministériel en éthique de la recherche et en intégrité scientifique” (MSSS, 1998), the membership requirements for Research Ethics Boards defined in Part C Division 5 of the Food and Drugs Regulations; acts in conformity with standards set forth in the United States Code of Federal Regulations governing human subjects research, and functions in a manner consistent with internationally accepted principles of good clinical practice.

We are pleased to inform you that expedited re-approval for the above-mentioned clinical protocol and the English and French consent forms is granted for a period of **one year**. For quality assurance purposes, you must use the approved REO stamped consent forms when obtaining consent by making copies of the enclosed ones.

Please be informed that this study proposal will be presented for corroborative approval at the next meeting of the Committee on June 15, 2007.

Expedited Re-Approval Date: May 8, 2007
Expiration date of Expedited Re-Approval: May 7, 2008

Au service de tous.

3755, CH. DE LA CÔTE-SAINTÉ-CATHERINE RD., MONTRÉAL, QUÉBEC H3T 1E2
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Care² For All.

APPENDIX X: APPROVED CONSENT FORMS FOR FAMILY CAREGIVERS AND PATIENTS

Family Caregiver Information Sheet for the Study:

**Family Caregivers of Seriously Ill Patients at Home-
The Pain-Management Process**

SMBD-Jewish General Hospital

Department of Oncology

Principal Investigator: Dr. Robin Cohen, Ph.D., Research Director and Assistant Professor
Departments of Oncology and Medicine, McGill University
Phone: 735-1650

Co-Investigator: Anita Mehta, MSc (A)
Doctoral Candidate, McGill School of Nursing
Phone: 735-1299 email: anita.mehta@mail.mcgill.ca

Purpose of the Study

We are interested in understanding how family caregivers of seriously ill people are helping manage their family member's pain while they are at home. We would like to meet with you and, if possible, with your ill family member in order to discuss what some of the strategies are that you use to manage pain, and how well you feel they work.

This understanding of your experience in terms of what you are facing and how you are managing will enhance our ability to provide appropriate help and support for other family caregivers in the future.

Who will be asked to participate

Participants will be competent adults who are family caregivers of people with a serious illness who have pain and are treated at the S.M.B.D. Jewish General Hospital and those being cared for by either the Victorian Order of Nurses (VON) West Island or the VON Montreal Inc. The patients will also be asked to participate.

What participation involves

If you agree to participate in this study, I will arrange to meet with you at a time and place of your choosing. At that time, we will discuss what types of pain you are helping your family member to manage, and how you determine when and how to intervene. We will also discuss how you determine if the strategies you are using work well or not to relieve your family member's pain. I would also like to meet with you approximately one week after the first interview in case you have new information to tell me and in order to clarify any responses I did not fully understand. I expect that this should take approximately one hour each time, although you can stop the interview whenever you want.

The conversations will be audio-taped to ensure that all information you share is captured and also that I can refer to it again if I need to.

June 20, 2005

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Risks and Benefits

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Consent Form

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Étude sur «Les proches aidants des personnes gravement malades et soignées à la maison : Le processus de la gestion de la douleur

Fiche d'information à l'intention des proches aidants

Hôpital Général Juif de Montréal- SMBD

Département d'Oncologie

Chercheuse principale : Robin Cohen, Ph.D., Directrice de la recherche et Professeure adjointe, Départements d'oncologie et de médecine, Université McGill
Téléphone : 735-1650

Chercheuse-adjointe : Anita Mehta, MSc (A)
Doctorante en Sciences Infirmières
École des sciences infirmières de McGill
Téléphone : 735-1299 ; Courriel : anita.mehta@mail.mcgill.ca

Objectif de l'étude

Nous aimerions comprendre comment les proches aidants de personnes gravement malades aident la personne malade à gérer sa douleur quand cette personne est à la maison. Nous souhaiterions vous rencontrer et, si possible, rencontrer le membre de votre famille qui est malade afin de discuter de certaines des stratégies que vous utilisez pour gérer la douleur ainsi que de l'efficacité de ces stratégies, selon vous.

La compréhension de votre expérience en terme de ce que vous vivez et comment vous gérez la situation augmentera notre capacité à fournir une aide et un soutien adéquats à d'autres proches aidants à l'avenir.

Qui participera à l'étude

Les participant(e)s seront des adultes aptes qui sont des proches aidants de personnes gravement malades qui souffrent et qui sont traitées à l'Hôpital général juif SMBD et celles soignées par le VON (Victorian Order of Nurses) de l'Ouest de l'Île ou par le VON Montréal Inc. On demandera également aux patient(e)s de participer.

Implications de la participation

Si vous acceptez de participer à cette étude, j'organiserai un rendez-vous avec vous à l'heure et au lieu de votre choix. À ce moment-là, nous discuterons des types de douleur pour la gestion desquels vous aidez le membre de votre famille et comment vous déterminez le moment et la manière d'intervenir. Nous discuterons également de la façon dont vous déterminez si les stratégies que vous utilisez aident ou pas à soulager la douleur du membre de votre famille qui souffre. J'aimerais également vous rencontrer

environ une semaine après la première entrevue au cas où vous auriez de nouvelles informations à me fournir et pour clarifier les réponses que je n'aurais pas parfaitement comprises. Ces entrevues devraient durer environ une heure chacune. Toutefois, vous pouvez mettre fin à l'entrevue quand vous le désirez.

Les conversations seront enregistrées sur cassette afin de s'assurer que toutes les informations que vous aurez communiquées sont bien comprises et aussi afin de pouvoir m'y référer si nécessaire.

Risques et avantages

Des études similaires à celle-ci, basées sur des entrevues, ont rarement causé de la peine. Cependant, il est possible qu'une question vous trouble. Il est également possible qu'en s'attardant sur un sujet particulier au cours de notre conversation, vous ressentiez une certaine détresse. Dans ces cas-là, vous êtes libre de ne pas répondre à la question et de passer à la question suivante ou d'interrompre votre participation. Cette recherche sera vraisemblablement utile aux futur(e)s patient(e)s et à leurs proches aidants dans leur tentative de gérer la douleur de la personne malade qui est soignée à la maison. Toutefois, les participant(e)s apprécient souvent l'opportunité qui leur est offerte de s'engager dans une discussion réfléchie et de contribuer à un projet de recherche.

Droits des participant(e)s de l'étude

La participation à cette étude se fait sur une base volontaire. Vous avez le droit de poser des questions à tout moment ou de refuser de répondre à une question. Vous pouvez interrompre votre participation tout simplement en le mentionnant à la chercheuse. Si vous choisissez de ne pas participer ou si vous arrêtez à tout moment, soyez assuré que les informations que vous nous aurez fournies n'auront aucune conséquence sur les soins dont vous bénéficiez.

Confidentialité

Les notes prises au cours de l'entrevue et l'enregistrement de la séance seront conservés, sous clef, dans un classeur, dans un bureau (le mien, Anita Mehta) fermé à clef. Ces documents seront gardés en toute confidentialité et ne seront accessibles qu'aux deux chercheurs qui conduisent l'étude. Les données seront conservées dans le bureau du Dr.Cohen durant cinq ans à partir de la date où l'étude sera terminée. Toutes les données seront détruites après publication. La cassette, mes notes, et tous les écrits concernant nos résultats ne permettront jamais de vous identifier par votre nom, car, nous nous servons d'un numéro d'identification que nous aurons nous-mêmes attribué à chacun des participants. Quand nous publierons ou présenterons les données, il sera impossible de vous identifier.

Contacts et informations supplémentaires

Si vous avez des questions au sujet de cette étude, n'hésitez pas à me contacter (Anita Mehta) au 514-735-1299 ou la directrice de la recherche Dr.Robin Cohen, Ph.D.,

au 514-735-1650. Si vous avez des inquiétudes concernant vos droits en tant que participant(e) à l'étude, veuillez contacter :
Mme Laurie Berlin, la protectrice des usagers à l'hôpital au (514) 340-8222, poste 5833
Mme Jane Lumsden, Directrice du VON (Victorian Order of Nurses) de l'Ouest de l'Île au (514) 695-8335, poste 101
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Formulaire de consentement

Après que j'aie répondu à toutes vos questions de manière satisfaisante, si vous acceptez de participer à cette étude, veuillez signer le formulaire de consentement figurant à la page suivante.

Patient Information Sheet for the Study:

Family Caregivers of Seriously Ill Patients at Home - The Pain-Management Process

SMBD-Jewish General Hospital

Department of Oncology

Principal Investigator: Dr. Robin Cohen, Ph.D., Research Director and Assistant Professor
Departments of Oncology and Medicine, McGill University
Phone: 735-1650

Co-Investigator: Anita Mehta, MSc (A)
Doctoral Candidate, McGill School of Nursing
Phone: 735-1299 email: anita.mehta@mail.mcgill.ca

Purpose of the Study

We are interested in understanding how family caregivers of seriously ill people are helping manage their family member's pain while they are at home. We would like to meet with you and the family member most involved in your pain management in order to discuss what some of the strategies are that they use, and how well you feel they work for you.

This understanding of your experience in terms of what you are facing and how you and your family caregiver are managing will enhance our ability to provide appropriate help and support for other family caregivers in the future.

Who will be asked to participate

Participants will be competent adults receiving care for a serious illness at the S.M.B.D. Jewish General Hospital and those being cared for by either the Victorian Order of Nurses (VON) West Island or the VON Montreal Inc. Their family caregivers will also be asked to participate.

What participation involves

If you agree to participate in this study, I will arrange to meet with you at a time and place of your choosing. At that time, we will discuss what types of pain your family member is managing, and what you think helps them determine when and how to intervene. We will also discuss if the strategies used work well or not to relieve your pain. I would also like to meet with you approximately one week after the first interview in case you have new information to tell me and in order to clarify any responses I did not fully understand. I expect that this should be approximately one hour each time, although you can stop the interview whenever you want.

The conversations will be audio-taped to ensure that all information you share is captured and also that I can refer to it again if I need to.

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